Remaking Biomedical Sexualities:
Health Technologies and the Governance of HIV in the United States

by

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Dedication

To my mother, Beth Lipham, “my best person ever,” whose belief in and support for me has made my life possible;

to Alex and David, who have nurtured me in my intellectual development unwaveringly, despite my many shortcomings;

and to the memories of Scott O’Hara (d. 1998) and my grandfather, Professor James M. Lipham (d. 1986), both of whom I wish I’d had the chance to know.

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Clams open on the table,
lambs are eaten by worms
on the plain. The motion

of change is beautiful,
as well as form called
in and out of being.
-Allen Ginsberg, excerpt from
“The Terms in Which I Think of Reality,” Spring 1950

The weight of the earth is about things in captivity:
animals and people and all that surrounds us.
-David Wojnarowicz, tape-recorded journal entry, November 1988

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I must first and foremost thank my mother, Beth Lipham, who has been my primary source of support for my entire life. Through many moves, periods of ups and downs, health events, job opportunities, and changes in life circumstances, she has been there for me, providing an emotional and material foundation so that I could succeed. In so many ways, I owe my life to her. It is a privilege to be her son.

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skills to support students, causes, and organizations with shared values and commitments – along with her intentional work to translate her research into policy outcomes and other forms of empowerment for the communities she partners with – is unparalleled. Alex has taught me, through deed and word, that one can act with unyielding conviction while also recognizing that the form of a statement is often as important as its conceptual content, that being inviting with one's speech is usually a more effective strategy for advancing one's positon than drawing bright metaphorical lines in the sand or planting discursive stakes in the ground, and that the ability to be thoughtful, considered, and even-handed (rather than reactive) is one of the greatest attributes of a leader and likely the greatest privilege of being an academic.

It has been an honor to pursue advanced study under the tutelage of David M. Halperin, who I also thank for his patience, support, and most of all for his immense, voluminous, and incisive feedback on my work during the last seven years. I was lent a copy of David's book *Saint Foucault: Toward a Gay Hagiography* by an undergraduate professor during winter break of my senior year during the 2010-2011 academic year. I devoured the text. *Saint Foucault*, along with a several other essays and books that I read during that period from the canon of queer and feminist theory, played a significant role in reshaping the course of my life. When I was applying to graduate school, David was kind enough to both take a phone call from me and to meet with me in person when I visited Ann Arbor. His "Late Foucault" seminar during my first semester at Michigan was the beginning of a series of ongoing conversations that have been among the most enriching of my life. David's relentless, meticulous, and appreciative comments on my writing – and on my writing style – have improved my scholarship immensely. David's admonitions to write without recourse to jargon, to "be good at your job," to "earn your attitude" (which he imparted to me by way of ACT UP Boston), and to be one's own harshest critic have all given me a greater appreciation for the possibilities of knowledge-production and of the stakes of "getting it right."

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These are lessons that I will continue to wrestle with and re-learn as the terrain of sexual politics transforms as I age, and as I continue to engage in struggles over sexuality, LGBTQ identity, and HIV/AIDS as an academic, an activist, and a Leatherman. The challenge of grappling with the theory of benign sexual variation and recognizing the value of constantly attending to the particularity of sexual politics are ones that I carry with me in my daily life. They are sources of abiding strength, resilience, and curiosity – and for that I largely have Gayle to thank. I also owe my commitment to empirical inquiry to Gayle. There are so many reasons for all of us to be thankful for Gayle Rubin.

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This dissertation is the culmination of seven years of work as a PhD student. However, it is also the result of a life, career, and undergraduate education which led me to choose to pursue graduate studies. From 2005-2012, I worked in a variety of roles focused on communications, research, and strategy in public affairs. It has taken me nearly the entire duration of my time as a doctoral student to recognize that my prior career in public affairs also deeply informs my approach to research, how I conceptualize data as an object of analysis, and my views on power relations and “the political.” For these experiences, I especially thank Joe Yuhas, Gary Kaasa, Pamala Milton Doan, Ruben Gallego, Alejandro Chavez, Selena Shilad, and Matt Hager.

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List of Acronyms and Key Terms

Technical note on use of acronyms:

This dissertation contains many acronyms related to LGBTQ health, HIV/AIDS, and health IT. Therefore, in the body of the text, rather than providing the full name of an agency or program only once, and then associating it with an acronym in parentheses that I will use for the remainder of the chapter or entire dissertation – e.g. “The U.S. Department of Health and Human Services (HHS)” – I often reintroduce the full name and acronym at the beginning of a major chapter subsection, and always at the beginning of a new chapter. I do this more frequently for obscure agencies or programs – e.g. the Council of State and Territorial Epidemiologists (CSTE) – than I do for well-known entities, such as the Centers for Disease Control and Prevention (CDC).

Acronym or Key Term	**Refers to**
21st Century Cures Act	2016 U.S. law intended in part to accelerate heath IT interoperability
90/90/80	See, 90/90/90; corresponding U.S. domestic targets set by the *National HIV/AIDS Strategy of the United States: Updated to 2020*
90/90/90	Global targets set by UNAIDS for achievement by 2020: 90% of people living with HIV diagnosed 90% of people diagnosed on treatment 90% on treatment virally suppressed
ACA	Patient Protection and Affordable Care Act of 2010
ACT UP	The AIDS Coalition to Unleash Power
AHF	AIDS Healthcare Foundation
AID Atlanta	A large HIV/AIDS Service Organization in Atlanta affiliated with AHF
AIDS	Acquired Immune Deficiency Syndrome
ARRA	American Recovery and Reinvestment Act of 2009
ART	Antiretroviral Therapy
ARTAS	The Anti-Retroviral Treatment and Access to Services Intervention; the gold standard HIV linkage and re-linkage intervention
ASO	HIV/AIDS Service Organization

CAP	The Center for American Progress, a liberal think tank
CAREWare	Software maintained by HRSA for Ryan White providers to manage data
CD4-T cell/T cells	White blood cells attacked by the HIV retrovirus. Normal range: 800-1500 copies/ml of blood Falling below 200 results in a diagnosis of AIDS (Stage 3 HIV)
CDC	Centers for Disease Control and Prevention
CEHRT	Certified Electronic Health Record Technology
Chart	Shorthand for a patient's full medical record. See, EHR.
CMS	Centers for Medicare and Medicaid Services
CRF	Case Report Form for Reporting New Cases of HIV
CSTE	Council of State and Territorial Epidemiologists
Data to Care	A federal program promoting the use of HIV surveillance data to identify and re-link individuals living with HIV identified as out of care.
“Dear Colleague” letter	A form of regulatory and technical guidance distributed by actors with authority to enact administrative or processual changes implemented by agencies “lower” in an organizational hierarchy; often used by federal agencies in communicating changes in policy to state agencies.
Do Ask, Do Tell	2012-15 campaign by Fenway and CAP to include SO/GI in federal EHR certification requirements, and to boost clinical SO/GI data collection
DPH	Department of Public Health
eHARS	Enhanced HIV/AIDS Reporting System software maintained by CDC for HIV surveillance
EHR	Electronic Health Record
ELR	Electronic Laboratory Reporting feeds, usually in reference to those established between testing laboratories and HIV surveillance systems
EMA/Atlanta EMA	The 20-County Atlanta "Eligible Metropolitan Area" designated to receive Ryan White Part A funding for hard-hit urban areas
EMR	Electronic Medical Record. See, EHR.
End of AIDS	See, 90/90/90; 90/90/80
Fenway	Fenway Health, an FQHC that also houses the Fenway Institute and the National LGBT Health Education and Training Center
FQHC	Federally Qualified Health Center
Free text	In the clinical context, unstructured notes taken in an EHR

Fulton County	Main county in which the city of Atlanta exists; also the municipal entity that houses the Atlanta Ryan White Program
GDPH	Georgia Department of Public Health
Gold Standard	Recognized best practice in biomedicine and health, ideally but not exclusively validated through randomized control trial.
HHS	The United States Department of Health and Human Services
HIE	Health Information Exchange
HIMSS	The Health Information Management and Systems Society
HITECH Act	The Health IT for Economic and Clinical Health Act of 2009; authorized over $30 billion in subsidies to digitize the U.S. healthcare system
HIV	Human Immunodeficiency Virus
HIV Care Continuum	A five-stage framework for managing HIV: (1) Diagnosed, (2) Linked to care, (3) Engaged in care, (4) Retained in Care, (5) Viral Suppression
HIV Care Continuum Initiative	2013 U.S. federal initiative to reorient the management of HIV in the country around the HIV Care Continuum framework
HIV HIE	HIV Health Information Exchange
HIV Risk Hierarchy	Taxonomic ordering of probable causes of HIV transmission risk
HIV Surveillance	The practice of systematically collecting data on new cases of HIV and patterns of engagement in medical care by people living with HIV
HIV Surveillance Report	Reports on the national HIV/AIDS epidemic and predecessor documents released by CDC annually since 1982
HIV Surveillance System	The technical and organizational infrastructures in place to conduct HIV Surveillance, usually operated by state DPHs
HL7	Health Level 7 International, the main set of health information exchange and interoperability standards used in health IT globally
HRSA	Health Resources and Services Administration
HTTP	HyperText Transfer Protocol
Informed Consent	The principle that patients and/or research subjects should have the opportunity to be educated about and to authorize procedures performed on them, data collected about them, and subsequent uses of those data.
IEEE	Institute of Electrical and Electronics Engineers
Interoperability	Per IEEE: "the ability of two or more systems or components to exchange information and to use the information that has been exchanged."
IOM	The United States Institute of Medicine

ISA	*Interoperability Standards Advisory*, non-binding guidelines set by ONC and released annually since 2015
Joint Commission	Main healthcare facility accreditation body in the United States
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer
Linkage-to-care	The process by which newly-diagnosed people living with HIV are linked to medical providers, ideally within 30 days of diagnosis
LOINC	Logical Observation Identifiers Names and Codes
MetroATLCare	A large HIV/AIDS Service Organization in metro Atlanta
MHS	See, Molecular HIV Surveillance
MIPA	The Meaningful Involvement of People Living with HIV/AIDS
Molecular HIV Surveillance	Using ELR data reported to HIV surveillance systems to track the emergence of "clusters" of HIV using phylogenetic methods
MSM	Men who have sex with men, also short for "male-to-male sexual contact"
MU	The “Meaningful Use” provider self-attestation component of the EHR Incentive Payment Program, renamed "Promoting Interoperability" in 2018
NASTAD	National Alliance of State and Territorial AIDS Directors
NCSD	National Coalition of STD Directors
New Consensus in LGBTQ Health	The incorporation of LGBTQ health actors' interests into federal health policy and health civil society norms in the United States, post-2011
NHAS	The National HIV/AIDS Strategy of the United States
NHAS 2020	The National HIV/AIDS Strategy of the United States: Updated to 2020
NIH	The National Institutes of Health
nPEP	See, PEP
ONC	The Office of the National Coordinator for Health Information Technology
OWL	The Georgia Out of Care Watchlist
PEP	Post-Exposure Prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief
PI	The "Promoting Interoperability" Program (formerly MU)
PrEP	Pre-Exposure Prophylaxis
Progress Note	An entry in an EHR made by a provider during a clinical visit

Quality Management	The practice of engaging in organizational review by healthcare entities to monitor, assure, or improve services or processes
Queer	See, sexual and gender minorities
Re-linkage	The linkage of people living with HIV who have "fallen out of care" to medical providers. See, ARTAS.
Ryan White	The Ryan White HIV/AIDS Program, payer of last resort for HIV-related medical care in the United States, named after a young hemophiliac boy
Ryan White Planning Council	Metropolitan Atlanta HIV Health Services Planning Council, governing entity of the Atlanta Ryan White Program, serving the 20-county EMA
SENDSS	The State Electronic Notifiable Disease Surveillance System, public health prevention software used in Georgia
Sexual and gender minorities	See, LGBTQ, but emphasizing the inclusion of an in-principle limitless range of other non-normative genders and sexualities
SNOMED CT	Systematized Nomenclature of Medicine - Clinical Terms
SO/GI	Sexual Orientation and Gender Identity generally, but especially as a Health IT standard
SPNS	HRSA Special Projects of National Significance
Structured Data	Data collected in a formatted as a discrete element, usually indexed in a database and often aligned with a standard
TasP	Treatment as Prevention
U=U	Undetectable = Untransmittable; as of 2018, the "Untransmittable" threshold is <200 copies of HIV/ml of blood
UDS	The Uniform Data System Report, filed annually by FQHCs
UNAIDS	The Joint United Nations Programme on HIV/AIDS
Undetectable	Low levels of HIV virus in the blood, usually as the result of adherence to ART and consistent engagement in medical care. Definitions have varied, and range from <20 to <200 copies of HIV/ml of blood. See, viral suppression.
Unicorn	Technology startup valued at over $1 billion
Untransmittable	See, viral suppression
Viral suppression	<200 copies of HIV/ml of blood
VPN	Virtual Private Network

Abstract

This dissertation shows that recent U.S. federal health information technology (IT) policies aimed at digitizing the health sector have been key drivers of basic changes in how sexual and gender minorities and people living with HIV are conceptualized and managed in a variety of health contexts. Knowledge that HIV treatment is an efficacious form of prevention, the incorporation of sexual orientation and gender identity into the national health architecture, and the development of a nationwide health IT infrastructure by the U.S. Department of Health and Human Services (HHS) have collectively altered the parameters around which lesbian, gay, bisexual, transgender, and queer (LGBTQ) people and people living with HIV receive clinical and public health services. The project demonstrates how these developments are remaking "biomedical sexualities:" sexualities as they become constituted as objects of knowledge and intervention in healthcare.

In the 2010s, the sexualities of people living with HIV have been reframed through a new focus on ensuring their continuous engagement in medical care as a mode of preventing HIV transmission. Since the mid-1990s, the suppression of viral load through the prescription of antiretroviral medications has been the key method for treating HIV. However, in the 2010s, viral suppression has also been promoted as the primary way to stop HIV transmission, especially via sexual routes. Thus, "treatment as prevention" has become a key tool in plans to "End AIDS" and for mitigating sexual risk in the governance of HIV. Utilizing the national health IT infrastructure, clinical and public health interventions have been constructed to keep people living with HIV engaged in care and to re-link individuals identified as out of care to providers. LGBTQ health advocates have also contributed to remaking biomedical sexualities during the 2010s, largely through efforts to regularize the collection and utilization of sexual orientation and gender identity data.

In six chapters, the dissertation documents transformations in the governance of HIV and describes the incorporation of LGBTQ health advocates' interests across branches of HHS from 2009-2017. The project emphasizes how new strategies for managing HIV and LGBTQ health have been effectuated through the nationwide health IT infrastructure, which has been built primarily through the dissemination of federal policy directives and economic incentives. Each chapter also explores the effects of federal policies on specific communities of practice, drawing on ethnographic fieldwork conducted in metropolitan Atlanta's HIV safety net and LGBTQ health communities from August 2016 to early 2019, at international conferences, and at an LGBTQ clinic and research institute in Boston.

Chapters also delineate ethical and policy problems raised by developments in U.S. health IT. Key cases include the adoption of sexual orientation and gender identity standards by HHS that employ outdated terminology in the underlying architecture to describe transgender and gay/lesbian people, and radical misalignments in HHS policies regarding when people living with HIV should be able to control the exchange of their HIV data. The project also problematizes notions of digital automation in healthcare by highlighting several health IT systems' ongoing reliance on low-waged labor performed predominantly by women of color to facilitate interoperability between infrastructures. "Remaking Biomedical Sexualities" is situated in Sexuality Studies, LGBTQ studies, Science and Technology Studies (STS), and Data Studies. It makes contributions to each of these fields and will also be of interest to practitioners in HIV/AIDS, LGBTQ health, health IT, and bioethics.

Introduction. How Transformations in U.S. Health Information Technology, the Governance of HIV, and LGBTQ Health are Remaking Biomedical Sexualities

I. Introduction: Setting the Scene

On a Friday in June 2017, I attended a daylong workshop on "Issues at the Intersection of HIV and Health's Social Determinants" in the basement of a progressive Christian church in Midtown, Atlanta. The event was attended by a diverse group of about 100 people, nearly all of whom worked in HIV. At the end of his presentation, a specialist in Black gay men's mental health dramatized how technologies can reinforce cultural stereotypes and systemic inequalities by searching for demographic groups on Google Images. Starting with a query for "pictures of Black people," the speaker scrolled through the representations that appeared, seeking reactions. The mix of stock photos showing African Americans in suits juxtaposed with celebrities and local news images of Black men being incarcerated elicited many responses, with the consensus being that Google's algorithm did, in fact, reinforce both positive and negative stereotypes about African Americans. The speaker repeated this process for "pictures of white people," "pictures of Indian people," "pictures of Middle Eastern people," and "pictures of Muslims." In each case, stock photos and images of *people* dominated the screen.[1]

He then asked: could anyone think of other groups?

Since my interest is in the categories, technologies, and epistemic frames that health practitioners use to understand sexuality, I asked: "what about pictures of 'men who have sex with men?'" Since the 1980s, this classification - abbreviated as "MSM" - has been a dominant category in HIV/AIDS, LGBTQ health, and public health discourses more broadly. MSM's original intent was to divorce gay identity from sexual behaviors. However, its continued use is the subject of much controversy and debate at the community level and among researchers and practitioners, especially in African American communities, but also in global health and HIV/AIDS discourses. MSM has been taken up by a small number of people as an identity category, disavowed as “reducing people to a sex act” by both Black gay male and white LGBTQ activists, and framed as a necessary tool by epidemiologists, researchers, and health educators. MSM is a category I had spent a lot of time thinking, reading, and talking about leading up to this day-long event at the church (including during fieldwork interviews and conversations with attendees – some of whom were long-term ethnographic interlocutors), and it is a classification to which I return many times in the pages that follow.[2]

Realizing that the images pulled up from a “men who have sex with men” search could be pornographic, I held my breath as the speaker keyed in the words. Much to my delight, the room mildly erupted when images not primarily of people, but of charts and graphs populated the screen, with just a few stock images of men from the Centers for Disease Control’s (CDC) “gay and bisexual men” page and other similar websites peppered in between the pie charts, line graphs, and histograms. Several attendees pointed out that MSM was the only group to be represented in this way, rather than predominantly through pictures of people. A man who works in substance use counseling among people living with HIV/AIDS in southwest Atlanta animatedly said “it’s because it’s clinical,” and others began to reflect on why we were looking at pictures of data, rather than persons.

Someone then suggested that the presenter search for “pictures of gay people,” which he did. The screen again filled up with bodies – this time, almost exclusively of (mostly, but not all, white) muscled gay men in various states of bedazzlement and undress at what appeared to be Gay Pride events or other similar occasions. One young African American man in the center of the room said, seeming upset, that “it is only showing pictures of MSM.” The presenter agreed, noting the absence of lesbians. Another attendee who was employed to conduct interviews for a CDC-funded HIV survey operated by the Georgia Department of Public Health (GDPH) responded, saying that she thinks MSM is just a term used in the HIV workforce. She recounted an incident when – while working as a medical case manager – she referred to a client as “an MSM” and was corrected by him. He identified as “same-gender loving” and found MSM offensive. However, just a moment before, MSM had appeared as an unproblematic synonym for gay identity (“it is only showing pictures of MSM”) – which bears no necessary relation to actually having sex with men (although most gay men do have sex with other men) – and as equivalent to “gay and bisexual men” (for example, the CDC webpage, the URL for which contains “/msm/”), even though MSM is ostensibly designed to capture individuals whose sexual self-identifications fall outside of those rubrics.[3]

At different moments, “MSM” took on several distinct forms: as a source of data about a population represented in charts, as a behavior, as a clinical category specific to HIV work, as equivalent to gay identity, and as synonymous with “gay and bisexual men.” None of these uses were “correct” or “incorrect.” Rather, MSM appeared multiply. It cohered in several distinct ways and on shifting terms from moment-to-moment, becoming constitutionally different depending on who was speaking and the context of their speech. To deploy idioms elaborated by scholars in Science and Technology Studies (STS), MSM was being *enacted, materialized* and *rematerialized*, or “built up and sustained” into existence in slightly different ways each time it was used.[4]

This scenario and other events that day dramatize issues that regularly arise during my fieldwork and health policy research on sexuality in HIV/AIDS, LGBTQ health, and health information technology (IT) in the United States and metropolitan Atlanta, as I try to make sense of how practitioners conceptualize sexuality and employ specific technologies, tools, frameworks, and materials to translate data about sexuality into stable collections of information that can be acted upon.[5] Other examples from the workshop at the church that day included presentations emphasizing the new scientific consensus that it is statistically impossible for HIV-positive individuals with undetectable viral loads – or who are "virally suppressed" – to transmit the virus to HIV-negative people (reinforced through the message "Undetectable Equals Untransmittable," or "U=U").[6] This information is a central component in the *National HIV/AIDS Strategy for the United States: Updated to 2020* (NHAS), and local campaigns to "End AIDS" or "Get to Zero" in specific jurisdictions. I participated in the creation of one such strategy as a member of the Intercultural Awareness Subcommittee of the Fulton County Task Force on HIV/AIDS from late 2016 to mid-2017.

As this knowledge is disseminated, relationships between sexuality, pleasure, and risk in the HIV workforce and communities affected by HIV are transforming. Pre-exposure prophylaxis (or PrEP) was a constant topic of conversation that day. Currently only available in the U.S. as a once-daily pill called TRUVADA manufactured by the biotechology giant Gilead Sciences, PrEP is the most effective available HIV prevention intervention, reducing infection rates by up to 99% with daily adherence. Post-exposure prophylaxis (PEP or nPEP) was also discussed. PEP is a 30-day regimen of antiretroviral medications that can prevent an individual from seroconverting (becoming HIV-positive) if started 72 hours or less after an exposure to HIV. Along with discussions of prevention and treatment best practices, attendees at this workshop also frequently brought up the tools and technologies they use to collect data about sexual behaviors, sexual identities, "risk," and HIV status at their organizations. Throughout the day, participants reflected on how the data gathered by those tools does or does not match the categories that circulate in discourses about sexuality in healthcare, the HIV world, and Atlanta. These included gay, bisexual, high risk, Leather, Black gay men, Black MSM, Latinx, LGBTQ, heterosexual female, same-gender loving, undetectable, sex in the past 12 months, transgender, lesbian, heterosexual contact with a person known to have (or to be at high risk for) HIV infection, MSM, and others – not all of which are strictly about sexuality, but all of which we had experienced as contributors to sexual reality in our personal and professional milieus.[7]

What is sexuality here? As we talked about HIV and its relationship to sex in that church basement, we were not trying to discern discrete, neatly locatable sexual identities, desires, tendencies, or ingrained practices. The literature in sexuality studies and queer studies has largely understood or assumed sexuality to exist in this fashion in what Gayle Rubin characterizes as “the folk wisdoms of Western societies” and contemporary biomedicine, particularly in psychology and psychiatry.[8] However, sexual essentialism wasn’t a major participant in this epistemic dance (although it was regularly appearing here and there). Rather, we were participating in a series of engagements where presentations of data, federal guidelines, disciplinary vocabularies, categories and technologies used in people’s daily work, and discussions of sexual behaviors, identities, racial health disparities, “risk,” and community norms were translated – or materialized – into tangible knowledge that could be collectively understood and worked with at a particular time of day. The terms of those materializations – which were necessarily perceived slightly differently by every person in the room, shaped by their professional training and life experience – changed and shifted as speakers provided their perspective, utilizing different data, languages, or tools, and starting new conversations. Through our actions, we were actively (re)making biomedical sexualities in that specific time and place.

II. Overview and Argument of the Dissertation

This dissertation shows that recent U.S. federal health information technology (IT) policies aimed at digitizing the health sector have been key drivers of basic changes in how sexual and gender minorities and people living with HIV are conceptualized and managed in a multiplicity of health contexts. Knowledge that HIV treatment is an efficacious form of prevention, the incorporation of sexual orientation and gender identity into the national health architecture, and the development of a "nationwide interoperable health IT infrastructure" by the U.S. Department of Health and Human Services (HHS) have collectively altered the parameters around which sexual and gender minorities and people living with HIV receive clinical and public health services.[9] The project utilizes federal health policy analysis and ethnographic methods, detailed further below. It is situated in, and makes contributions to, LGBTQ studies, sexuality studies, Science and Technology Studies (STS), infrastructure studies, social studies of HIV/AIDS, and the growing field of data studies. However, it is my hope that the chapters will also be useful to a variety of health practitioners in HIV/AIDS, LGBTQ health, health IT, and bioethics.

The dissertation has three through-lines that cut across six chapters. The first through-line addresses transformations in federal health IT policy. It describes how the development of the nationwide interoperable health IT infrastructure by HHS, following passage of a $30 billion federal subsidy to digitize healthcare in 2009, has transformed how health data are managed and utilized across the clinical, public health, and research sectors. The second through-line builds on the first, and describes how LGBTQ health advocates worked with the Obama administration to both incorporate their interests across branches of HHS and to cultivate a "new consensus in LGBTQ health" among key civil society actors in healthcare. A major element of this work of what I call "LGBTQ incorporation" involved the addition of sexual orientation and gender identity (SO/GI) health IT standards to the national health IT infrastructure. The dissertation's third through-line focuses on how the federal approach to managing HIV was transformed following the release of the *National HIV/AIDS Strategy* in 2010. The national strategy for governing HIV became reoriented around "treatment as prevention" (TasP). It focused on utilizing health IT capacities bolstered by the new nationwide health IT infrastructure to enact new methods of monitoring the frequency with which people living with HIV engage in medical care, and then to link them to medical providers. This work was done both to treat individuals' HIV disease and as a key method for stopping the sexual transmission of HIV by encouraging people living with HIV to become virally suppressed and thus non-infectious. In a CDC paradigm called "Data to Care," new methods for managing HIV have included state and local health departments identifying people living with HIV who are "out of care," and then conducting proactive outreach to re-link them to providers. This practice carries wide-ranging implications for patient privacy, confidentiality, and informed consent. Together, the three through-lines demonstrate how health IT infrastructures have become critical vehicles through which institutions and practitioners in HIV/AIDS and sexual and gender minority health have played a role in reshaping how sexuality is managed in biomedicine and health during the past decade.

Herein, I show how these developments are remaking "biomedical sexualities," which I define as sexualities as they become materially constituted as objects of knowledge and intervention in health contexts. I also show biomedical sexualities to be constitutive of broader "sexual realities" or "situated sexual realities:" frameworks I use to describe the constitution of the modern sexual system in the specific ways that it takes on material form in particular times and places. I try to capture this process in the ethnographic vignette that opens this introduction, and define the terms with greater specificity below.

In the 2010s, the sexualities of people living with HIV have been reframed through a new focus on ensuring their continuous engagement in medical care as a primary mode of preventing HIV transmission. Since the mid-1990s, the suppression of viral load through the prescription of antiretroviral medications has been the key method for treating HIV. However, in the 2010s, viral suppression has also been promoted as the primary way to stop HIV transmission, especially via sexual routes. Thus, “treatment as prevention” (TasP) has become a primary tool in plans to “End the Epidemic” and for mitigating sexual risk in the governance of HIV.[10] Partly by utilizing the national health IT infrastructure, new clinical and public health interventions have been constructed by state and local health departments to keep people living with HIV engaged in care and to re-link individuals identified as out of care to medical providers. These programs have been built utilizing guidance from CDC in a paradigm called “Data to Care,” which links epidemiological (or, in public health jargon, “HIV surveillance”) infrastructures operated by health departments to public health prevention and clinical safety net infrastructures.[11] LGBTQ health advocates have also contributed to remaking biomedical sexualities during the 2010s, largely through efforts to regularize the collection and utilization of sexual orientation and gender identity (SO/GI) data in healthcare and to standardize SO/GI questions and data fields across survey instruments, public health infrastructures, and clinical health IT infrastructures.

In six chapters, “Remaking Biomedical Sexualities” documents transformations in the governance of HIV and describes the incorporation of LGBTQ health advocates’ interests across branches of HHS from 2009-2017. The project emphasizes how new strategies for managing

HIV and the health of sexual and gender minorities have been effectuated through the development of the nationwide health IT infrastructure, which has been built primarily through the dissemination of federal policy directives and economic incentives. Each chapter also explores the effects of federal policies on specific communities of practice. I conducted ethnographic fieldwork in metropolitan Atlanta's HIV safety net and LGBTQ health communities from August 2016 to early 2019, at three international conferences, and at a major LGBTQ clinic and research institute in Boston. In the reminder of this introduction, I describe how the dissertation is structured, its primary sources of data and the methods used to interpret those data, and the project's main contributions to the fields in which it is situated.

Federal Health IT Policy

The central argument and first through-line of the dissertations is that transformations in federal health IT policy from 2009 onward have played a key role in reshaping the governance of HIV and the creation of medical knowledge about sexual and gender minorities in clinical and public health contexts. Specifically, I focus on how the rapid development of a "nationwide interoperable health IT infrastructure" by HHS has created a new set of conditions within which sexual orientation and gender identity (or SO/GI) data can be collected and exchanged. I also document how health IT infrastructures have facilitated new uses of data about people living with HIV and their engagements in HIV-related medical care. Following CDC guidance, HIV surveillance systems operated by state health departments – which capture the names and other vital information about people living with HIV – have leveraged new knowledge about HIV treatment as effective prevention, and new health IT capacities to effectuate new public health activities focused on re-linking individual people living with HIV who have been identified as "out of care" to medical providers. In the 2010s, new health IT infrastructures – combined with new best practices and standards of care for LGBTQ people and people living with HIV – became key vectors through which biomedical sexualities have been remade.

The development of the nationwide interoperable health IT infrastructure has been led by an office within HHS called the Office of the National Coordinator for Health Information Technology (ONC). The process was largely funded by an over $30 billion appropriation in the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH), federal legislation that was included in the 2009 American Recovery and Reinvestment Act (commonly called “the stimulus package”).[12] In just under a decade, HITECH digitized the U.S. healthcare system, fundamentally changing how healthcare is administered in the United States and how health data are exchanged and utilized in clinical, research, and public health contexts.[13]

HITECH did this primarily by empowering ONC and the Centers for Medicare and Medicaid Services (CMS) to incentivize healthcare organizations to digitize. In the United States, healthcare is a sector that has long lagged behind other industries in processes of digitization. In 2009, the year of HITECH’s passage, U.S. healthcare organizations continued to rely overwhelmingly on paper records and systems.[14] Chapter two explains the mechanisms that ONC employed to do this work, particularly through the provision of financial incentives to clinical providers for adopting federally-certified electronic health records (EHRs), establishing state-based health information exchanges (HIEs), and publishing recommended sets of health IT “interoperability standards” designed to facilitate the easy exchange of data between healthcare organizations. Chiefly, HITECH funded and empowered ONC to build programs to certify EHRs and other health IT systems, and then provided mechanisms for the Centers for Medicare and Medicaid Services (CMS) to distribute incentive payments to providers who self-attested to their “Meaningful Use” of certified EHRs. This program, called the EHR Incentive Payment Program, began in 2010 and proceeded in three phases. It has been highly effective in creating a baseline for digitization in U.S. healthcare. By 2017, over 96% of hospitals were utilizing federally-certified EHRs, and 86% of office-based physicians had adopted an EHR.[15] By comparison, in 2010 (the year the EHR Incentive Payment Program began), office-based physicians using a "fully-functional" EHR was estimated at 10.1%,[16] and at 16.1% for all hospitals.[17]

Federally-certified EHRs utilized by providers, the network of state-based exchanges set up by ONC, and recommended interoperability standards would become the backbone of the new nationwide interoperable health IT infrastructure. In this "health IT ecosystem," whereby data were imagined as moving evermore-freely between IT systems and across domains of practice as U.S. healthcare became further digitized.[18] Using digital studies scholar Wendy Chun's notion of a "programmed vision," I frame the pursuit of total interoperability as a kind of digital utopian discourse that was typical of the 2000s and 2010s.[19] In sweeping plans, ONC and health IT proponents spoke of health data becoming "liberated," "liquid," and more readily able to be more utilized by clinical and non-clinical healthcare organizations, researchers, public health officials, and patients.[20]

As I document in chapters two, three, and four, however, the new interoperability paradigm has been accompanied by a huge range of challenges. These include difficulty in automating interoperability between health IT systems, and systems' ongoing reliance upon paper forms and analog labor performed by teams (many of which are made up predominantly of women of color) to function and to interoperate with other systems. The healthcare workforce – from medical providers to executives and data entry personnel – regularly express extreme frustration in working with difficult EHR interfaces and other health IT systems.[21]

One key development in the construction of the nationwide interoperable health IT infrastructure has been the incorporation of sexual orientation and gender identity data (or "SO/GI") fields into EHR certification criteria and health IT interoperability standards.[22] The addition of these standards to EHR certification criteria and ONC's *Interoperability Standards Advisory* in 2015 were critical elements in what I characterize as the "incorporation" of LGBTQ health advocates' interests into HHS policy from 2009-2017 and in the cultivation of a "new consensus in LGBTQ health" among healthcare civil society organizations.[23] These shifts drove transformations in sexual and gender minority healthcare, and constitute another central focus of the dissertation's descriptions of how biomedical sexualities were transformed in U.S. healthcare in the 2010s.

LGBTQ Incorporation at HHS and the New Consensus in LGBTQ Health

The second major through-line of the dissertation focuses on the development of a new consensus in LGBTQ health, which was driven and buttressed by the systematic incorporation of LGBTQ health advocates' interests and new standards of care for sexual and gender minorities into the federal health policy apparatus by the Obama administration from 2009-2017, with the support of key civil society actors in healthcare. In chapter three, I show that the addition of SO/GI data collection elements across the U.S. healthcare system, and in EHR certification criteria, were central to this process of incorporation. The wide availability of data about LGBTQ people in clinical, public health, and research contexts was framed by advocates as a wellspring from which many other positive outcomes would flow for the healthcare system and for sexual and gender minorities.

A major 2011 U.S. Institute of Medicine (IOM) report on LGBTQ health instigated and guided much of the federal and private sector LGBTQ health reforms during this period. The report is titled *The Health of Lesbian, Gay, Bisexual, and Transgender People: Toward a Foundation for Better Understanding*.[24] Four out of the seven recommendations issued by the report concerned data collection and the improvement of data collection instruments to grow the knowledge-base around LGBTQ health issues and disparities.[25] The Obama administration would aggressively pursue the goals articulated in this document. For example, the administration established an all-HHS LGBT Issues Coordinating Committee that coordinated agency activities and produced annual accounts of pro-LGBTQ actions taken by HHS. The agency also responded to LGBTQ health advocates' requests to incorporate sexual orientation and gender identity questions in federal surveys and to include SO/GI data in federal EHR certification criteria and health IT interoperability standards.

This form of incorporation of LGBTQ health actors' interests into HHS policies did not equate to the creation of robust federal infrastructures specifically to support LGBTQ health through direct programmatic work or service-delivery streams aimed at sexual and gender minorities. More than a set of centralized infrastructures to administer services to sexual and gender minorities, "LGBTQ health" is a set of preferred policies, desires, known issues, and a loose network of researchers, institutions, and advocates. Unlike in HIV and health IT, there is no centralized set of federal LGBTQ health institutions or a well-developed and funded federal apparatus to manage programs dedicated to services for queer and trans people.

The dedicated LGBTQ health infrastructures that do exist are usually emergent or new, in entities like the Sexual and Gender Minority Research Office at the National Institutes of Health. "LGBTQ health" is, rather, disbursed unevenly throughout different arms of the healthcare system, and takes place through the addition of questions about sexuality and gender to survey research questions and federal EHR certification criteria, or the inclusion of LGBTQ health goals or “sexual orientation and gender identity” in guiding documents like the *National HIV/AIDS Strategy*, federal health disparity group guidelines produced by the Centers for Medicare and Medicaid Services, or *Healthy People* (a document released every ten years which sets general guiding priorities for the national public health system, and which included “LGBT objectives” for the first time in its 2010 edition).[26] The addition of LGBTQ non-discrimination and “cultural competency” requirements to healthcare facility accreditation requirements or continuing education curricula for medical professionals are other examples of areas of advances in LGBTQ health.[27]

Further, health policy analysis research and fieldwork done for this dissertation revealed that, insofar as federal LGBTQ health infrastructures and biomedical knowledge about LGBTQ people do exist, much of this is because of HIV-related programming, given the epidemic’s disproportionate effects on gay and bisexual men and transgender people. The authors of the landmark 2011 U.S. Institute of Medicine LGBT health report note this, as did many fieldwork interlocutors in Atlanta and elsewhere.[28] Further – and as I discuss in chapter three – following the election of Donald Trump in 2016, many federal gains in LGBTQ health policy are being undone or rolled back, or face an uncertain future.[29] However, even as these efforts move forward, the new administration has maintained a commitment to “Ending AIDS,” launching *Ending the HIV Epidemic: A Plan for America*, in February 2019.[30] As I detail below, this strategy (met with a mixture of praise and skepticism by advocates) will leverage advances in health IT and knowledge about treatment as prevention to address the epidemic, accelerating policies put in motion during the Obama years.[31]

So, while this dissertation focuses on the incorporation of SO/GI data and LGBTQ health actors’ priorities into the U.S. healthcare system and health IT infrastructure, it is equally about

HIV and the interwoven infrastructures that exist in the U.S. to manage HIV. This is both because HIV disproportionately affects LGBTQ people and because new knowledge about HIV treatment as prevention, paired with IT systems built to manage the risk of sexual HIV transmission, have been key vectors through which biomedical sexualities are being remade.

HIV Data Infrastructures and Governing the Active AIDS Crisis in the United States and Metro Atlanta

HIV proved to be an ideal case for studying transformations in biomedical sexualities in U.S. healthcare during the 2010s for two reasons. The first is primarily because HIV care, prevention, and surveillance infrastructures are centrally-administered by CDC and the Health Resources and Services Administration (HRSA), both of which are agencies within HHS. Because of this centralized form of bureaucratic management, the health IT infrastructures used to manage the HIV epidemic and data about HIV have been relatively easy to integrate with one another when compared to other areas of the healthcare system such as health information exchanges predominantly used by private providers. Further, the development and transformation of HIV data infrastructures has been well-documented through correspondence between federal agency personnel and state and local health departments, a process that lends them to comparatively easy study.

The second reason HIV made an ideal case is because HIV programs have collected detailed data on the sexualities of people living with and affected by HIV for nearly four decades. They have done so particularly through a framework called the “HIV risk hierarchy” – the history and current uses of which I examine in chapter one – and more recently by tracking rates of HIV “viral suppression” at the individual and group level as key methods of monitoring the epidemic and making determinations about how to manage sexual risk, which I examine in chapters five and six. I refer to the collection of strategies for managing HIV at the individual and group level in the United States as “the governance of HIV.” Transformations in methods used to govern HIV disease and to prevent the sexual transmission of HIV during the 2010s are the result of new HIV treatment guidelines recommending universal antiretroviral therapy for people living with HIV, paired with new uses of HIV data by public health entities to monitor how individual people living with HIV engage in medical care, and then to re-link people identified as out of care to medical providers using HIV surveillance data in a paradigm called “Data to Care.”[32]

HIV surveillance as practiced in the United States is one of the most distinct aspects of the national response. For the last decade, the federal response to the domestic HIV/AIDS crisis has not been to dramatically change the way that people living with HIV receive healthcare and other services, but to engage in increasingly precise methods of surveillance to monitor and respond to the epidemic as it evolves, in order to better allocate limited federal resources. Chapters one, five, and six describe the history and current practice of HIV/AIDS surveillance in the U.S., framing it as the keystone of the U.S. approach to managing to HIV/AIDS epidemic. However, as I detail below, the use of data to manage the HIV/AIDS epidemic in the United States has evolved radically over time, with surveillance systems becoming increasingly linked to care and public health prevention infrastructures as the national health IT infrastructure develops. In the current moment, CDC, HRSA, and state and local health departments use knowledge about HIV treatment as effective HIV prevention and new health IT capacities to engage in novel forms of planning, resource-allocation, and re-linkage to care.

To wit, HIV is often framed as a “chronic manageable illness” – and it is, for those who can stay retained in HIV-related medical care and on a daily regimen of antiretroviral medications for the duration of their life. Further, those who can maintain a consistent undetectable viral load are also unable to transmit HIV to others (Undetectable equals Untransmittable/treatment as prevention). However, the ability to remain in medical care (and thus to stay undetectable) is not the reality for most people living with HIV/AIDS globally, in the United States, or in metropolitan Atlanta. Owing to inadequate public health infrastructure and supportive social services, a person dies of AIDS-related causes in Georgia at the rate of about one per day.[33] Rates of viral suppression among people diagnosed with HIV in Georgia and metro Atlanta hover around 49% and 52%.[34] Viral suppression or "undetectability" (measured in 2019 as less than 200 copies of HIV virus per milliliter of blood) is the most commonly-employed measure of immune health for people living with HIV; it also means that an individual's HIV is "untransmittable."[35] Georgia and Atlanta's overall viral suppression numbers are not exceptional. They are, in fact, close to the national rate of viral suppression in the United States, which is estimated to be somewhere between 52% and 55%.[36] However, in Atlanta's city center, rates of viral suppression among individuals diagnosed with HIV can be as low as 35%.[37] Further, figures for Atlanta and Georgia do not include many of the individuals in the estimated 15% of people living with HIV who are not aware of their diagnosis.[38]

According to CDC – itself headquartered in Atlanta – metro Atlanta has the fourth highest rate of new HIV infections of any urban jurisdiction in the country.[39] Georgia has the highest HIV rate of any U.S. state, and the second highest rate of new infections among youth.[40] In the absence of a transformed approach to healthcare in the U.S., one in two Black gay and bisexual men in the Southeastern United States is projected to become HIV-positive in their lifetime.[41] These rates are generally understood to be higher among transgender women, although reliable estimates do not exist.[42] The city of Atlanta, the metro area, the state of

Georgia, the U.S. South, and the United States itself are all epicenters of the ongoing transnational AIDS crisis.[43]

And yet, along with a chorus of voices that includes global civil society organizations such as The Joint United Nations Programme on HIV and AIDS (UNAIDS), CDC, HHS, and activists in localities around the world, advocates in metro Atlanta have promoted and built policy frameworks to bring about the "End of AIDS" – also called an "AIDS-free Generation," the "End of the HIV Epidemic," or a world with "Zero New Infections."[44] In the U.S., a main method to pursue these goals has been through the systematic linkage of data infrastructures from different domains of HIV practice to one another in new ways.[45]

Throughout the dissertation, I refer to three main "domains" of HIV work: HIV care, HIV surveillance, and HIV prevention.[46] CDC oversees HIV the domains of HIV surveillance and prevention through its Division of HIV/AIDS Prevention. HRSA oversees the domain of HIV care through its HIV/AIDS Bureau and administration of the Ryan White HIV/AIDS Program, which is the payer of last resort for HIV/AIDS care and support services in the United States. In the 2010s, person-level HIV surveillance data – what were formerly epidemiological data held by state departments of public health and used exclusively for monitoring and planning responses to state and local HIV epidemics – started to be utilized for direct prevention activities.

Further, the nature of HIV surveillance data changed.[47] As I discuss in chapters, one, five, and six, HIV surveillance is a subfield of public health surveillance with a very specific history and form in the United States: one which has gone from an inexact process of aggregating data about AIDS cases and AIDS-related conditions, to the mandatory reporting of all new HIV cases in 1997, to names-based reporting in all U.S. jurisdictions at time of diagnosis by 2008, to (since 2013) continuous and ongoing measurement of the amount of virus in individuals' blood and their patterns of engagement in HIV-related medical care through a framework called the "HIV Care Continuum." In 2013, the U.S. HIV apparatus essentially reoriented itself around the Care Continuum following the launch of the HIV Care Continuum Initiative by the Obama White House and corresponding changes in the national HIV surveillance infrastructure designed to measure viral load and engagements in care by people living with HIV.[48] In 2018, this trajectory gave rise to "molecular HIV surveillance," which traces the particular strain (or strains) of HIV virus that an individual has in their body and the movement of strains of within "transmission networks" or "clusters" using phylogenetic testing methods.[49]

These "Electronic Lab Reporting" (ELR) data are generated in clinical contexts and serve a wide range of clinical purposes. They help clinicians decide what medications to prescribe patients based on viral resistance profiles, and other issues. They also require informed consent to be collected by a clinician. However, ELR data are also used for surveillance purposes, a domain of public health which does not require patients' informed consent. Further, since the launch of "Data to Care" in 2014, state HIV surveillance data are increasingly linked to prevention infrastructures, whereby public health departments use surveillance data to identify and locate "out of care" individuals and then re-link them to care. Thus, one of this dissertation's chief concerns is describing how classes of HIV data that were formerly distinct from one another have been increasingly collapsed into each other through the infrastructures that are used to manage HIV programs and health data infrastructures in clinical and public health contexts. This is done with the dual-aim of treating individuals' HIV disease and ensuring that they become non-infectious to others – the key vehicle through which biomedical sexualities are being remade in the realm of HIV practice.

The use of person-level HIV surveillance data in this way is a major and seriously under-appreciated development in the history of HIV data in the United States, the history of the governance of HIV in the United States, and the history of sexuality. I explain the federal Data to Care paradigm in chapter five. Then, in chapter six, I describe how the Georgia Department of Public Health has pursued a statewide Data to Care strategy through the creation of an HIV "Out of Care Watchlist" (OWL) made up of people living with HIV who have not reported HIV-related bloodwork in 15-to-24 months, and an HIV Health Information Exchange (HIV HIE) connected to the electronic health records of three safety net health clinics in Atlanta. Data to Care raises serious bioethical questions, particularly since there is no way for people living with HIV to opt out of these programs, and since informed consent is not required for re-uses of these data by public health entities.[50]

III. Methods and Data for the Dissertation

For a full discussion on methods and sources, I encourage readers to consult this dissertation's Appendix. However, the main methodologies employed in this dissertation are health policy analysis and ethnography. The project takes federal policy developments in health IT, sexual and gender minority health, and the governance of HIV as investigatory starting points. However, each chapter also explores the effects of federal policies on specific communities of practice, drawing on ethnographic fieldwork in metropolitan Atlanta's HIV safety net and LGBTQ health communities from August 2016 to early 2019, at three large international conferences, and at an LGBTQ clinic and policy in Boston.

Health policy analysis research proceeded in several distinct waves and on an ongoing basis during fieldwork. Federal health IT policy research is synthetic in nature, and focused on reading and annotating large volumes of published material and grey literature produced by federal agencies and select civil society organizations and private sector actors in the health IT industry.[51] I systematically gathered and stored documents from federal agency, civil society, and advocacy organizations' websites on issues related to LGBTQ incorporation, the governance of HIV, and the development of the nationwide interoperable health IT infrastructure. I also utilized the Federal Register online portal to conduct analyses of proposed regulations (or "rules"), public comments solicited on those initial rules, and final rules. This is especially true for health IT rulemaking processes led by the Office of the National Coordinator for Health Information Technology (ONC). During research and fieldwork, I also consumed a large volume of health IT industry trade media and health policy media, including journalistic content as well as technical guidance issues by branches of HHS, white papers, and reports published by trade press outlets and private firms.

The main ethnographic tools that I utilized to gather data were interviews, participant-observation, and attendance at public events and meetings. The kind of ethnography and ethnographic description that I practice is quite technical, and rooted in STS, infrastructure studies, and the sociology and anthropology of biomedicine and health. During interviews and participant-observation work, I would often sit with healthcare workers as they wrestled with a particular piece of technology, or would ask them to reflect on their use of a specific data collection tool or software. I would generally also gather and analyze operational documents related to the processes they described to me for examination later; I would often then follow up with further questions. A large portion of my fieldwork also pertained to the categories that institutions and personnel use to understand sexuality – particularly the category "MSM" for "men who have sex with men," and other categories contained in sexual orientation taxonomies and other classifications in the HIV risk hierarchy (which is the subject of chapter one). Thus, I would often ask interlocutors to reflect on their use of specific categories, or to discuss how they understood differences between categories such as “MSM” and “gay and bisexual men.” The technical nature of the ethnography is showcased by my descriptive methodologies, which are focused on producing exacting accounts of the precise ways that actors conceptualize and work with tools, categories, and technologies.[52]

I chose metropolitan Atlanta as my field site because of the severity of the HIV/AIDS epidemic in Atlanta, because there were opportunities to become involved in policy and advocacy efforts as an engaged scholar and advocate for LGBTQ people and people living with HIV, and because the local LGBTQ health community and key actors in the Ryan White infrastructure in Fulton County were open to my ethnographic engagements. Atlanta is also a neglected site in the LGBTQ studies and sexuality studies literature, and I aim to help fill that gap with this dissertation.

Gold Standards

I employ the notion of a “gold standard” throughout the dissertation. I do so because much of the project is focused on tracing the implementation of new or emergent best practices in health IT, LGBTQ health, and HIV; many of these have only recently become (or are in the process of becoming) “gold standards.” I draw my use of the term primarily from STS scholars Stefan Timmermans and Marc Berg’s work on the subject. They define a gold standard as a variety of different kinds of “evidence-based guidelines” that are employed by health professionals in their work, with an emphasis on medical standards or guidelines that have been validated through randomized control trials.[53] I use the term “gold standard” slightly more capaciously, to describe published or recognized best practices or available guidelines that exist in a specific area of practice. Sometimes, as in HIV care and prevention, gold standards are rooted in knowledge from randomized control trials. However, other times, what I refer to as a "gold standard" has not been subjected to a great deal of testing, but has been derived from other sources of knowledge or testing methods – sometimes with a relatively small evidence-base.

For example, as I show in chapter three, clinical sexual orientation and gender identity (SO/GI) data collection best practices and SO/GI health IT standards disseminated by groups like Fenway Health were subjected to very limited testing before being adopted as "national standards" by ONC.[54] "LGBTQ cultural competency" trainings are another area where a great deal of work takes place without much of a hard evidence-base beyond the experiences of trainers working in LGBTQ health contexts, especially at the local level.[55] As I show in chapter one, the HIV risk hierarchy, as show in chapter one, is a gold standard not as the result of testing, but as the result of its near-universal uptake in the U.S. HIV apparatus over time. As a paradigm in the governance of HIV, Data to Care has itself only been subjected to more rigorous tests of efficacy following its implementation, not before (yet CDC Data to Care guidance functions as the gold standard for state and local health departments).[56] Thus, in "Remaking Biomedical Sexualities," the term gold standard refers to available best practices as they exist and as I observed or documented them being taken by practitioners and institutions, even if evidence for those best practices is limited or only emergent in the literature.

IV. Biomedical Sexualities and Sexual Realities

I employ the term "biomedical sexualities" to refer to sexualities as they become constituted as objects of knowledge and intervention in health contexts. In this dissertation, "biomedical sexualities" refer especially to sexualities as object of knowledge in clinical and public health settings – and particularly those biomedical sexualities related to HIV and sexual and gender minority health.[57] However, the concept can be extended and utilized in any inquiry where data about sexuality, sexual health, sexual risk, or other information related to sex is gathered and utilized in order to generate actionable knowledge in health settings (for example, in research contexts). Biomedical sexualities are distinct from other frameworks for understanding sexual subjectivity or identity. However, biomedical sexualities are also partly *constituted by* and *constitutive of* these and other modalities for understanding, organizing, governing, or creating knowledge about sex. As in the history of modern sexuality, medical knowledge about sex in the contemporary moment exists in a mutually-informative relation to sexual practices and LGBTQ cultures.[58]

For example, the verifiable existence of sexual and gender minority patients and LGBTQ health disparities via the collection of sexual orientation data in electronic health records, or the development and execution of a sexual and gender minority research agenda by NIH, helps major LGBTQ advocacy organizations make appeals in other areas of policy. Biomedical sexualities are one critical element in the broader realm of discourse about the governance of sexuality, sexual and gender minority populations, and public health issues related to sexuality, such as the mitigation of HIV and STD incidence by public health institutions. As an analytical tool and orienting framework, "biomedical sexualities" captures how sources of data about sexuality, gender, and HIV status create parameters within which sexuality emerges as an object of knowledge in health. The term further captures how new tools or data come to be constitutive of sexuality in a clinical or public health environment that were not previously, such as the conversion of data about HIV viral load and viral suppression into knowledge about risk of sexual HIV transmission in the 2010s.[59]

Thus, to reiterate, this dissertation's central claim is that biomedical sexualities have been "remade" during the 2010s in U.S. healthcare – especially for people living with HIV and sexual and gender minorities – and that health IT has been a central vehicle through which these transformations have taken place. For people living with HIV, biomedical sexualities have primarily been remade through new strategies for governing HIV as a public health issue and managing HIV disease that are rooted in "treatment as prevention" as the central modality for governing sexual risk and mitigating HIV transmission. For LGBTQ people and other sexual and gender minorities, biomedical sexualities have primarily been remade via the incorporation of LGBTQ health advocates' interests into HHS policies by the Obama administration from 2009-2017, as outlined above and in chapter three.[60]

In STS parlance, biomedical sexualities are *enacted* or *materialized* into existence by actors in healthcare who work with technologies, data, and interpretive methods to gather data and convert it into meaningful and thus actionable information that can structure specific health interventions.[61] Biomedical sexualities acquire material form in health contexts, and thus become actionable things that a variety of practitioners can work with in clinical, public health, research, and other varied settings. Biomedical sexualities have less to do with sexual self-identification or behaviors than with the full sum of data that are gathered during a healthcare event (or which are present in a health record or health IT system), how those data are interpreted (and with what tools), and then how practitioners use that information and their own disciplinary training to generate knowledge and structure action.

The refashioning of biomedical sexualities in the governance of HIV and sexual and gender minority health practice has had broader effects that are affecting, reshaping, and altering the contours of the modern sexual system outside of healthcare. For example, in chapters five and six, I demonstrate how shifts in the management of sexual knowledge in HIV are creating new forms of *de facto* criminalization for people living with HIV who cannot remain in continuous medical care. These individuals, placed on “out of care lists” and (in some states) subject to different HIV disclosure laws than their “undetectable” peers, are framed as sexually dangerous subjects and bad actors in the healthcare system.[62] Changes in healthcare and transformations of biomedical sexualities are thus contributing to broader, ongoing reorganizations of contemporary sexuality itself.

Thus, working in a constructivist mode shaped by constructivist STS and sexuality studies scholarship, I treat biomedical sexualities and other concepts or frameworks for thinking about sex such as “sexuality,” “sexual orientation,” “sexual risk,” or “sexual health” as constitutive elements of “sexual realities” that are particular to specific times and places. Like biomedical sexualities, sexual realities must, in the parlance of actor-network theorist John Law, be “held up and sustained” by the actors and institutions at play in a particular time and place using “methods assemblages,” or tools and ways of interpreting and acting on available information in a specific context.[63]

My use of “sexual reality” comes from Robert Padgug’s seminal essay “Sexual Matters: On Conceptualizing Sexuality in History.” The term is intended to be capacious and to capture the full breadth of elements that can shape how sexuality takes on material and discursive form – or how sexuality shapes a particular state-of-affairs. In that piece, Padgug writes that

> sexual reality is variable, and it is so in several senses. It changes within individuals, within genders, and within societies, just as it differs from gender to gender, from class to class, and from society to society. Even the very meaning and content of sexual arousal varies according to these categories. Above all, there is continuous *development and transformation* of its realities.[64]

As analytical frameworks, “biomedical sexualities” and “sexual realities” are designed to capture complexity, but also to help identify and describe specific elements or components of sexual reality in a specific time and place, along with the processes that make those elements cohere.

Sexual realities are always situated, or spatiotemporally and situationally bounded.[65] They materialize in assemblages: a multiplicity of entangled practices, discourses, and things that are reproduced continuously, habitually, and creatively by human and non-human actors.[66] Drawing on Deleuze and Guattari, I employ what I call "diagrammatic" methods to describe the specific constitution of biomedical sexualities and sexual realities in specific organizations, areas of disciplinary or public health practice (such as "HIV" or "LGBTQ health"), or geographic locations.[67]

Diagrammatic methods treat realities as the effect of many intermingled forces converging from multiple scales at once – scales I sometimes refer to as the *macro*, *meso*, *micro*, and *molecular*. For example, information collected during clinical encounters where an organization undertakes an assessment of sexual health often include data about sexual behaviors, identity, attractions, and orientation. However, the situated sexual realities enacted in clinical workflows generally also encompasses a great deal of other information, such as a patient's history of sexually transmitted infections (STIs), previous and current laboratory test results, cardiovascular health, whether one has been vaccinated against conditions such as hepatitis A and B or viral meningitis, how one *feels* about the sex they are having, required questions or patient assessment tools imposed upon clinical organizations by funding agencies such as CDC or HRSA, specific sexual practices discussed, medication adherence and viral load count (in the case of people living with HIV/AIDS), whether a patient is perceived to be a member of an "at-risk" group based on demographic attributes that may not be about sexuality *per se* (such as race and age), the tools an individual reports using to practice safer sex, and observable bodily markers such as the presence of foreskin or genital warts.

The examples just given show how biomedical sexualities are conditioned by a wide array of forces, whenever actors work them into existence in a given time and place: from CDC guidelines (a macro scale) to laboratory test results to determine viral load or the presence of an STI (a molecular scale), and policies specific to a given healthcare organization (a meso scale). Further, as I describe in the case of new forms of *de facto* criminalization of people living with HIV who cannot maintain an undetectable viral load, these biomedical sexualities often go on to shape the constitution of sexual realities outside of health contexts. Thus, "Remaking Biomedical Sexualities" describes the refashioning of medical knowledge about sex as part of the broader project – well beyond the scope of this dissertation and collectively pursued by a range of scholars of contemporary sexuality – of re-articulating the constitution of the sexual system itself in an era of biomedicalization.[68]

"Queer," or "Sexual and Gender Minorities and People Living with HIV"

I also frequently use the term "queer" in this dissertation. My deployment of the term draws from three distinct tendencies in writing on sexual politics, sexual and gender minority issues, and HIV/AIDS. I use it in specific ways or to refer to particular groups ("queer" as an attribute connoting sexual otherness), and also as shorthand for all sexual and gender minorities and people living with HIV.

The first thread emerges from sexuality studies and is my primary analytical orientation; it supersedes the other two. This use of "queer" takes non-heterosexuality, non-heteronormative styles of living, and various forms of embodied, felt, or perceived deviance related to sex as its key definitional axis.[69] In my use, queerness always refers to sexual categories, sexual subjectivities, sexual power structures, or sexual acts that do not fit within the parameters of heteronormative acceptability, progression toward domestic familial life, and/or sexual tendencies beyond the narrow range allowed in what Gayle Rubin calls "the charmed circle."[70]

Like Rubin, I understand sexuality as a system of power with "its own internal politics, inequities, and modes of oppression."[71] Sexuality is informed and held up by – but is not reducible to the effects of – other systems of power such as gender, race, class, and disability. Sexuality is thus able to be analytically parsed from and described independently of other systems of power that organize society. Queerness can, in part, be an effect of other vectors of power such as race, gender, class, or disability. However, this is true only insofar as these other systems affect one's position within the sexual system, thus working to situate them on the low end of what Rubin calls "the sex hierarchy."[72]

My second use of queer stems from the first: as an umbrella term for "sexual and gender minorities," "LGBTQ people," or "sexually othered persons." Queer, here, is what David M. Halperin calls "an identity without an essence…available to anyone who is or who feels marginalized because of his or her sexual practices" or sexually non-normative modes of living.[73] Notably, this use of queer marks transgender and gender nonconforming individuals as queer. However, it does so not through a kind of "lumping in" of non-cisgender subjects with LGB subjects or other sexual minorities (such as fetishists). Rather, my use of queer in this second mode marks gender minorities as queer using the logics of the first mode: as positioned on the low rungs of sexual hierarchies.

Taking cues from Cathy Cohen in "Punks, Bulldaggers, and Welfare Queens," this use of queer frames persons and bodies who do not conform to other normativites in ways that mark them as being sexually deviant or abnormal within the logics of the sexual system.[74] This queer marking occurs much in the same way for gender minorities as it does for heterosexual people who remain uncoupled for their entire lives and are thus queer because of their patterns of non-cohabitation with romantic partners, or in the ways that certain classes of Black women are framed as sexually dangerous or excessive and thus queer, or in the manner that people who cannot have sex in the modalities that able-bodied persons can (such as many disabled and elderly people) are queerly marked.[75]

These subjects are queer not because of their gender, race, age, or disability, but as an effect of their bodies or subjectivities not fitting into the charmed circle sustained by the sexual system. To say it another way: queerness in this second mode is not an effect of gender, race, class, disability, or even "sexual orientation" (in the case of the uncoupled heterosexual). This queerness is an outcome of how the modern sexual system positions trans, racialized, disabled, and other non-normative subjects within its hierarchies, which are specific to the politics of sex.

The third tendency that informs my use stems from Cindy Patton's use of queer in her 1985 text *Sex and Germs: The Politics of AIDS* and her elaboration of "the queer paradigm" in her 1990 book *Inventing AIDS*.[76] More recently, Adam Geary adopted "the queer paradigm" as part of his work to build up a "materialist epidemiology."[77] Patton's books were published before queer theory existed. Her use of queer is, in the first instance, about how homosexuality and queer sexual practices deemed deviant or dangerous became even more so when associated with AIDS. However, in its expanded mode, Patton's "queer paradigm" refers to "the 4-H paradigm:" homosexuals, hemophiliacs, heroin addicts, and Haitians. These were the groups most commonly associated with AIDS in U.S. epidemiological and media discourses in the mid-to-late 1980s, as I discuss in chapter one.

When I use queerness in this third mode, I do so as an extension of both the first and second: queer as sexually deviant because of a characteristic that is not (per se) about sexuality –

HIV-positive serostatus – but which marks an individual as aberrant within the logics of the sexual system. Thus, my use of queer also encompasses *all people living with HIV*. All people living with HIV are queer because their HIV-positive status marks them as such, owing to HIV's association with deviant sexuality and sexual risk. However, I also emphasize how *certain classes of people living with HIV are queerer than others*. People living with continuously suppressed HIV virus, for example, are less queer than are, on the other extreme, people with untreated HIV disease who may fetishize its transmission. There are infinite degrees between these two poles, which I work out more systematically in chapter six, on HIV "Data to Care" activities in Georgia, "the new sex hierarchy for people living with HIV," and the *de facto* criminalization of people living with HIV in the United States who are not in consistent medical care.

V. Plan of the Dissertation

Each of the dissertation's six chapters is designed to explain a specific federal policy or a set of federal policy frameworks pertaining to health IT, LGBTQ health, and/or the governance of HIV. Each chapter also describes how those federal frameworks affect or shape one or more local, organizational, or disciplinary communities of practice. Every chapter draws on both federal health policy analysis research and fieldwork data. However, some are more focused on explaining federal paradigms and then demonstrating their effects in local or bounded contexts (specifically chapters one, two, three, and five), while others are centered on local ecologies of actors in metro Atlanta, with federal policies or infrastructures guiding the local investigation (chapters four and six).

The order of chapters one through four is designed to historicize the study and to demonstrate its methodologies (chapter one), then to explain the development of the nationwide interoperable health IT infrastructure from 2009 onward (chapter two), then to describe federal policies regarding the incorporation of LGBTQ health advocates' interests into the national healthcare architecture and health IT infrastructure (chapter three), and then finally to focus on how federal policies shape local communities of practice and how they work with different kinds of data about sexuality, gender, and HIV in their situated milieus (chapter four).

Chapters five and six address transformations in the governance of HIV, particularly pertaining to new uses of HIV surveillance data for public health prevention purposes and the management of sexual risk in the era of treatment as prevention. Chapter five focuses on federal policy paradigms in this area, specifically the "HIV Care Continuum Initiative" and "Data to Care," while chapter six focuses on explaining the effects of these policies in the state of Georgia and their broader consequences for HIV practitioners and people living with HIV. Below, I briefly describe each chapter. I explain the organizational logic of its placement in the dissertation and provide an overview of its methodology, main sources of data, and key findings.

Chapter one offers an historical, ethnographic, and technical analysis of the "HIV Risk Hierarchy," a taxonomy in HIV practice that is used in a wide variety of care, prevention, surveillance, research, and other contexts. The hierarchy is primarily designed to measure the most likely reason that an individual became HIV-positive, or to catalogue "risk factors" that might cause an individual to become HIV-positive. I show that practitioners imagine the HIV risk hierarchy as a singular taxonomy imposed upon actors working in HIV by CDC. However, the central contribution of the chapter is to show that, while the hierarchy is imagined as monolithic and imperially-imposed upon local actors in the HIV world by CDC, it only takes material form in practice by appearing as many different versions of itself as it is employed by practitioners. What appears to be a single, rigid standard is actually a multiplicity of differently-constituted iterations of that thing. Further, HIV risk hierarchy data are used in many different ways, including as a stand-in for data about "sexual behaviors" or "sexual orientation."

Chapter one comes first to provide historical context for the full dissertation project, and also because it demonstrates the various methodologies that appear throughout subsequent chapters. It showcases approaches in both ethnography and health policy analysis that focus on explaining highly technical issues, on describing uses of categories by a wide variety of actors and institutions, and on illuminating the particularities of specific forms of biomedical practice and the biomedical sexualities they produce. In addition to incorporating data from ethnography and policy research, a central source of data for this chapter is a genealogical analysis of technical notes defining the hierarchy from the *HIV Surveillance Report*, released annually by CDC since 1982. In addition to analyzing the hierarchy itself, the chapter offers an analysis of its most contested category: "male-to-male sexual contact," which was previously called "men who have sex with men" (MSM) and is still often reported out in data reports using that language.

Chapter two provides the data and context to understand developments in federal health IT policy and the growth of the nationwide interoperable health IT infrastructure that have fundamentally changed how health data are collected, managed, and exchanged in clinical and public health contexts. This has largely taken place due to the over $30 billion subsidy for EHR utilization and the construction of state-based health information exchanges provided for in the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH). Understanding the development, structure, and aims of the nationwide interoperable health IT infrastructure is vital for the chapters that follow. The adoption of clinical EHRs, the addition of sexual orientation and gender identity (SO/GI) data to all federally-certified EHRs, and the implementation of new exchange infrastructures and health IT systems in the U.S. health sector during the 2010s has played a critical role in facilitating transformations in how data about sexuality, gender, and HIV status are used in healthcare. I articulate HHS's vision of nationwide interoperability as a utopian "programmed vision" of perfect and totalizing interconnectivity, and the chapter explores the pitfalls of interoperability – a problem I return to in chapter four in a local investigation of HIV care data infrastructures in Atlanta.[78]

Chapter three builds a bridge between my analyses of transformations in federal health IT policy, LGBTQ health, and the governance of HIV. It illuminates how federal LGBTQ health advocates utilized the development of the nationwide interoperable health IT infrastructure to successfully incorporate SO/GI health IT standards into binding federal EHR certification criteria and the non-binding *Interoperability Standards Advisory*. Drawing on federal health policy research, I frame the incorporation of SO/GI into the nationwide health IT infrastructure as central to the development of a new consensus in LGBTQ health and the incorporation of LGBTQ health actors' interests into the federal health policy apparatus by the Obama administration.[79] I also introduce the concept of "data ontology management" in the chapter, which describes how actors in various health contexts conceptualize and utilize different classes of data about sexuality and HIV status in their work. I build conceptual bridges between the sociological literatures on identity management and "strategic outness" and Gilles Deleuze and Felix Guattari's philosophical notions of "identity in the concept" and "conceptual neighborhoods" to articulate how various data classes and their habituated use create specific forms of biomedical sexuality.[80]

Chapter three concludes with a figure titled "Coordinates for Sexual Orientation Data Ontology Management," which visually presents when, how, and in what circumstances certain kinds of data (such as data about "HIV Risk Factors" or "sexual identity") can or cannot function in practice as data about sexual behaviors, identities, attractions, “sexual orientation.” The chart thus draws chapters one, two, and three together and provides a visual map of how different key concepts in the management of biomedical sexualities are enacted in practice, based on how interlocutors and other study data revealed these processes to me.

Chapter four turns back to the question of interoperability in the new nationwide health IT ecosystem, and specifically to the materiality of data and the forms of labor that make health IT infrastructures function. It draws on discussions of the shortcomings of interoperability in chapter two to illuminate interoperability challenges faced by HIV care providers in Atlanta. Specifically, chapter four focuses on Fulton County Ryan White program’s deployment of a piece of software called CAREWare in the 20-county Atlanta metropolitan area. CAREWare is maintained by the Health Services and Resources Administration (HRSA) to assist Ryan White-funded agencies in reporting data about patients to funders. Fulton County requires all Ryan White-funded agencies in the Atlanta metro area to use the software. CAREWare is a “boundary infrastructure” which is interoperable with agencies EHRs and other systems largely because of analog labor performed by teams of people – mostly made up of women of color – often using paper forms and complicated “quality assurance” workflows to translate data between systems.[81] This is still the case at several entities in Atlanta, despite investments of federal and local resources into attempts to foster automated interoperability between CAREWare and EHRs.

Chapter five describes federal HIV surveillance and prevention practices that were launched following the federal HIV Care Continuum Initiative in 2013. I focus on “Data to Care” programs that link HIV care, prevention, and surveillance infrastructures to one another in new ways in order to re-link people living with HIV who have been identified as “out of care” (and are thus more likely to be in poor health and able to transmit HIV to others) to medical providers.

I describe the federal policy justifications for these programs in detail, emphasizing Data to Care program guidance published by CDC and disseminated to state and local departments of public health. I show these programs to reveal substantive misalignments in how various branches of HHS govern uses of patients' electronic health information. Specifically, Data to Care exists as a paradigm for managing HIV, despite the fact that the *Federal Health IT Strategic Plan, 2015-2020* and other governing documents produced by HHS explicitly state that people living with HIV should have the ability to control the exchange of their sensitive health information.[82]

In chapter six, I provide a thick account of the HIV Data to Care program implemented by the Georgia Department of Public Health (GDPH), using CDC guidelines. I focus on the creation and distribution of an HIV "Out of Care Watchlist" (OWL) through an HIV Health Information Exchange (HIV HIE) and the state's public health prevention apparatus. I describe how GDPH builds the out of care list by identifying individual people living with HIV in the state who have not reported HIV-related bloodwork for 15-to-24 months through automated Electronic Laboratory Reporting (ELR) feeds, which send data to the state HIV surveillance system every time a person living with HIV receives medical care. I use this data to describe what I characterize as a "new sex hierarchy for people living with HIV," which I present in a visualization near the end of the chapter. This hierarchy emphasizes the importance of people living with HIV remaining in medical care, not only for their own health, but also (and sometimes primarily) in order to make them non-infectious to others. This results in new forms of *de facto* criminalization of people living with HIV who cannot remain in continuous medical care: a group disproportionately made up of individuals who do not have private insurance or are otherwise marginalized. I conclude the chapter with an extended review of materials covered in the preceding two chapters, with concrete proposals for building a multi-stakeholder, reform-oriented research agenda to assess the HIV data landscape and propose new models for HIV workforce and patient education, the development of new best practices in the areas of informed consent and HIV data exchange, and other regulatory reforms.

This dissertation shows how transformations in the ways that digital health data are collected, managed, and exchanged in the practice of U.S. healthcare are remaking biomedical sexualities. It demonstrates some of these critical transformations in federal policy, in specific communities of practice organized by discipline in HIV and LGBTQ health, in federal policy, and among practitioners and organizations in metropolitan Atlanta. The project also shows how transformations in contemporary biomedical sexualities are changing aspects of the modern sexual system, and specific sexual realities. The chapters herein will be of interest to scholars of sexuality, gender, and health in a variety of social scientific and humanistic disciplines, but also to practitioners in public health, HIV, LGBTQ health, and bioethics. The ethnographic and health policy analysis methods used herein will also hopefully help shape future investigations into the constitution of sexuality in and through biomedicine.

References for the Introduction

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[1] For a discussion of the relationship between the logics of digital algorithm and race, see John Cheney-Lippold's discussion of how "White Wanda" and "Black Desi" were differently interpellated by an HP computer in *We Are Data: Algorithms and the Making of Our Digital Selves* (New York: New York University Press, 2017), 15-18.

See also, Virginia Eubanks, *Automating Inequality: How High-Tech Tools Profile, Police, and Punish the Poor*, First Edition (New York, NY: St. Martin's Press, 2017); Safiya Umoja Noble, *Algorithms of Oppression: How Search Engines Reinforce Racism* (New York: New York University Press, 2018); Cathy O'Neil, *Weapons of Math Destruction: How Big Data Increases Inequality and Threatens Democracy*, (New York: Crown, 2016); Simone Browne, *Dark Matters: On the Surveillance of Blackness* (Durham: Duke University Press, 2015).

[2] In addition to multiple activist discourses that contest the validity of MSM that I have encountered during fieldwork in Atlanta, there is now an interdisciplinary literature in public health and LGBTQ studies devoted to debating the category. I consider this work at various points in this dissertation, which is dedicated to an analysis of the MSM category.

However, for a somewhat representative sampling of literature from both practical and critical perspectives, see, Jonathan Garcia et al., "The Limitations of 'Black MSM' as a Category: Why Gender, Sexuality, and Desire Still Matter for Social and Biomedical HIV Prevention Methods," *Global Public Health* 11, no. 7–8 (September 13, 2016): 1026–48, doi:10.1080/17441692.2015.1134616; Tom Boellstorff, "BUT DO NOT IDENTIFY AS GAY: A Proleptic Genealogy of the MSM Category," Cultural Anthropology 26, no. 2 (May 2011): 287–312, doi:10.1111/j.1548-1360.2011.01100.x; Richard Parker, Peter Aggleton, and Amaya G. Perez-Brumer, "The Trouble with 'Categories': Rethinking Men Who Have Sex with Men, Transgender and Their Equivalents in HIV Prevention and Health Promotion," *Global Public Health* 11, no. 7–8 (September 13, 2016): 819–23, doi:10.1080/17441692.2016.1185138., the introduction to a special issue of that journal devoted to the topic; Simon Watney, "Emergent Sexual Identities and HIV/AIDS," in *Imagine Hope: AIDS and Gay Identity* (New York, NY: Routledge, 2000).

[3] Centers for Disease Control and Prevention (CDC), "Gay and Bisexual Men's Health," accessed October 5, 2017, https://www.cdc.gov/msmhealth/index.htm; Centers for Disease Control and Prevention (CDC), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Division of HIV/AIDS Prevention (DHAP), "Gay and Bisexual Men | HIV By Group | HIV/AIDS | CDC," accessed October 5, 2017, https://www.cdc.gov/hiv/group/msm/index.html.

[4] The phase "built up and sustained" comes from John Law, *After Method: Mess in Social Science Research* (London ; New York: Routledge, 2004), 13. On "materialization," see, Karen Barad, "Getting Real: Technoscientific Practices and the Materialization of Reality," *Differences: A Journal of Feminist Cultural Studies* 10, no. 2 (1998): 90-93, 98-102, 109; Karen Barad, *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (Durham: Duke University Press, 2007), 189-122. On "materialization" and "rematerialization," see, Michelle Murphy, *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Durham [N.C.]:

Duke University Press, 2006), 14; Tom Waidzunas and Steven Epstein, "'For Men Arousal Is Orientation': Bodily Truthing, Technosexual Scripts, and the Materialization of Sexualities through the Phallometric Test," *Social Studies of Science* 45, no. 2 (April 1, 2015): 189–90, 192-3; On "enactment," see, Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002), 32-6.

These are all related key frameworks in STS that are used describe how actors work with methods and tools to sustain specific regimes of truth or realities in particular times and places, and are vocabularies I employ throughout the dissertation.

[5] "Translation" is a central concept in actor-network theory, information studies, and STS. Michel Callon describes translation as "the capacity of certain actors to get other actors - whether they are human beings, institutions, or natural entities - to comply with them" and "during which the identity of actors, the possibility of interaction and the margins of manoeuvre are negotiated and delimited;" making translation also transformational for the actors involved in the act of translation. See, Michel Callon, "Some Elements of a Sociology of Translation: Domestication of the Scallops and the Fishermen of St Brieuc Bay," *The Sociological Review* 32 (May 1984): 196–233, doi:10.1111/j.1467-954X.1984.tb00113.x.: 201, 203.

In their essay on boundary objects, Susan Leigh Star and James R. Greisemer define translation as a kind of "many-to-many mapping" process whereby specific technologies, tools, or things mediate between different sets of actors and fulfilling their distinct informational needs. Susan Leigh Star and James R. Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39," *Social Studies of Science* 19, no. 3 (August 1989): 387–420: 388-393.

[6] Anthony S. Fauci, "U=U: Science and Policy" (July 22, 2018), https://www.youtube.com/watch?v=ewxa8UW6h_0.

[7] On the effects of PrEP on the place of sexuality in HIV prevention and medicine, see, Kane Race, "Reluctant Objects: Sexual Pleasure as a Problem for HIV Biomedical Prevention," *GLQ: A Journal of Lesbian and Gay Studies* 22, no. 1 (2016): 1–31. For a reflection on the experience of taking PrEP as a low-income gay man of color, see, Marcos Santiago Gonsalez, "Blue Dream: PrEP Allows Gay Men of Color to Feel Cared for but Also Managed and Made into Data," *The New Inquiry*, August 30, 2017, https://thenewinquiry.com/blue-dream/.

[8] Patrick R. Grzanka, Katharine H. Zeiders, and Joseph R. Miles, "Beyond 'born This Way?' Reconsidering Sexual Orientation Beliefs and Attitudes.," *Journal of Counseling Psychology* 63, no. 1 (2016): 68, https://doi.org/10.1037/cou0000124; Patrick R. Grzanka, "Queer Survey Research and the Ontological Dimensions of Heterosexism," *Women's Studies Quarterly* 44, no. 3/4 (Fall 2016): 132-3; David M. Halperin, *What Do Gay Men Want?: An Essay on Sex, Risk, and Subjectivity* (Ann Arbor, MI: University of Michigan Press, 2007), 1-2, 8-10; Gayle Rubin, "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality," in *Deviations: A Gayle Rubin Reader* (Durham: Duke University Press, 2011), 146, 150, 155-158; Elizabeth Jane Ward, *Not Gay: Sex between Straight White Men*, Sexual Cultures (New York: New York University Press, 2015), 34.

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[9] See, ONC, “Connecting Health and Care for the Nation: A Ten-Year Vision to Achieve an Interoperable Health IT Infrastructure” (The Office of the National Coordinator for Health Information Technology (ONC), 2014), https://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf; ONC, “Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0” (The Office of the National Coordinator for Health Information Technology (ONC), 2015), https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf.

[10] See, for example, Anthony S. Fauci et al., “Ending the HIV Epidemic: A Plan for the United States,” *JAMA* 321, no. 9 (March 5, 2019): 844, https://doi.org/10.1001/jama.2019.1343; Anthony S. Fauci, “U=U: Science and Policy”; Fulton County Task Force on HIV/AIDS, “Phase III Progress Report: Building the Strategy to End AIDS in Fulton County” (Fulton County, GA: Fulton County, July 31, 2017).

[11] CDC, “Data to Care Program Guidance: Using HIV Surveillance Data to Support the HIV Care Continuum” (Atlanta, GA: Centers for Disease Control and Prevention (CDC), August 2017), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/datatocareprogramguidance.pdf; CDC, “Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum (the ‘Data to Care Toolkit’” (Atlanta, GA, 2014), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/pdf-of-important-considerations.pdf; Project Inform Staff, “Using Surveillance and Other Data to Improve HIV Care Linkage and Retention” (San Francisco, CA: Project Inform, June 7, 2012).

[12] “The Health Information Technology for Economic And Clinical Health Act (HITECH),” H.R. 1-112 § 13001 (2009), https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/coveredentities/hitechact.pdf.

[13] Julia Adler-Milstein and Ashish K. Jha, “HITECH Act Drove Large Gains In Hospital Electronic Health Record Adoption,” *Health Affairs* 36, no. 8 (August 2017): 1416–22, https://doi.org/10.1377/hlthaff.2016.1651; ONC, “2016 Report to Congress on Health IT Progress” (Washington, DC: The Office of the National Coordinator for Health Information Technology (ONC), November 2016), https://dashboard.healthit.gov/report-to-congress/2016-report-congress-examining-hitech-era-future-health-information-technology.php; Marsha Gold and Catherine McLaughlin, “Assessing HITECH Implementation and Lessons: 5 Years Later: Assessing HITECH Implementation and Lessons,” *The Milbank Quarterly* 94, no. 3 (September 2016): 654–87, https://doi.org/10.1111/1468-0009.12214

[14] Don Rucker, “Achieving The Interoperability Promise Of 21st Century Cures,” *Health Affairs Blog*, June 19, 2018, https://www.healthaffairs.org/do/10.1377/hblog20180618.138568/full/; Don Rucker, “Automation in Healthcare Is Transforming Medicine,” *HIMSS Blog*, October 1, 2018, https://www.himss.org/news/healthcare-automation-transforming-medicine.

[15] ONC, “Non-Federal Acute Care Hospital Electronic Health Record Adoption: Four out of Five Hospitals Have a Basic EHR System” (Washington, DC: The Office of the National Coordinator

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for Health Information Technology, 2017), https://dashboard.healthit.gov/quickstats/pages/FIG-Hospital-EHR-Adoption.php; JaWanna Henry et al., “ONC Data Brief 35: Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015” (Washington, DC: The Office of the National Coordinator for Health Information Technology (ONC), May 2016), https://dashboard.healthit.gov/evaluations/data-briefs/non-federal-acute-care-hospital-ehr-adoption-2008-2015.php.

[16] Chun-Ju Hsiao et al., “Electronic Medical Record/Electronic Health Record Systems of Office-Based Physicians: United States, 2009 and Preliminary 2010 State Estimates” (Washington, DC: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Health Care Statistics, December 2010), https://www.cdc.gov/nchs/data/hestat/emr_ehr_09/emr_ehr_09.pdf. This definition of “fully-functional” fell short of EHR certification and Meaningful Use criteria and functionalities that were first released in 2010.

[17] ONC, “Non-Federal Acute Care Hospital Electronic Health Record Adoption: Four out of Five Hospitals Have a Basic EHR System.” See also, Adler-Milstein and Jha, “HITECH Act Drove Large Gains.”

[18] ONC, “Connecting Health and Care for the Nation: A Ten-Year Vision to Achieve an Interoperable Health IT Infrastructure” (The Office of the National Coordinator for Health Information Technology (ONC), 2014), https://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf, 2.

[19] Wendy Hui Kyong Chun, *Programmed Visions: Software and Memory* (Cambridge, MA: MIT Press, 2011), 9.

[20] ONC, “Connecting Health and Care for the Nation: A Ten-Year Vision”; Don Rucker, “Achieving The Interoperability Promise Of 21st Century Cures”; ONC, “Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0” (The Office of the National Coordinator for Health Information Technology (ONC), 2015), https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf.

[21] Explorations of these topics make up much of the substance of several chapters of the dissertation. However, for an accessible and non-academic overview of many of these issues, see, Fred Schulte and Erika Fry, “Death By 1,000 Clicks: Where Electronic Health Records Went Wrong,” *Kaiser Health News with Fortune Magazine*, March 18, 2019, https://khn.org/news/death-by-a-thousand-clicks/.

[22] Sean R. Cahill et al., “Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health,” *LGBT Health* 3, no. 2 (April 2016): 100–102, https://doi.org/10.1089/lgbt.2015.0136.

[23] In chapter three, I build on sociologist Steven Epstein’s notion of LGBT “inclusion” into federal regulatory frameworks governing biomedical research, arguing that the Obama era

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ushered in much more far-reaching forms of "incorporation" into federal health policy generally. See, Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago, IL: University of Chicago Press, 2007); Steven Epstein, "Sexualizing Governance and Medicalizing Identities: The Emergence of 'State-Centered' LGBT Health Politics in the United States," *Sexualities* 6, no. 2 (May 1, 2003): 131–71, https://doi.org/10.1177/1363460703006002001.

[24] Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (Washington, DC: National Academies Press, 2011).

[25] Ibid., 9-10.

[26] For a full discussion of these issues, see chapter three.

[27] See, for example, The Joint Commission, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community* (Oak Brook, IL: The Joint Commission, 2011); The Joint Commission, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* (Oakbrook Terrace, IL: The Joint Commission, 2010). The Joint Commission is the main organization in the United States charged with maintaining hospital and healthcare facility accreditation criteria.

[28] IOM, *The Health of LGBT People*, 67-74.

[29] For a review of actions taken by the Trump administration between the beginning of 2017 and the end 2018, with an emphasis on LGBTQ health, see, Sean Cahill and Timothy Wang, "Trump Administration Continued to Advance Discriminatory Policies and Practices against LGBT People and People Living with HIV in 2018" (Boston, MA: The Fenway Institute, January 16, 2019), https://fenwayhealth.org/wp-content/uploads/Trump-Administration-Impact-on-LGBTs-Year-Two-Brief_Web.pdf.

[30] Department of Health and Human Services, "Ending the HIV Epidemic: A Plan for America," February 7, 2019, https://www.hhs.gov/sites/default/files/ending-the-hiv-epidemic-fact-sheet.pdf; Anthony S. Fauci et al., "Ending the HIV Epidemic: A Plan for the United States."

[31] For a skeptical view of the Trump administration's plan to end the HIV/AIDS epidemic, see, Sean Cahill, "Trump's Dubious Promise about Ending HIV," *The Boston Globe*, February 6, 2019, https://www.bostonglobe.com/opinion/2019/02/06/trump-dubious-promise-about-ending-hiv/Lys3X53Y38eaWjO1mtYB4L/story.html.

For a more supportive view, see, The AIDS Institute, "President Trump Proposes Bold Initiative to End HIV in the United States: The AIDS Institute Applauds Historic Action and Urges Congressional Support" (Washington, DC: The AIDS Institute, February 5, 2019), http://www.theaidsinstitute.org/sites/default/files/attachments/State%20of%20the%20Union%20press%20release_0.pdf.

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[32] CDC, "Data to Care Program Guidance: Using HIV Surveillance Data to Support the HIV Care Continuum" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), August 2017), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/datatocareprogramguidance.pdf; CDC, "Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum (the 'Data to Care Toolkit'" (Atlanta, GA, 2014), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/pdf-of-important-considerations.pdf; Project Inform Staff, "Using Surveillance and Other Data to Improve HIV Care Linkage and Retention" (San Francisco, CA: Project Inform, June 7, 2012).

[33] Georgia Department of Public Health, "HIV Surveillance Fact Sheet - Georgia, 2017" (Atlanta, GA, January 28, 2019), https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV_EPI_2017_Fact_Sheet_20190128.pdf.

[34] HIV Epidemiology Section, Georgia Department of Public Health, "Georgia HIV Care Continuum Update: Persons Living with HIV, 2016, and Persons Diagnosed with HIV, 2015" (Atlanta, GA, 2018), https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV_Care_Continuum_2016_PLWH_%26_2015_NewDx_09.13.17.pptx; Georgia Department of Public Health, HIV Epidemiology Section, "Georgia HIV Care Continuum Update: Persons Living with HIV, and Persons Diagnosed with HIV, 2017" (Atlanta, GA: Georgia Department of Public Health, January 28, 2019), https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV_EPI_2017_Care_Continuum_Slides_20190128.pptx; Fulton County Ryan White Part A Program. "Fiscal Year 2017 Funding Application Narrative." Fulton County, June 2017. http://www.ryanwhiteatl.org/wp-content/uploads/2016/11/Narrative-FY17-Atlanta-EMA-H89HA00007.pdf, 9.

[35] Prevention Access Campaign, "Risk of Sexual Transmission of HIV From a Person Living with HIV Who Has an Undetectable Viral Load: Messaging Primer and Consensus Statement," July 21, 2016, https://www.preventionaccess.org/consensus; Eugene McCray and Jonathan Mermin, "'Dear Colleague' Letter Announcing CDC's Position That 'People Who Take ART Daily as Prescribed and Achieve and Maintain an Undetectable Viral Load Have Effectively No Risk of Sexually Transmitting the Virus to an HIV-Negative Partner.,'" Dear Colleague Letter, September 27, 2017, https://www.cdc.gov/hiv/library/dcl/dcl/092717.html; Fauci, "U=U: Science and Policy."

[36] Kaiser Family Foundation, "HIV Viral Suppression Rate in U.S. Lowest Among Comparable High-Income Countries" (Kaiser Family Foundation, March 20, 2019). Kaiser Family Foundation, "HIV Viral Suppression Rate in U.S. Lowest Among Comparable High-Income Countries" (Kaiser Family Foundation, March 20, 2019), https://www.kff.org/hivaids/slide/hiv-viral-suppression-rate-in-u-s-lowest-among-comparable-high-income-countries/; Heather Bradley, Eli S. Rosenberg, and David R. Holtgrave, "Data-Driven Goals for Curbing the U.S. HIV Epidemic by 2030," *AIDS and Behavior* 23, no. 3 (March 2019): 557–63, https://doi.org/10.1007/s10461-019-02442-7; Eli S Rosenberg et al., "Improving Estimation of HIV Viral Suppression in the United States: A Method to Adjust HIV Surveillance Estimates From the Medical Monitoring Project Using Cohort Data," *American Journal of Epidemiology* 187, no. 9 (September 1, 2018): 1962–69, https://doi.org/10.1093/aje/kwy039.

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[37] I refer readers to the interactive map of Atlanta ZIP codes: AIDSVu, "HIVContinuum.Org - Atlanta," 2019, http://hivcontinuum.org/city-complete.html?city=Atlanta,%20GA&cd=atl. Using 2015 HIV surveillance data, the 30303 ZIP code recorded a viral suppression rate of 35% among all people living with diagnosed HIV. In numerous ZIP codes, viral suppression among those aged 13-24 fell well below 40%.

See also, Linda Villarosa, "America's Hidden HIV Epidemic: Why Do America's Black Gay and Bisexual Men Have a Higher H.I.V. Rate than Any Country in the World?," *The New York Times Magazine*, June 6, 2017; Fulton County Task Force on HIV/AIDS, "Phase II Progress Report: Building the Strategy to End AIDS in Fulton County" (Fulton County, GA: Fulton County, June 27, 2016).

[38] This 15% figure comes from the Georgia Department of Public Health: Georgia Department of Public Health, HIV Epidemiology Section, "HIV Care Continuum," 2019, https://dph.georgia.gov/hiv-care-continuum.

[39] Centers for Disease Control and Prevention, "HIV Surveillance Report Supplemental Report: Diagnoses of HIV Infection among Adults and Adolescents in Metropolitan Statistical Areas—United States and Puerto Rico, 2016" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), May 2018), https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-23-2.pdf, 5.

[40] Centers for Disease Control and Prevention, "HIV Surveillance Report, 2016" (Centers for Disease Control, July 2017), https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf, 110, showing a higher rate of HIV infection from 2015 to 2016. Among youth, see, Centers for Disease Control and Prevention, "HIV Surveillance Report Supplemental Report: Diagnoses of HIV Infection among Adolescents and Young Adults in the United States and 6 Dependent Areas 2011–2016" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), May 2018), https://www.cdc.gov/hiv/pdf/library/reports/ surveillance/cdc-hiv-surveillance-supplemental-report-vol-23-3.pdf, 39

[41] Villarosa, "America's Hidden HIV Epidemic"; Kristen L. Hess et al., "Lifetime Risk of a Diagnosis of HIV Infection in the United States," *Annals of Epidemiology* 27, no. 4 (April 2017): 238–43, https://doi.org/10.1016/j.annepidem.2017.02.003.

[42] As fieldwork was concluding in 2019, CDC was working with several state health departments to begin a transgender pilot survey to estimate HIV rates among transgender women and potentially other transgender and/or gender nonconforming individuals.

[43] See this news story, in which Carlos del Rio, a prominent HIV physician in Atlanta and Director of the Emory Center for AIDS Research is quoted saying that "Downtown Atlanta is as bad as Zimbabwe or Harare or Durban" – a problematic statement in an imperfectly-assembled and framed media story, but one that nonetheless is true by the numbers: David Huddleston, "Atlanta's HIV 'epidemic' Compared to Third World African Countries," *WSB-TV*, November 30, 2018, https://www.wsbtv.com/news/2-investigates/atlantas-hiv-epidemic-compared-to-third-world-african-countries/263337845. See, again, Villarosa, "America's Hidden HIV Epidemic."

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[44] UNAIDS, “90-90-90: An Ambitious Treatment Target to Help End the AIDS Epidemic” (Geneva, Switzerland: UNAIDS, October 2014), http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf; Anthony S. Fauci and Hilary D. Marston, “Ending the HIV–AIDS Pandemic — Follow the Science,” *New England Journal of Medicine* 373, no. 23 (December 3, 2015): 2197–99, https://doi.org/10.1056/NEJMp1502020; HHS, “Ending the HIV Epidemic”

[45] Project Inform Staff, “Using Surveillance and Other Data to Improve HIV Care Linkage and Retention”; CDC “Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum”

[46] I sometimes also refer to the domains of HIV research, HIV advocacy, and HIV integrated planning. However, these areas are secondary in my analysis.

[47] Public health surveillance is a misunderstood discipline, particularly given negative connotations with the word “surveillance” as a kind of ominous and negative force in society. However, public health surveillance takes many forms, is an entire subfield of epidemiology, and a routine practice in public health and a core function of public health institutions. Surveillance is defined by CDC in a baseline template training module for public health personnel as "[the] ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control," see, Centers for Disease Control and Prevention, “Public Health 101 Series: Introduction to Public Health Surveillance” (Atlanta, GA, n.d.), https://www.cdc.gov/publichealth101/documents/introduction-to-surveillance.pptx.

[48] Barack Obama, “Executive Order -- HIV Care Continuum Initiative” (2013), https://obamawhitehouse.archives.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative.

[49] Nanette Dior Benbow, “Ethical Considerations for Molecular HIV Surveillance in the United States” (Galter Health Science Library, 2018), https://doi.org/10.18131/G3MT7B; Alexandra M. Oster et al., “Using Molecular HIV Surveillance Data to Understand Transmission Between Subpopulations in the United States:,” *JAIDS Journal of Acquired Immune Deficiency Syndromes* 70, no. 4 (December 2015): 444–51, https://doi.org/10.1097/QAI.0000000000000809; HIV Prevention Policy Project, “Molecular HIV Surveillance: Engaging HIV Community Stakeholders to Examine the Promise and Risks from the New Technology (Conference Program),” June 14, 2018; Martha Kempner, “CDC Explains and Defends Molecular Surveillance System,” *The Body Pro: The Complete HIV/AIDS Resource*, March 18, 2019, http://www.thebody.com/content/81662/cdc-explains-defends-molecular-surveillance-system.html?ic=700102; Alexander McClelland, Adrian Guta, and Marilou Gagnon, “The Rise of Molecular HIV Surveillance: Implications on Consent and Criminalization,” *Critical Public Health*, February 20, 2019, 1–7, https://doi.org/10.1080/09581596.2019.1582755; Manon Ragonnet-Cronin et al., “HIV Transmission Networks among Transgender Women in Los Angeles County, CA, USA: A Phylogenetic Analysis of Surveillance Data,” *The Lancet HIV*, February 2019,

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https://doi.org/10.1016/S2352-3018(18)30359-X; CDC, "Technical Guidance for HIV Surveillance Programs," unpublished document.

[50] I refer readers to chapters six and seven for more information about this. However, see, CDC, "Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum (the 'Data to Care Toolkit'"; CDC, "Data to Care Program Guidance"; Project Inform Staff, "Using Surveillance and Other Data to Improve HIV Care Linkage and Retention."

[51] I adopt the Fourth International Conference on Grey Literature's definition of grey literature as "[that] which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers." Fourth International Conference on Grey Literature. "What Is Grey Literature?" The New York Academy of Medicine, 1999. http://www.greylit.org/about.

[52] Bruno Latour describes this analytical process as "tracing associations" and producing "good accounts." A good account "*traces a network*…a string of actions where each participant is treated as a full-blown mediator" and is "a narrative or a description or a proposition where all the actors," human and non-human, "*do something* and don't just sit there," and where "each of the points in the text may become a bifurcation, an event, or the origin of a new translation." See, Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory* (Oxford: Oxford University Press, 2005).

[53] Stefan Timmermans and Marc Berg, *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care* (Philadelphia, Pa.: Temple University Press, 2003), http://public.eblib.com/choice/publicfullrecord.aspx?p=496404, *passim*, and especially 26-30.

[54] On the definition of a "national standard" in health IT, see, Dixie B Baker, Jonathan B Perlin, and John Halamka, "Evaluating and Classifying the Readiness of Technology Specifications for National Standardization," *Journal of the American Medical Informatics Association* 22, no. 3 (May 2015): 738–43, https://doi.org/10.1136/amiajnl-2014-002802.

[55] This is a finding that primarily comes from fieldwork data, especially with Linda Ellis, Executive Director of both The Phillip Rush Center (Atlanta's LGBTQ center), and an organization called The Health Initiative: Georgia's Voice for LGBTQ health.

[56] See, for example, Rachel Hart-Malloy et al., "Implementing Data-to-Care Initiatives for HIV in New York State: Assessing the Value of Community Health Centers Identifying Persons out of Care for Health Department Follow-Up," *AIDS Care* 30, no. 3 (March 4, 2018): 391–96, https://doi.org/10.1080/09540121.2017.1363851; Julia C. Dombrowski et al., "'Out of Care' HIV Case Investigations: A Collaborative Analysis Across 6 States in the Northwest US," *Journal of Acquired Immune Deficiency Syndromes (1999)* 74 Suppl 2 (February 1, 2017): S81–87, https://doi.org/10.1097/QAI.0000000000001237.

[57] I will note that the term "biomedical sexualities" is completely indifferent to the question of the "origin" of sexual orientation and I (along with the biomedical consensus and social

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constructionist approaches to the study of sexuality) entirely reject the notion of an "etiology" of sexual orientation. "Biomedical sexualities" is intended, as the definition notes, to describe how practitioners work with data and tools to make sense of sexuality in particular times and places; thus, their constitution is infinitely variable and given consistency only through the repeated use of specific methods over time.

[58] See specifically, Rubin, "Thinking Sex," 146-8. See generally, Michel Foucault, *The History of Sexuality, Vol. 1*, trans. Robert Hurley (New York, NY: Vintage Books, 1978); Arnold I Davidson, *The Emergence of Sexuality: Historical Epistemology and the Formation of Concepts* (Cambridge, MA: Harvard University Press, 2004); Jeffrey Weeks, *Coming Out: Homosexual Politics in Britain from the Nineteenth Century to the Present* (New York, NY: Quartet Books, 1977); George Chauncey, "From Sexual Inversion To Homosexuality: Medicine And The Changing Conceptualization of Female Deviance," *Salmagundi* 58/59, no. Fall 1982-Winter 1983 (1983): 114–46; David M. Halperin, *How to Do the History of Homosexuality* (Chicago: University of Chicago Press, 2002); Marlon M. Bailey, *Butch Queens up in Pumps: Gender, Performance, and Ballroom Culture in Detroit*, Triangulations: Lesbian/Gay/Queer Theater/Drama/Performance (Ann Arbor: University of Michigan Press, 2013).

[59] The development of biomedical knowledge about suppressed viral load and "untransmittability" was equally as important as the dissemination of this knowledge among domestic and global community of stakeholders in HIV. This has been the focus of a concerted, multi-year effort by an array of organizations, and merits its own history and retelling. See, for example, Center for HIV Law and Policy, "Consensus Statement on HIV 'Treatment as Prevention' in Criminal Law Reform (2017)" (The Center for HIV Law and Policy, July 13, 2017), https://www.hivtaspcrimlaw.org/the-consensus-statement; Prevention Access Campaign, "Risk of Sexual Transmission of HIV From a Person Living with HIV Who Has an Undetectable Viral Load: Messaging Primer and Consensus Statement."

[60] For an example of LGBT incorporation at HHS, see, HHS LGBT Issues Coordinating Committee, "Advancing LGBT Health & Well-Being: 2015 Report," Annual (Washington, DC: U.S. Department of Health and Human Services, December 2015).

[61] On "enactment," see, Mol, *The Body Multiple*, 32-6 and *passim*. On "materialization," see Barad, "Getting Real: Technoscientific Practices and the Materialization of Reality," 90-93, 98-102, 109; Murphy, *Sick Building Syndrome and the Problem of Uncertainty*. For uses of these concepts in the context of sexuality studies, see, Tom Waidzunas and Steven Epstein, "'For Men Arousal Is Orientation.'"

[62] See, for example, North Carolina's "HIV Control Measures," which I discuss in chapter six, Victoria Mobley, "Modernization of North Carolina's HIV Control Measures," March 13, 2018, https://www.mecknc.gov/HealthDepartment/CDControl/ForProviders/Health%20Advisory%20Documents/Updated%20NC%20HIV%20Control%20Measures.pdf.

[63] Law, *After Method*, 13-14, 94, 160, and *passim*.

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[64] Robert A. Padgug, "Sexual Matters: On Conceptualizing Sexuality In History," *Radical History Review* 1979, no. 20 (April 1, 1979): 3–23, https://doi.org/10.1215/01636545-1979-20-3, 10.

[65] I draw my use of "situatedness" and particularity in the construction of viewpoint and reality from Donna Haraway's seminal essay "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective," in *Simians, Cyborgs, and Women: The Reinvention of Nature* (New York: Routledge, 1991), 183–202. My deployment of "situatedness" in the ethnographic context also draws from Tom Boellstorff's work on queer anthropology, where he also cites Haraway's seminal essay. See, Tom Boellstorff, *A Coincidence of Desires: Anthropology, Queer Studies, Indonesia* (Durham: Duke University Press, 2007), 13-20.

[66] Law's full definition of "methods assemblage" in *After Method* is "enactments of relations that make some things (representations, objects, apprehensions) present 'in-here', whilst making others absent 'out-there'. The 'out-there' comes in two forms: as manifest absence (for instance as what is represented); or, and more problematically, as a hinterland of indefinite, necessary, but hidden Otherness," 14. I do not adopt his language wholesale. Rather, Law's ideas exist, for me, in an assemblage of other ideas in multiple constructivist and social constructionist traditions, extending across various threads of STS, queer studies, and sexuality studies, frameworks from which I often draw upon and co-deploy. For an application of Law's framework in the context of sexuality and survey research methods, see, Martin Holt, "Enacting and Imagining Gay Men: The Looping Effects of Behavioural HIV Surveillance in Australia," *Critical Public Health* 23, no. 4 (December 2013): 404–17, https://doi.org/10.1080/09581596.2013.796038. See also, John Law, "Seeing Like a Survey," *Cultural Sociology* 3, no. 2 (July 1, 2009): 239–56, https://doi.org/10.1177/1749975509105533.

[67] Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi (Minneapolis: University of Minnesota Press, 1987), 142-6.

[68] On biomedicalization, see, Adele Clarke et al., "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine," *American Sociological Review* 66, no. 2 (April 2003): 161–94. For examples of other scholars doing the work of rearticulating sexuality in the era of biomedicalization, see, Kane Race, "Reluctant Objects: Sexual Pleasure as a Problem for Biomedical HIV Prevention," *GLQ: A Journal of Lesbian and Gay Studies* 22, no. 1 (2016): 1–31, https://doi.org/10.1215/10642684-3315217; Paul B. Preciado, *Testo Junkie: Sex, Drugs, and Biopolitics in the Pharmacopornographic Era* (New York, NY: The Feminist Press at the City University of New York, 2013); Tom Waidzunas and Steven Epstein, "'For Men Arousal Is Orientation.'"

[69] I adopt Michael Warner's deployment of "heteronormativity" from his introduction to *Fear of a Queer Planet: Queer Politics and Social Theory*: "Het culture thinks of itself as the elemental form of human association, as the very model of inter-gender relations, as the indivisible basis of all community, and as the means of reproduction without which society wouldn't exist," (Minneapolis: University of Minnesota Press, 1993), xxi. See also, Lauren Berlant and Michael Warner, "Sex in Public," *Critical Inquiry* 24, no. 2 (Winter 1998): 547–66.

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[70] Per Rubin, "This kind of sexual morality has more in common with ideologies of racism than with true ethics. It grants virtue to the dominant groups, and relegates vice to the underprivileged." See, "Thinking Sex," 153-4.

[71] Ibid., 138.

[72] Ibid., 153

[73] David M. Halperin, *Saint Foucault: Towards a Gay Hagiography* (Oxford: Oxford University Press, 1995), 62.

[74] Cathy J. Cohen, "Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics?," *GLQ: A Journal of Lesbian and Gay Studies* 3, no. 4 (January 1, 1997): 437–65.

[75] Ibid,; Robert McRuer, "Introduction: Compulsory Able-Bodiedness and Queer/Disabled Existence," in *Crip Theory: Cultural Signs of Queerness and Disability*, Cultural Front (New York: New York University Press, 2006), 1–33.

[76] Cindy Patton, *Sex and Germs: The Politics of AIDS*, (Boston: South End Press, 1985), 10-12; Cindy Patton, *Inventing AIDS* (New York, NY: Routledge, 1990), 117.

[77] Adam M Geary, *Antiblack Racism and the AIDS Epidemic: State Intimacies*, 2014.

[78] Chun, *Programmed Vision*, 9; ONC, "Connecting Health and Care for the Nation: A Ten-Year Vision," 2.

[79] This includes the incorporation of SO/GI data collection requirements into a key arm of the national clinical public health safety net, with the requirement that all Federally Qualified Health Centers (FQHCs) collect SO/GI data beginning in 2016. See, Health Resources and Services Administration (HRSA) Bureau of Primary Health Care (BPHC), "Program Assistance Letter: Approved Uniform Data System Changes for Calendar Year 2016 (PAL 2016-02)," March 22, 2016, https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/pal201602.pdf.

[80] Jason Orne, "'You Will Always Have to "out" Yourself': Reconsidering Coming out through Strategic Outness," *Sexualities* 14, no. 6 (December 2011): 681–703, https://doi.org/10.1177/1363460711420462; Gilles Deleuze, *Difference and Repetition*, trans. Paul Patton (New York: Columbia University Press, 1994), 16, 220; Gilles Deleuze and Félix Guattari, *What Is Philosophy?*, trans. Hugh Tomlinson and Graham Burchell (New York: Columbia University Press, 1994), 19-32.

[81] On "boundary infrastructure," see, Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, MA: MIT Press, 2000), 271. I further defined CAREWare as a boundary infrastructure in the chapter.

[82] Office of the National Coordinator for Health Information Technology (ONC), "Federal Health IT Strategic Plan, 2015-2020" (Washington, D.C.: Office of the Secretary, United States

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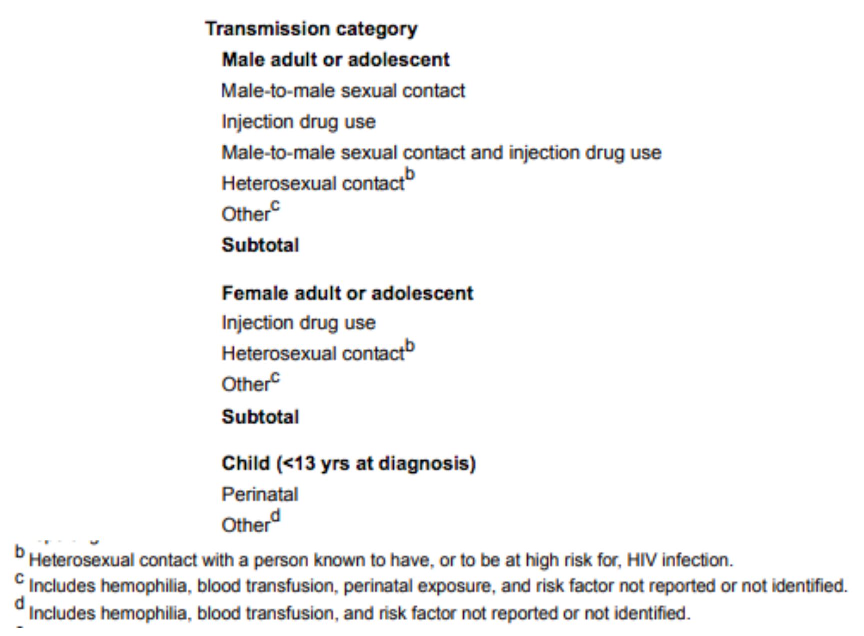
Department of Health and Human Services, 2015), https://www.healthit.gov/sites/default/files/9-5-federalhealthitstratplanfinal_0.pdf, 25.

Chapter 1: The Lives of the HIV Risk Hierarchy and "Male-to-Male Sexual Contact": An Account of a Ubiquitous HIV/AIDS Taxonomy and Its Most Contested Category

I. Introduction

The HIV risk hierarchy is a taxonomic ranking of individual factors that are most likely to transmit HIV, ordered from highest to lowest probability of transmission. "Male-to-male sexual contact" is the hierarchy's top category, indicating highest risk of transmission. Figure 1.1, below, shows the hierarchy as it is most regularly presented in tables of the *HIV Surveillance Report*, published annually by CDC.

Figure 1.1. The HIV Transmission Risk Hierarchy as Represented in Table 3b of the 2008 HIV Surveillance Report[1]



Transmission category

Male adult or adolescent
Male-to-male sexual contact
Injection drug use
Male-to-male sexual contact and injection drug use
Heterosexual contact[b]
Other[c]
Subtotal

Female adult or adolescent
Injection drug use
Heterosexual contact[b]
Other[c]
Subtotal

Child (<13 yrs at diagnosis)
Perinatal
Other[d]

[b] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.
[c] Includes hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified.
[d] Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

The hierarchy and its categories are used throughout the global HIV/AIDS apparatus – in prevention, care, surveillance, and research domains. However, the gold standard definition of the hierarchy and each of its classifications is contained in the footnotes and technical notes of the annual *HIV Surveillance Report*.

While the hierarchy is imagined by practitioners as a monolithic and imperially-imposed framework that is maintained and defined by "CDC" (in quote marks to indicate that "CDC" functions as more of an imagined entity when referred to in this way than it does as the actual set of institutions that make up the Centers for Disease Control and Prevention), the hierarchy only coheres as such because it appears in practice in a multiplicity of different ways. The hierarchy's singularity is produced not by its perfect reproduction across contexts, but by its repeated deployment as many different versions of itself in consistent and habituated fashions by a variety of actors in the healthcare system.[2]

Uses of the hierarchy by specific institutions or individual actors during particular events are shaped by many overlapping forces which determine the hierarchy's constitution in the milieu of its appearance. One such force is the evolution and transmutation of the hierarchy's taxonomy since the first cases of what would come to be called AIDS were reported in 1981. This results in a kind of "taxonomic accumulation" whereby categories that have been jettisoned from the gold standard hierarchy used by CDC in *Surveillance Reports* continue to appear anachronistically in iterations of the hierarchy that are used in the present by social service agencies, state and local health departments, Electronic Health Record (EHR) vendors, and others. Another force is the discursive and technical commixing and commingling of HIV risk hierarchy data and categories from the hierarchy with classifications and taxonomies from different (but conceptually proximate) areas, such as sexual orientation and gender identity. This results in a variety of conceptual and infrastructural frictions, and, in some cases, the normalization of uses of hierarchy data to express information using concepts from those other frameworks. For example, data about HIV transmission via “male-to-male sexual contact” are regularly expressed as data about “men who have sex with men,” “gay and bisexual men,” or “gay men.”

I demonstrate these claims about the HIV risk hierarchy by using three different methodologies, each in its own section of this chapter. Firstly, I employ genealogical inquiry to show how the hierarchy’s taxonomy has evolved and accumulated many different meanings over time since it first began to take shape in 1981. Data for that section come from an analysis of the technical notes, footnotes, and tables presented in *HIV Surveillance Reports* and predecessor documents that have been released since 1982, which CDC makes publicly available. To gather and organize data for the genealogical analysis, I extracted key sections from *HIV Surveillance Reports* and predecessor documents. Employing diagrammatic strategies, I then chronologically arranged these data from 1981 to present into a single master reference table, which tracked evolutions in the name of the HIV hierarchy itself in *Surveillance Reports*, definitions of the HIV risk hierarchy in technical notes, and definitions for all of the individual categories that have ever appeared in the taxonomy of the HIV risk hierarchy. Taking the present as the “surface of emergence” for analyses of the past, the charts begin with the contemporary hierarchy and then work forward from 1981 to the present.[3]

I then employed methods of textual re-assemblage in historical analysis that Michelle Murphy calls “recursive origami.”[4] From the master table, I culled seven separate, smaller tables. The first traced the evolution of the hierarchy itself – its name and its technical definition. The next six tables each traced the evolution of one of the main categories in the contemporary hierarchy. These tables presented specific categories’ chronological evolution from 1981 to

2016, accounting for both categorical transmutations (e.g. from “homosexual males” to “male-to-male sexual contact”) and definitional changes in technical notes, each in separate columns.

Employing the master table and these seven tables (while cross-referencing my data set with primary source material in *HIV Surveillance Reports*), I distilled a single chart. This chart traces changes in the name of the hierarchy and its taxonomic evolution by breaking the hierarchy’s evolution into six distinct time blocks, which I determined by considering when the taxonomy of the hierarchy experienced major definitional changes. I also present (in hierarchical ordering) the key categories that appeared in each of the six historical periods in the evolution of the hierarchy from 1981 to 2016. This chart is a focal point of the genealogical analysis, and appears in this chapter as Figure 1.4.

In the section that follows the genealogical analysis, I provide a technical account of the hierarchy in several contemporary health information systems and data collection instruments that I reviewed during fieldwork and health IT policy analysis. This technical analysis foregrounds how the HIV risk hierarchy is produced and presented in a technical guidance manual that was written for health IT product developers and other health IT and health informatics professionals by a working group of Health Level 7 International (HL7), a major private health information exchange standards-setting organization. This technical guidance document directs stakeholders about which health IT standards should be used to gather and report HIV-related data in health IT products. The section of the document I excerpt and analyze provides guidance about using health IT standards to populate HIV risk hierarchy data in health IT systems such as EHRs. My technical account of the HIV risk hierarchy also includes an examination of a survey instrument that I encountered during fieldwork, which places a category usually associated with the HIV risk hierarchy ("MSM") in both a sexual orientation demographic question and an HIV transmission question.

Following the technical analysis, I provide an ethnographic account of the HIV risk hierarchy, describing how I observed different organizations in Atlanta employ it to make sense of their client population(s). I show how technical, conceptual, and taxonomic misalignments – which are an effect of practitioners' training, issues in the structure of health IT systems, and the history of the hierarchy – give the hierarchy its complex (but specifically-constituted) underlying ontological multiplicity.

In each approach, a view of the hierarchy emerges that shows it to be a singularly-imagined, non-singular taxonomy. It appears as a framework that is inexactly reproduced in almost every instance it is used, but which actualizes in practice as a coherent and unified thing across contexts. This is, on the one hand, a logical paradox. On the other hand, it is a demonstration of an overarching argument of this dissertation, regarding how uses of specific technologies, infrastructures, concepts, and taxonomies in particular arrangements of people and institutions produce epistemic and material frictions, specific methods of managing data, biomedical sexualities, and ultimately situated sexual realities.

Following my analysis of the HIV risk hierarchy in these genealogical, technical, and ethnographic modalities, I consider its most regularly-contested category: "male-to-male sexual contact," also at times "men who have sex with men," or simply the decontextualized acronym "MSM." I employ a hybrid approach using all three methods in tandem (genealogical, technical, and ethnographic analysis) to describe how "male-to-male sexual contact" and related terms take shape in practice. I focus on a generalized anxiety about the potential of the term "MSM" to transmute into a category of subjective self-identification in the vein of "gay," "bisexual," or "same-gender loving" that reflects an indelible part of a person's sense of self.

An interdisciplinary range of researchers and interlocutors believe that this is a widespread phenomenon. However, I offer an alternative and complementary view that is drawn from a review of the secondary literature (especially a close reading of a 2009 article on the MSM category by Anthropologist Tom Boellstorff), consideration of the term's history in HIV surveillance, the many ways that I have encountered the category during fieldwork, and how my interlocutors have reflected on (or explained their understanding of) the category to me during conversations. I suggest that, while identifications "as MSM" are real and that some people do "identify as MSM" in the way that others identify as gay or bi (that is to say, as part of their internalized and indelible sense of self), these "identifications" are far more often provisional labels taken up for the purposes of engagement in healthcare. I say this while also acknowledging that the emergence of internalized "MSM identities" is a real phenomenon that presents a particular range of complexities with which practitioners must contend, but ought not try to "fix" or reverse. Resistance to MSM's emergence as an identity – which is widespread in Atlanta and elsewhere among professionals and activists – potentially stigmatizes individuals who do identify as MSM. However, these new identities (to the limited extent that they exist) merit validation and respect, even if these do not fit within current queer lexicons and are perceived to be imparted onto men (and particularly young black gay men) who might otherwise identify as gay by large public health institutions such as "CDC."

In the conclusion, I discuss the contested status of transgender people in HIV surveillance infrastructures in Georgia and the United States, pondering the future of trans HIV surveillance and what emerging best practices in this space might mean for the future of the HIV risk hierarchy. I discuss advocacy undertaken by transgender women of color in Georgia that led to the Georgia Department of Public Health (GDPH) changing how that institution reports trans surveillance data as well as a systematic audit of state HIV surveillance data to identify transgender cases. I also provide an overview of the status of transfolk in the *HIV Surveillance Report* and the National HIV Surveillance System (from which report data are generated). I frame methods used to report transgender data using a revised version of the hierarchy in the *Ryan White HIV/AIDS Program Annual Client-Level Report* (2016) as a potential model for transgender-inclusive surveillance futurities.

I ultimately follow emerging trends in arguing for a new, trans-inclusive, HIV risk hierarchy that does not refer to gender or sexual orientation, but simply to "sexual transmission." I also emphasize that, like sexual orientation and gender identity (SO/GI) taxonomies, the HIV risk hierarchy and its classifications produce conditions of sexual possibility that correspond specifically to them, and that uses of the risk hierarchy in relation to languages of sexual orientation and gender identity, health IT standards used to capture this data, and other frameworks such as "special populations" and "target populations" in HIV work and sexual and gender minority health enact sexual realities that are only possible because of how these co-extant frameworks come into unstable coexistence with one another. When the HIV risk hierarchy, SO/GI, and other paradigms come into friction in practice, certain ways of making sense of sexuality in a particular milieu are brought forth.

II. What is the HIV Risk Hierarchy?

The HIV risk hierarchy is a list of the most likely routes of HIV transmission, ordered from highest to lowest probability of transmission (see page 1, Figure 1.1, above).[5] However, the HIV risk hierarchy is also a kind of standard, ideal type, data collection instrument, and regulated taxonomy. It contains specific categories that have precise definitions and are ordered based on probability of transmission. Everybody who works in HIV has at least a basic understanding of this (at least everyone that I have met during fieldwork who works in HIV – to a person – knows this). It is basic knowledge, "101," spoken about constantly, and literally in the air that practitioners breathe and in the sweat and oils that move from their hands and into the paper documents and digital devices that they use in the daily work of informatic practice in the administration of HIV programs and the collection and reporting of data.[6] In this way, the HIV risk hierarchy is real and has a very powerful material existence as a framework that shapes nearly all aspects of the global HIV apparatus and actors working in nearly every conceivable context therein.

However, the following is also true: the HIV risk hierarchy does not exist. At least, the hierarchy does not exist in the way that biomedical gold standards or health IT standards usually do – in rigidly standardized taxonomies and technical protocols with exacting specifications for the capture, storage, and exchange of data that are maintained by standards-setting institutions in order to ensure the functionality and interoperability of particular kinds of data within and between different systems.[7] At least from those vantages, the hierarchy does not exist.

Rather, it is a set of discursive, conceptual, and sociotechnical coordinates – not a single thing associated with neat uniformity and consistency of reproduction across contexts. The hierarchy exists *typologically* or *topologically*, in the way that a certain type of sandwich can be said to exist.

Standard Like a Reuben

Consider the Reuben sandwich. Reubens bear formal similarities to HIV risk hierarchies, both in concept and in practice. Like the HIV risk hierarchy, the Reuben has a contested origin story and a vocal minority of people have strong opinions about how Reuben sandwiches should be made. Reubens bears certain properties (e.g. they are served on rye bread) and have an acceptable range of potential ingredients (e.g. sauerkraut). They are ubiquitous in sandwich shops and restaurants in the United States (like the hierarchy is ubiquitous in the HIV world), and are supposed to appear and taste a certain way: like only a Reuben can. [8] And, ultimately, that flavor is culled from a set of cognitive and affective coordinates that are informed by an individual's past encounters with Reubens. These are mapped onto the experience of sensing and consuming individual sandwiches, thus reaffirming and/or altering one's sense of what a Reuben is or could be.[9]

Like sexual realities conditioned by the HIV risk hierarchy, Reubens materialize through interactions between matter, mind, and meaning. No two are *exactly* alike. However, each dining establishment's version is likely to be consistent year-over-year, visit-to-visit, and sandwich-to-sandwich. Some restaurants and delicatessens even stake their reputations on such things, or go out of their way to make their Reubens special or exemplary, much in the way that some HIV/AIDS Service Organizations (ASOs) tout the quality of their services or of the data they report to funders.[10] This exploration of the different ways a Reuben might materialize, of course, raises some ontological questions. At what point does an assemblage of ingredients bear Reuben-esque qualities, but fail to materialize as a Reuben? What degree of approximation is acceptable before a "Reuben" becomes… something else? The figure on the following page shows several varieties of Reubens (and "Reubens") that dramatize this ontological quandary.

Figure 1.2. Varieties of Reubens[11]

Reuben from Zingerman's in Ann Arbor, MI - an acclaimed delicatessen

"Reuben the Great" from Jason's Deli, a chain with a Midtown, Atlanta location

A "Reuben" from SUBWAY®, offered seasonally in some markets in the mid-2010s

The *Rachael Ray Every Day Reuben Wrap*, made with pork shoulder and flour tortilla

Whether a food item is a Reuben (or, for that matter, a "sandwich," as the classification "wrap" in quadrant four shows) is dependent on relations between whomever is planning to eat it, the entity assembling and presenting it, and all the other potential forces that go into creating the moment within which it comes into presence for consumption.[12] For example, it is doubtful that regular consumers of Reuben sandwiches would take the *Rachael Ray Every Day Reuben Wrap* represented in quadrant four of Figure 1.2 very seriously as a Reuben for any number of reasons. However, some people evidently *do* understand it to be a Reuben – even people with epistemic authority and clout in the realm of gastronomy such as celebrity chef Rachael Ray, who published the recipe in her magazine and the magazine's website.

The HIV risk hierarchy exists in this way far more than it does as a standardized taxonomy imperially imposed by higher-order actors such as CDC on actors lower in the organizational structure of HIV care, prevention, and surveillance. It is a general typology, topology, and set of cognitive and sociotechnical coordinates that are assembled collectively by creators, users, consumers, and infrastructures during event-processes of conceptualization, assemblage, and deployment in practice.[13]

Just as Reubens are differently constituted, the hierarchy varies widely and wildly in regard to what it is called, in regard to the taxonomy that distinct iterations contain, in regard to how classifications are defined in official definitions and by actors in practice, in regard to the underlying health IT specifications that correspond to iterations of the hierarchy in health information infrastructures, and in regard to the terms used to express hierarchy data. In different domains of practice or subdisciplines, from agency-to-agency, or even within specific documents or conversations, how the hierarchy and hierarchy data are collected, defined, arranged, and reported is amazingly inconsistent. Yet, in each setting and in each individual instance, a hierarchy materializes. Further, each is shaped by genealogical forces (the history of the taxonomy), technical matters (usually related to the constitution of the hierarchy in a data infrastructure or health IT system), and other material and discursive dimensions that occasion specific uses (such as the protocols in place at an organization where the hierarchy is used on a regular basis, whether for data collection, reporting, or some other reason).

Hierarchies Repeated with a Difference

Consider what longtime HIV practitioner Leisha McKinley-Beach had to say about the hierarchy when asked about the relationship between the terms “men who have sex with men” and “gay and bisexual men.” As I explore below, some professionals (and governing documents such as *The National HIV/AIDS Strategy of the United States*) treat these categories as synonymous or coextensive with one another, while others emphasize that they are different and should never be discussed as equivalent.

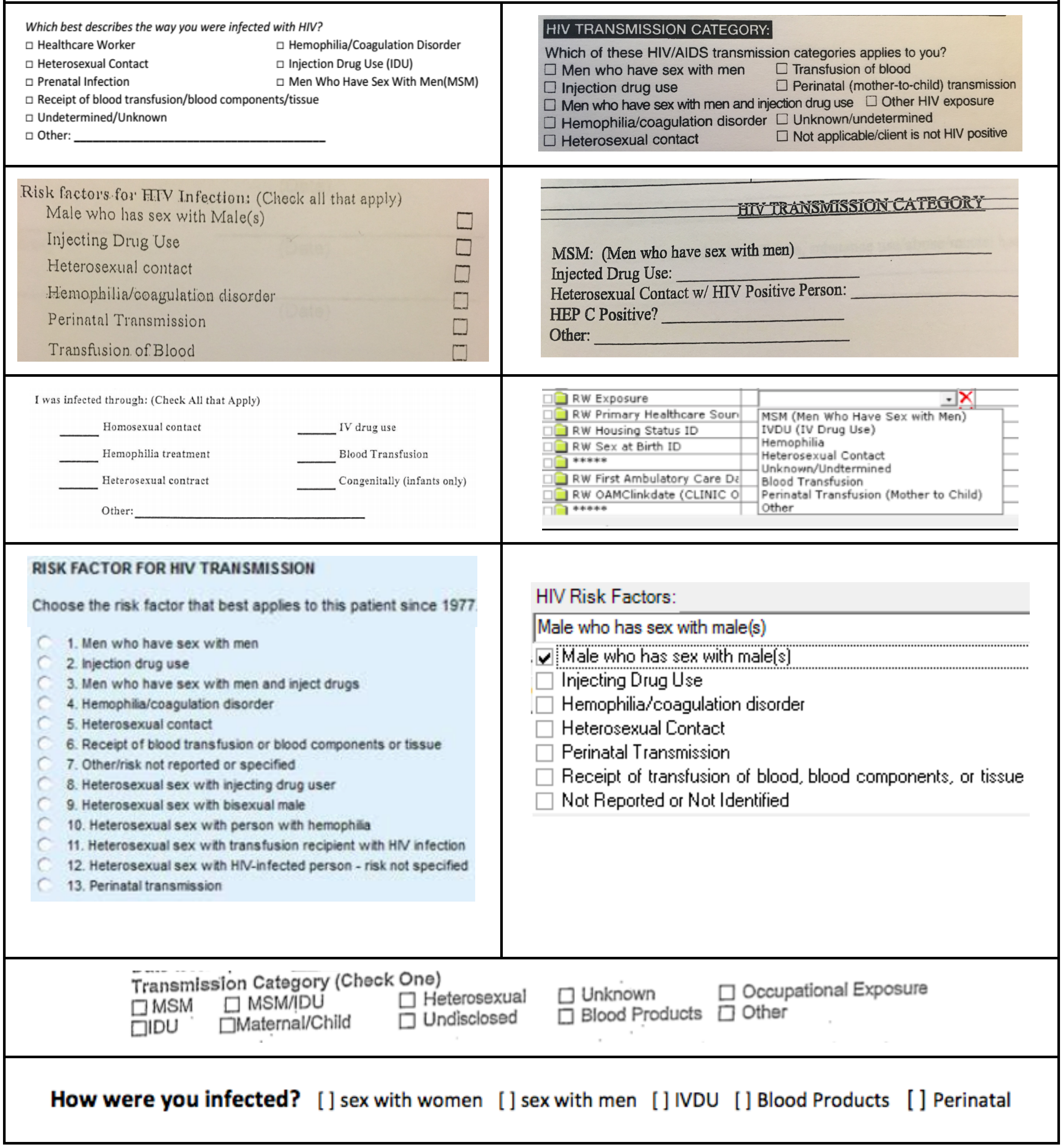
> **Leisha McKinley-Beach, longtime HIV/AIDS professional in the Southeast:** Well, I think, this is very complicated. Many years ago, I was on the bandwagon for the term "MSM" because I thought that using the term "homosexual" or "gay" perpetuated the stigma that this is the only community that would be infected with HIV…And when I think now of the term "men who have sex with men," it's like we're trying to address this one component of this person's life and them having sex with another man. I'm not so sure anymore that that truly is the risk.
>
> What were the social determinants that may have affected that? Was this person involved in a sexual act for food? Was this person involved in a sexual act for housing? And when we say men who have sex with men...Was the behavior oral sex? Because we consider that sex! We know that there is little to no risk of becoming HIV positive from oral sex, but yet this is a man who has sex with another man.
>
> And so, I just think it's time now to come back to the table and review the terminology. Is it about anal sex? And the answer is "yes," but are men who have sex with men the only people who have anal sex? Absolutely not. And so there seems to be this kind of hierarchy of risk. I also don't like the term any more, "high-risk"…those terms – they stigmatize our community.[14]

McKinley-Beach does not question the fact of the hierarchy's existence. In fact, its taken-for-granted existence is what allows her to take direct aim at it. Her response manifests ideas embedded in the hierarchy - such as "risk," "sex," "men," and "MSM" - while also critiquing the hierarchy for failing to adequately define those terms or to include others that she thinks would be more instructive (such as "survival sex work" or detailed reports about behaviors that would further operationalize, define, and contextualize "sex"). For her and most others, "the hierarchy of risk" remains one thing insofar as it is conceptualized as a monolithic taxonomy, but also something that is also always being contested and is (re)materializing in relation to other analytics, such as sexual identity (gay and bisexual), sexual behaviors (oral vs. anal), sexual motivators (sex for food or housing), and other "social determinants" of health.

This sort of discourse about the hierarchy and its categories is normal in the HIV world. Living with the hierarchy's incoherencies – while also conceptualizing it as a singular taxonomy because nearly everyone is forced to work with it, and because it is a common reference point – is part of working in HIV. Even if a specific presentation of hierarchy data in a public meeting by one individual does not align with another person's understanding of how hierarchy data ought to be reported out, the decision to use a specific vocabulary – such as employing the terms "gay and bisexual men," "men who sleep with men," or "MSM" to report data about "male-to-male sexual contact" – is not likely to cause a stir. Indeed, employing different terminologies to present information using terms from the hierarchy, sexual orientation taxonomies, and other frameworks (such as data about commercial sex work) is a feature of conferences, events, and other meetings in HIV and sexual and gender minority health. However, sometimes (intentionally or spontaneously), conversations about the hierarchy or specific categories become animated. In these controversies (which occur in venues as varied as meeting rooms, conversations, and special journal issues), constituencies who do not feel represented – such as transgender people – engage in fierce contestations over how terminologies are developed and used. As the genealogy of the hierarchy, analyses of technical iterations of the hierarchy in EHRs and health IT systems, and conversations with practitioners about the hierarchy during fieldwork has revealed, agonism is written into the fabric of the hierarchy's existence, just as agonism is written into every aspect of the HIV/AIDS epidemic and the history of sexual and gender minority health.[15]

Figure 1.3, below, shows nine excerpts from intake forms or EHR fields that are used to collect "HIV Risk Factor" data at Ryan White clinics in Atlanta, and one in Boston. All of these were in active use during 2017.

Figure 1.3. Excerpts from Intake Forms and EHR fields at Ryan White Agencies in Atlanta, and One in Boston



Which best describes the way you were infected with HIV?

☐ Healthcare Worker
☐ Heterosexual Contact
☐ Prenatal Infection
☐ Receipt of blood transfusion/blood components/tissue
☐ Undetermined/Unknown
☐ Other: ____________________
☐ Hemophilia/Coagulation Disorder
☐ Injection Drug Use (IDU)
☐ Men Who Have Sex With Men(MSM)

HIV TRANSMISSION CATEGORY:

Which of these HIV/AIDS transmission categories applies to you?

☐ Men who have sex with men
☐ Injection drug use
☐ Men who have sex with men and injection drug use
☐ Hemophilia/coagulation disorder
☐ Heterosexual contact
☐ Transfusion of blood
☐ Perinatal (mother-to-child) transmission
☐ Other HIV exposure
☐ Unknown/undetermined
☐ Not applicable/client is not HIV positive

Risk factors for HIV Infection: (Check all that apply)

Male who has sex with Male(s) ☐
Injecting Drug Use ☐
Heterosexual contact ☐
Hemophilia/coagulation disorder ☐
Perinatal Transmission ☐
Transfusion of Blood ☐

HIV TRANSMISSION CATEGORY

MSM: (Men who have sex with men) ____________________
Injected Drug Use: ____________________
Heterosexual Contact w/ HIV Positive Person: ____________________
HEP C Positive? ____________________
Other: ____________________

I was infected through: (Check All that Apply)

_____ Homosexual contact
_____ Hemophilia treatment
_____ Heterosexual contract
_____ IV drug use
_____ Blood Transfusion
_____ Congenitally (infants only)

Other: ____________________

RW Exposure
RW Primary Healthcare Sourc
RW Housing Status ID
RW Sex at Birth ID
*****
RW First Ambulatory Care Da
RW OAMClinkdate (CLINIC O
*****

MSM (Men Who Have Sex with Men)
IVDU (IV Drug Use)
Hemophilia
Heterosexual Contact
Unknown/Undtermined
Blood Transfusion
Perinatal Transfusion (Mother to Child)
Other

RISK FACTOR FOR HIV TRANSMISSION

Choose the risk factor that best applies to this patient since 1977

○ 1. Men who have sex with men
○ 2. Injection drug use
○ 3. Men who have sex with men and inject drugs
○ 4. Hemophilia/coagulation disorder
○ 5. Heterosexual contact
○ 6. Receipt of blood transfusion or blood components or tissue
○ 7. Other/risk not reported or specified
○ 8. Heterosexual sex with injecting drug user
○ 9. Heterosexual sex with bisexual male
○ 10. Heterosexual sex with person with hemophilia
○ 11. Heterosexual sex with transfusion recipient with HIV infection
○ 12. Heterosexual sex with HIV-infected person - risk not specified
○ 13. Perinatal transmission

HIV Risk Factors:

Male who has sex with male(s)

☑ Male who has sex with male(s)
☐ Injecting Drug Use
☐ Hemophilia/coagulation disorder
☐ Heterosexual Contact
☐ Perinatal Transmission
☐ Receipt of transfusion of blood, blood components, or tissue
☐ Not Reported or Not Identified

Transmission Category (Check One)

☐ MSM
☐ IDU
☐ MSM/IDU
☐ Maternal/Child
☐ Heterosexual
☐ Undisclosed
☐ Unknown
☐ Blood Products
☐ Occupational Exposure
☐ Other

How were you infected? [ ] sex with women [ ] sex with men [ ] IVDU [ ] Blood Products [ ] Perinatal

Note the differences. No two excerpts above contain exactly the same taxonomy. Some pose a question about how one became infected, while others simply present a list of options, some of which include acronyms with no corresponding words or definitions. Some are ordered hierarchically; others, seemingly at random. Some iterations ask for respondents to select multiple choices, while others insist that only one be chosen. One form even requires the respondent to fill-in-the-blank (while also asking if the client has hepatitis C). Further, some of these fields are clearly meant for the individual receiving services to fill out, while others are intended for a member of the agency's staff to complete. Indeed, the (sexual) realities that might be enacted during the use of one of the fields shown above are shaped as much by the content of the fields presented as by the clinical workflow within which the data will be populated, and by the tools used to collect the data. Data gathered through these fields are used to enact sexual realities not only during clinical encounters, but also after the fact, when data are aggregated and informatics staff use hierarchy data to determine disparities within populations or to measure patient load.

However, despite their differences – both taxonomically and formally speaking (some are from analog paper forms, others digital screenshots) – the excerpted images are HIV risk hierarchies that I encountered during fieldwork and are readily recognizable *as HIV risk hierarchies*. They all fulfill basically the same function, and are all ultimately used to populate a single field required for every client included in agencies' mandated reports. These excerpts come into appearance as HIV risk hierarchies not because they adhere to a gold standard, or even because they are hierarchically arranged. Rather, they appear as hierarchies because they resemble what a hierarchy "ought to" look like.

As a taxonomy and a standard, the hierarchy is strange. It is a gold standard that is imagined singularly, and therefore really exists as a unitary framework imperially-imposed by an institution that actors usually refer to obliquely as "CDC." However, it is also not locatable in any one place as a workable health IT standard, nor is it used in the same way by any two people or institutions. It materializes singularly only because it and its categories are deployed repeatedly in different ways. It achieves trans-contextual consistency only through its constant appearance as many different versions of itself.

III. A Genealogical Account of the HIV Risk Hierarchy, 1981-2016

This section uses genealogical methods to analyze what the hierarchy has been called and how its taxonomy has evolved and accumulated since cases of *Pneumocystis* pneumonia and Kaposi's Sarcoma were first reported among "active homosexuals" in Southern California by CDC in 1981.[16] Methodologically, I draw from Gilles Deleuze's monograph *Foucault*, Foucault's essay "Nietzsche, Genealogy, History," and David M. Halperin's "How to do the History of Male Homosexuality" to remap the historical trajectory of the hierarchy and its taxonomy in a fashion that attends to how they have been defined and transformed through intentional shifts and gradually over time in *HIV Surveillance Reports* and predecessor documents. These documents are publicly available on a CDC HIV Surveillance website dedicated to housing old reports for reference purposes.[17]

I analyze the historical development of the hierarchy in the domain of surveillance through thick description of its evolution using data from the *Reports* and the reports' technical notes.[18] I culled the chronological table that appears below using data from the master table that I describe creating in the beginning of this chapter. The chart in Figure 1.4 – a kind of diagram and a Deleuzian "new cartography" – traces the hierarchy and its taxonomy from 1981, when initial reports of conditions affecting previously-healthy young gay men appeared, to the 2016 *Report*. Since 2003, the official name of the hierarchy has been "transmission category."[19]

Before a close analysis of the chart, which appears on the following page and which I return to throughout the genealogical analysis, I provide the *de facto* official history of the hierarchy produced by CDC. Like the hierarchy itself, its history does not exist in a single place. Instead, I (re)produce an official history myself through an analysis of several publications by CDC that reflect on the development of the National HIV Surveillance System (NHSS). The NHSS aggregates state-level HIV surveillance data and is the basis for data reported in annual *HIV Surveillance Reports* and other quantitative information about the national epidemic in documents such as the *National HIV/AIDS Strategy of the United States* (*NHAS*).

Figure 1.4. Chart of the Genealogical Development of the HIV Risk Hierarchy, 1981-2016

Years	Name of the Hierarchy	Key Categories Included During This Period
1981-1982 (No hierarchical ordering; period of confusion)	No name (1981) Sexual Orientation (1982)	Homosexual Men Young men, all active homosexuals Frequent homosexual contacts with various partners Homosexual Males Bisexual Males Heterosexual Males Males of Unknown Sexual Orientation
1983-1987 (Period of flux; "4-H"; Hierarchical ordering begins in 1984)	Patient Characteristics (1983) Patient Groups (1984-85) Transmission categories (1986-87)	Homosexual or Bisexual (reported without regard to gender) Homosexual or Bisexual Men Intravenous (IV) Drug User Haitian (only in 1983-1984) Hemophiliac Hemophilia Hemophilia/Coagulation Disorder Heterosexual Contact Transfusions with Blood/Blood Products Transfusion Blood/Components None of the above/other Undetermined
1988-1990 (Period of greater consistency)	Exposure category (1988-90)	Male homosexual/bisexual contact Intravenous (IV) drug use (female and heterosexual male) Male homosexual/bisexual contact and IV drug use Hemophilia/coagulation disorder Heterosexual contact (with breakdown by partner type) Pattern-II country Receipt of transfusion of blood, blood components, or tissue
1991-2001 (Period of emergent solidification)	Exposure category (1991-2001)	Men who have sex with men Injecting drug use Men who have sex with man and inject drugs Hemophilia/coagulation disorder Heterosexual contact (with breakdown by partner type) Pattern-II country (ends in 1993) Receipt of blood transfusion, blood components, or tissue Other/undetermined Other/risk not reported or identified
2002-2007 (Categories solidify into contemporary hierarchy in 2002, name changes to "transmission category" in 2004)	Exposure category (2002-03) Transmission category (2004-07)	Male-to-male sexual contact Injection drug use Male-to-male sexual contact and injection drug use Heterosexual contact Hemophilia/coagulation disorder Receipt of blood transfusion, blood components, or tissue Other/risk not reported or identified Other
2008-2016 (Contemporary hierarchy)	Transmission category (2008-16)	Male-to-male sexual contact Injection drug use Male-to-male sexual contact and injection drug use Hemophilia/coagulation disorder Heterosexual contact

Official/*De Facto* History of the Hierarchy

The official history of the hierarchy generally reflects the positivist orientation of public health and the historical amnesia typical of large institutions. This orientation toward the past treats disciplinary developments and change-over-time as necessarily constituting improvement upon past shortcomings and therefore not worthy of extended consideration. In this literature (written by practitioners), the development of the HIV risk hierarchy is situated within a narrative of scientific progress.[20] Official histories such as this tend to gloss over meaningful changes that took place over long periods as the result of evolving scientific understandings of HIV and its cause of transmission, as well as changes in best practices regarding the language used to discuss people living with and disproportionately affected by HIV.

The official history of the hierarchy, insofar as one exists, is simplistic and is generally offered as one part of an overview of HIV surveillance in the United States. A 2011 CDC publication entitled "HIV Surveillance --- United States, 1981-2008" opens with the following factually incorrect narrative: "Within 1 year of the initial report in 1981 of a deadly new disease that occurred predominantly in previously healthy persons and was manifested by *Pneumocystis carinii* pneumonia and Kaposi's sarcoma, the disease had a name: acquired immune deficiency syndrome (AIDS). Within two years, the causative agent had been identified: human immunodeficiency virus (HIV)."[21]

This retelling is both descriptively flat and false. It fails to mention that the "previously healthy persons" referenced in the 1981 *MMWR* "epidemiologic note" were all identified as "active homosexuals," not simply "healthy persons." Further, it does not discuss that there was significant debate about what to call AIDS, what caused AIDS, who was affected by AIDS, and massive controversy over what the retrovirus was, what to officially call it ("human immunodeficiency virus"/HIV or "human T-lymphotrophic virus-3"/HTLV-3), and who "really" discovered it until the late 1980s.[22] The official historiography does not consider that understandings of how HIV is transmitted changed substantially during the epidemic's early years, as well as the fact that the categories used in surveillance have been totally transformed several times since 1982. These changes are reflected in Figure 1.4. The 2011 article, published in 2011 in CDC's flagship *Morbidity and Mortality Weekly Report* (*MMWR*), simply reports out current surveillance numbers using the following categories, as if they had always existed as such: "MSM," "IDU (male)," "IDU (female)," "MSM and IDU," "Heterosexual contact (male)," "heterosexual contact (female)," and "other." The 2011 article's use of "MSM" does not only erase these categories' historical emergence and change-over-time; it is also temporally anachronistic or out-of-synch with best practices at the time of its publication in 2011, considering that "men who have sex with men" was eliminated from the *HIV Surveillance Report* in 2002 and replaced with "male-to-male sexual contact." Additionally, the article's presentation of the hierarchy, which divides "IDU" and "heterosexual contact" by gender in a single tabular presentation, is quite an uncommon way of presenting hierarchy data. This demonstrates that, even among surveillance specialists and epidemiologists at CDC, the hierarchy's constitution in practice is quite inconsistent, despite it being imagined as trans-contextually and even trans-historically uniform.

A different, 2014 article published by CDC scientists in the journal *Public Health Reports* titled "The Status of the National HIV Surveillance System, United States, 2013," does not even present charts that include the hierarchy. Instead, the article focuses on how the NHSS and state HIV surveillance systems can now facilitate new kinds of longitudinal monitoring of individuals, subgroups, and specific strains of HIV virus over extended periods of time.[23] These advances follow from the implementation of names-based reporting in all states by 2008 and electronic laboratory reporting (ELR) data feeds in 2013 that report bloodwork results to state and local health departments every time people living with HIV receive a blood draw (ideally twice per year). These programs, and their implementation in Georgia, are the focus of chapters five and six of this dissertation.

As I describe in those chapters, ELR infrastructures are facilitating new kinds of surveillance and public health interventions aimed at people living with HIV. These are focused on determining the time intervals between medical visits for individuals living with HIV as well as "molecular surveillance" tools that allow state and local departments of public health to track viral load data, CD4-T cell counts, the emergence of antiviral medication resistance in "transmission networks" or specific geographic areas, and the transmission and circulation of specific strains of HIV within "clusters" or subpopulations.[24] While there is no tabular presentation of hierarchy data in the 2014 article, the piece does mention the hierarchy in the body of the text, saying that "HIV transmission occurs through sexual contact with infected partners, sharing of contaminated needles between injection drug users, and exposure to contaminated blood or blood products."[25] However, the authors emphasize new surveillance methods enabled by advances in health IT and biomedical knowledge about HIV, rather than the transmission risk hierarchy.

In another example of how the hierarchy is framed without regard for its genealogy, a surveillance-oriented "Terms, Definitions, and Calculations Used in CDC HIV Surveillance Programs" fact sheet hosted on a CDC website intended for public consumption and practitioner education eschews the history of the hierarchy entirely.[26] This document simply reports definitions for key terms of a partial version of the hierarchy where the categories appear in a different order than they do in *HIV Surveillance Reports*, and thus, in a different order than the greatest “risk” to lowest, as the hierarchical arrangement of the classifications is intended to signify.

The *de facto* official history of the hierarchy is more correctly characterized as an absence of history. Further, official presentations of the history of HIV surveillance in the practice-orientated literature are often out of alignment with both the hierarchy’s actual historical genealogy and sometimes even the current gold standard as reflected in *HIV Surveillance Reports*.

Genealogy of the HIV Risk Hierarchy

Throughout my analysis of the genealogical development of the HIV risk hierarchy from 1981 to present, I refer to Figure 1.4, above. That table chronologically charts – or diagrams – how the hierarchy has evolved and become condensed into an increasingly consistent set of categories over time, at least in the presentation and definition of the taxonomy and its individual classifications as they are presented in the annual *HIV Surveillance Report* and predecessor documents (which function as the gold standard for the taxonomy). It is a kind of chronological topography of the hierarchy as it has developed through time and as its key categories have transmuted.

The first two iterations of what would become the hierarchy are not, in fact, hierarchies at all. In 1981, there were simply references to “homosexual men” or related terms in individual reports published in the *Morbidity and Mortality Weekly Report* (*MMWR*); this expanded to “sexual orientation” in 1982. The hierarchy only materialized as a hierarchical ordering of what were thought to be potential transmission factors in 1983, and has stayed hierarchically-arranged ever since.

The second column of Figure 1.4 – “The Name of the Hierarchy” – reflects that the name of the hierarchy has changed seven times since 1981: from some variation of “male homosexuals,” to “sexual orientation,” to “patient characteristics” in 1983, which continued with relative taxonomical consistency until 1985 under the label “patient groups.” From 1986 to 1987, the hierarchy was called “transmission categories” (plural), which transformed into “exposure category” (singular) from 1988 to 2003, before solidifying into “transmission category” (singular) in 2004. The definition of the hierarchy – and the determination of one’s transmission category in cases when multiple risk factors are reported – has remained quite consistent since 1988. This is because, by the late 1980s, all major routes of HIV transmission were known. Essentially, if multiple “risk factors” are reported, the single most likely mode of transmission is reported out, except for men who report sex with men and injection drug use, who make up their own separate category, owing (it is implied) to those two risk factors being co-equal.

The formal categorical definitions, mode of determining single most likely transmission factor, and the data collection instrument used in surveillance case report forms, collectively result in some strange outcomes. The most notable quirk of surveillance data pertains to the “male-to-male sexual contact” category. Per CDC technical guidance distributed to HIV surveillance systems operated by state and local health departments (which transmit data to the National HIV Surveillance System operated by CDC), the “male-to-male sexual contact” category in surveillance applies to any reported sexual contact (without reference to specific kinds of sex acts) during the course of someone’s entire life. Therefore, if a man in his 40s who tested positive for HIV in 2015, reported no injection drug use, knew with certainty that he had become HIV positive through sex with a cisgender woman, and had only had sex with cisgender women for the past 20 years, but had performed oral sex (which does not transmit HIV) or engaged in what a Georgia Department of Public Health (GDPH) epidemiologist described as "experimental" sexual behavior with other men even a single time in his life (even if this was 25 years prior to his diagnosis), he would be reported as a "male-to-male sexual contact" case, *not* as a "heterosexual contact" case, even though he acquired HIV from sex with a woman and knows this with certainty. This is chiefly because "male-to-male sexual contact" data are collected on case report forms filed when someone becomes HIV-positive without regard to *when* sexual contact with the male partner happened. This is an effect of how the data collection mechanisms (HIV case report forms) developed over time. It is not an intentional feature of the "male-to-male sexual contact" category in HIV surveillance. Indeed, multiple interlocutors at GDPH expressed to me that they wished the data collection instrument used to populate the category on case report forms was different, but that they were bound by CDC guidance. Further, the "male-to-male sexual contact" category does not behave this way in other HIV contexts such as prevention and research, where data collected about sexual behaviors is usually limited to the past 12 months. This strange feature of "male-to-male sexual contact" data in HIV surveillance is specific to genealogy of the HIV risk hierarchy as something that has developed over a long period of time, and which has become more entrenched and thus difficult to change or revise as it has solidified.

The only major change in how cases with multiple recorded risk factors were reported out using a single risk factor occurred in 2007. That year, a statistical method called multiple imputation that is used primarily to populate missing fields in survey response data was adopted to determine most likely risk factor, versus simply selecting the category highest in the hierarchy as an individual's reported category and/or leaving the field blank if no risk factor was reported.[27] The technical definition of "transmission category" has remained unchanged since

2008: “the classification of cases that summarizes a person’s possible HIV risk factors; the summary classification results from selecting, from the presumed hierarchical order of probability, the one risk factor most likely to have been responsible for transmission.”

The hierarchy’s taxonomy has undergone significant transformations during the course of its nearly four decades of existence. Rather than describing the taxonomy’s development chronologically (which one can do by examining the chart in Figure 1.4), I discuss three prevailing trends in its development. The first is an oscillation between *types of persons* and *kinds of behaviors*. The second is *increasing taxonomic consistency as time advances*, as reflected in the relative solidification of categories after 1988. The third tendency is *an oscillation between value-neutral and value-laden classifications* in the hierarchy’s history.

Before 1988, the hierarchy was much less concerned with behaviors than it was with *types of people*, owing to the fact that the causes of HIV transmission remained relatively murky even into the mid-1980s. The emphasis on positionality or subject-position over-and-above potentially HIV-transmitting behavior is reflected in the taxonomy’s use of categories like “Homosexual or Bisexual Men” and “Haitians” before 1988, and “Pattern-II” country transmission until 1992. “Pattern II” was a category that grew out of the “Haitian” category, and was used to classify HIV transmission attributed (often wrongly) to “heterosexual contact” in non-Western nation-states predominantly in the Caribbean and Sub-Saharan Africa. “Pattern-II” is a classification that requires its own history and analysis using a transnational lens. It faded from the HIV/AIDS lexicon by the mid-1990s, and was removed from *Surveillance Reports* starting in 1993. However, the definition of “Pattern-II” was not stable during the years it was employed in HIV surveillance in the United States, and certainly took on varied meanings in practice while it was in wider use. Further, the notion of a “high risk” country – which, again, began with the identification of HIV with “Haiti” and then “Pattern II” countries – persists in a multiplicity of global public health contexts.[28]

Before 1988, when the transition to behavioral categories occurred somewhat definitively in the domain of HIV surveillance, the classification of HIV cases based on behavior or individual positionality was inconsistent and uneven. Transmission via “heterosexual contact” oscillated between behavior and sexual identity, with both “heterosexual contact” and “heterosexual cases” being used interchangeably. This made someone who was reported as being HIV-positive in 1985 due to “heterosexual contact” a full-blown “heterosexual” in the 1986 and 1987 reports. What had been reported as a sexual act in previous years transmuted into data about sexual identity, and then back to behavioral data again starting in 1988 – at least based on the terms used to report out data by CDC in *Surveillance Reports*.

After 1988, the transition from identity to behaviors in the realm of sexual transmission was essentially complete in U.S. HIV surveillance. However, the transition to behavioral descriptors did not hold for people who inject drugs, who were referred to as both “intravenous drug abusers” and “intravenous drug users” (types of people) until the category changed to “injecting drug use” (a behavior) in 1993. The replacement of “intravenous” with “injecting” makes this a substantive categorical transformation, and a kind of official recognition in the realm of HIV surveillance (intentional or unwittingly) that drug use via hypodermic needle can be subcutaneous and does not require a vein. “Injecting drug use” itself transmuted into “injection drug use” in 2002 – a rather superficial change, but a change nonetheless. “Injection drug use” remains the classification used to the present.

However, the problem of positionality, identity, and subject-position has never fully left the categories contained in the HIV risk hierarchy’s taxonomy at the level of technical definition. It was not until 1991 that the word "homosexual" (a subject-position, not a behavior) was fully jettisoned from the hierarchy's taxonomy, and "sex with bisexual male" remained in the breakdown under "heterosexual contact" in *Surveillance Report* tables until as late as 2007. In the exploration of the "male-to-male sexual contact" category later in this chapter, I discuss the fact that "homosexual" and "bisexual" remain in the technical definition of that category until the present day. Just as "sexual orientation" is part of the genealogy and conceptual undergirding of what is called "transmission category" in the 2016 *Report*, and given that the hierarchy itself was called "sexual orientation" briefly in 1982, homosexuality and bisexuality will always remain in some way central to "male-to-male sexual contact." This is true both as the category has evolved over time and in the many ways that data generated using instruments designed to record transmission via "male-to-male sexual contact" are expressed by different institutions (e.g. using the language of "gay and bisexual men" or "MSM").

Further, "men who have sex with men" and "male-to-male sexual contact" are not strictly behavioral classifications. They are also grounded in a subject-position: that of "man" or "male." As I explain in the section of this chapter dedicated to "male-to-male sexual contact," in HIV surveillance and care infrastructures, "male" refers to sex assigned at birth – not to gender identity. This means that transgender women are coded as "MSM" in HIV surveillance systems. This is true even in systems that collect both "sex assigned at birth" and "gender identity" data categories. Most state, territorial, and local health departments do collect both sex assigned at birth and gender identity data in HIV surveillance, and CDC includes this in its recommended case report form, which was updated in 2018.[29] However, CDC has chosen not to report transgender data in national reports, for reasons I explore in the conclusion of this chapter, and much to the consternation of LGBTQ health advocates within and outside of the HIV movement.

The solidification of the hierarchy across time tracks along with the institutionalization of the infrastructures that have been developed to fund and administer care, prevention, and surveillance programs. The hierarchy's further solidification followed the development of scientific consensuses and best practices in the 1980s and 1990s, such as the existence of a single retrovirus that ultimately caused HIV disease to progress to AIDS and the recognition of a set number of known transmission pathways. The calcification of the taxonomy is most notable from 2003 onward.[30]

While the ascription of positive or negative value to labels and categories is largely dependent on the interpreter of the sign – "men who have sex with men" is a classification I repeatedly return to that interlocutors and researchers value positively, negatively, and/or ambivalently – some cut more clearly in one direction. This is particularly true for people who inject drugs, who are called "abusers" until 1987. However, the association of seropositivity with negative valuation is embedded in the hierarchy's taxonomy until 2007 via the label "HIV-infected" under the breakdowns included under "heterosexual contact" in tables of *HIV Surveillance Reports*. People living with HIV have long advocated against the phrase "HIV-infected" and claimed it to be stigmatizing. "Person-first" language, such as "people living with HIV" versus "HIV-infected person" and "people who inject drugs" versus "injection drug user" is preferred.[31]

Finally, the term "high risk heterosexual contact" is notable for its introduction in 2005 and fast abandonment by 2008. This change in nomenclature was accompanied by lengthy rationales for the changes in the technical notes corresponding to that category during the relevant report years between 2005 and 2008. However, elsewhere in the HIV apparatus, the term "high risk heterosexual" (or simply "HRH") continues to exist as a descriptor of both heterosexuals living with HIV and of heterosexuals who are (demographically speaking) more likely to become HIV-positive. The notion of a “high risk” subject-position therefore provides some of the conceptual undergirding for “heterosexual contact,” the full definition for which continues to be “heterosexual contact with a person known to have, or to be at high risk for, HIV infection” to the present day.

In sum, the genealogy of the HIV risk hierarchy is one of taxonomic transmutation, accumulation, and layering, which has taken place as various categories have been introduced and abandoned and as concepts from other taxonomies (such as sexual orientation) haunt technical definitions and data collection and reporting instruments. The conceptual proximity of categories like “male-to-male sexual contact” with terms like “gay,” and “heterosexual contact with a person known to have, or to be at high risk for, HIV infection” with “heterosexuals” in the genealogical development of the HIV risk hierarchy deeply shapes and informs how hierarchy data are given material existence or expression in practice. These issues come to the fore in actual uses of the hierarchy by health informaticists and other HIV professionals, as I will show in the following two sections.

IV. A Technical Account of the HIV Risk Hierarchy

This section offers a technical account of the HIV risk hierarchy as I have observed it in three different areas of health information management: (1) in health IT standards-setting and technical guidance produced by health IT organizations that instruct healthcare entities about how to utilize health IT standards to populate their HIV risk hierarchies in their IT systems, (2) in a survey instrument used in metropolitan Atlanta that includes a question about HIV transmission risk as well as a demographic question about sexual orientation, but mixes the two taxonomies together in the sexual orientation question, and (3) in a health IT system utilized in the clinical and HIV services domain, specifically in Fulton County's build of CAREWare (used in the Atlanta metro area's Ryan White community) and the underlying CAREWare database.

Through this exploration of technical issues in the constitution of the HIV risk hierarchy and misalignments between the gold standard taxonomy in *Surveillance Reports*, the underlying architecture of health information systems, data collection instruments, and front-end displays, I show that the hierarchy's multiplicity is not merely an effect of its historical development, taxonomic accumulation over time, or its many different uses in practice. Rather, the hierarchy's multiplicity is also built into the software architectures, instructional guidance materials and technical manuals, and data collection instruments that provide the groundwork for the many realities enacted by practitioners and institutions who use the hierarchy and hierarchy data.

Health IT: Hierarchies, Hierarchies Everywhere, But Not a Standard to Be Found

Despite its pervasiveness in health information management systems, the HIV risk hierarchy does not have an associated "International Statistical Classification of Diseases and Related Health Problems" (ICD-10) code, and neither do any of the individual categories that its taxonomy contains.[32] ICD-10 is the global gold standard for health-related classifications, from diagnostic codes to observed behaviors.[33] Similarly, neither the hierarchy nor its individual classifications are associated with "Logical Observation Identifiers Names and Codes" (LOINC), "Systemized Nomenclature of Medicine-Clinical Terms" (SNOMED CT), or Health Level 7 (HL7) codes. These sets of standards all perform different functions. Together, they provide key components of the technical grammar that is used to capture, store, and exchange data in healthcare. If a classification or taxonomy is not present in these nomenclatures, no functional health IT standard exists. Where standards do not exist, health IT professionals must make available standards function in the underlying architecture in ways that provide the appearance of standardization to both front-end users and systems administrators.

In the case of the HIV risk hierarchy, a technical assistance document instructing health IT and health informatics professionals about how to build HIV risk hierarchies by compiling other standards does exist. It is called “HL7 Implementation Guide for CDA® Release 2: HIV/AIDS Services Report, Release 1 - US Realm,” and was published by HL7’s Structured Documents Workgroup in 2013.[34]

HL7 standards are health IT exchange standards. Exchange standards refer to other sets of health IT standards that are used for the capture and storage of data, such as LOINC and SNOMED CT. Health IT standards used for capture and storage, in turn, usually refer to diagnostic codes in indexes such as ICD-10 or the Current Procedural Terminology (CPT) maintained by the American Medical Association and utilized by the Centers for Medicare and Medicaid Services primarily for billing purposes. Health IT standards, and the function of different classes of standards in relation to one another and within federal health IT policy, are the subject of this dissertation’s next chapter.

For the purposes of this specific exposition regarding how health IT standards facilitate the creation of HIV risk hierarchies in health information systems such as electronic health records (EHRs), it is only critical to understand that HL7 standards’ main function is to define how data captured using health IT standards need to be structured during the exchange of those data between two different health IT systems. HL7 standards facilitate automated interoperability and data flows between different infrastructures. Since automated data exchange is important for organizations that want to ease processes related to reporting clinical data to funders or to transferring data between different healthcare organizations, exchange standards like HL7 function as crucial guidelines in the construction of health IT systems. This is the main function of the HL7 HIV implementation manual: it provides guidance for building health IT systems that can easily capture and exchange many different kinds of data related to the provision of clinical HIV care and related services – from laboratory test results and common HIV comorbidities or AIDS-related conditions such as Kaposi's Sarcoma to HIV risk hierarchy data.

While the "HL7 Implementation Guide for CDA® Release 2: HIV/AIDS Services Report, Release 1 - US Realm," document has many potential uses, one of its main utilities is to assist EHR vendors, other health IT entities and product developers, and Ryan White-funded organizations in building modules that can easily populate client-level "HIV Risk Factors" fields that are required for annual Ryan White Service Reports (RSRs) that are submitted by every agency that receives Ryan White funds annually to the Health Services and Resources Administration (HRSA). Figure 1.5, below, is excerpted from the 2013 HL7 HIV technical assistance document. The chart provides instructions on how to populate the "HIV Risk Factors" value set using existing SNOMED CT codes. However, in the absence of SNOMED CT codes that exactly reflect the hierarchy's taxonomy (e.g. "heterosexual contact with a person known to have, or to be at high risk for, HIV infection"), HL7 recommends SNOMED CT standards that resemble, or are in close conceptual proximity to, the categories in the HIV risk hierarchy.

Figure 1.5. “HIV Risk Factors Value Set” in HL7 Technical Guidance on “HIV/AIDS Service Report[s]”

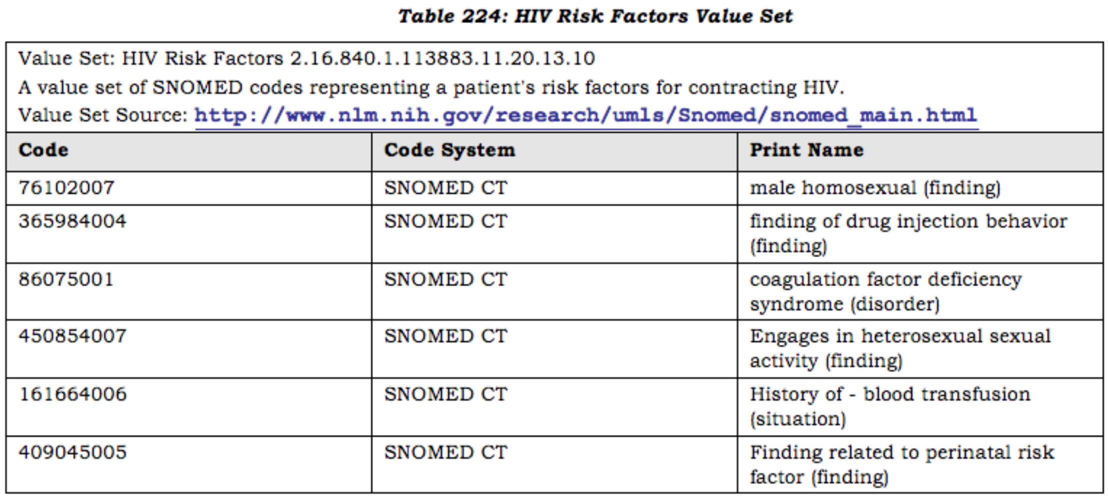


Table 224: HIV Risk Factors Value Set

Value Set: HIV Risk Factors 2.16.840.1.113883.11.20.13.10
A value set of SNOMED codes representing a patient's risk factors for contracting HIV.
Value Set Source: http://www.nlm.nih.gov/research/umls/Snomed/snomed_main.html

Code	Code System	Print Name
76102007	SNOMED CT	male homosexual (finding)
365984004	SNOMED CT	finding of drug injection behavior (finding)
86075001	SNOMED CT	coagulation factor deficiency syndrome (disorder)
450854007	SNOMED CT	Engages in heterosexual sexual activity (finding)
161664006	SNOMED CT	History of - blood transfusion (situation)
409045005	SNOMED CT	Finding related to perinatal risk factor (finding)

Rather than creating a single standard or even drawing on codes that correspond exactly to the hierarchy as defined by CDC, HL7’s technical guidance cobbles together a list of SNOMED CT codes that approximate those in the hierarchy, such as “male homosexual (finding)” in place of “male-to-male sexual contact.”

These SNOMED CT codes basically fulfill the informational needs of the “HIV Risk Factors” field required by the Federal Ryan White program via logics of conceptual proximity and inference, rather than that of strict one-to-one equivalence. While none of the SNOMED CT codes provided match the hierarchy categories dictated by CDC exactly, they resemble them well enough to allow for data to be collected in a fashion that makes them interoperable between systems and to function as hierarchy data without the need to develop new standards.

As I discuss in chapters two and three, it is possible to develop of new health IT standards. However, doing so takes time and resources and would entail piloting, testing, and organizing a group of stakeholders to lobby a health IT standards-setting organization like LOINC or SNOMED CT to add those standards to its central index. Further, rolling out the standards on a wide scale would also require health IT product developers to change the standards in their systems and technical guidance materials; for example, the HL7 Structured Documents Workgroup would need to draft, review, approve, and release a revision of its 2013 technical guidance manual with the updates hierarchy standards. Rolling out standards is a complicated and overlaid array of sociotechnical processes that would likely result in many unforeseeable errors, bugs, or other issues requiring ongoing maintenance and tuning. It is much easier (although, conceptually speaking, less exacting) to simply use existing health IT standards such as "male homosexual (finding)" to populate HIV risk hierarchy fields such as "male-to-male sexual contact" than it is to build new standards working with stakeholders and institutions like SNOMED CT and HL7.[35]

Further, this conceptual equivocation via logics of approximation and inference more-or-less works in practice. This is because, as I have shown (both in practice and in the genealogy of the hierarchy), the SNOMED CT classifications used in place of HIV risk hierarchy categories are next-door neighbors in what Deleuze and Guattari would characterize as a shared "conceptual neighborhood:"[36] "male homosexual," "gay and bisexual men," "gay men," "men who have sex with men," "MSM," "men who sleep with men," and "male-to-male sexual contact" are often treated synonymously by practitioners or in the governing documents of the HIV/AIDS apparatus such as the *National HIV/AIDS Strategy of the United States*. While many actors in HIV/AIDS and LGBTQ health actively contest this categorical equivocation, it is a real feature of HIV practice that these concepts come to stand in for one another (or are used in place of one another) with great frequency.

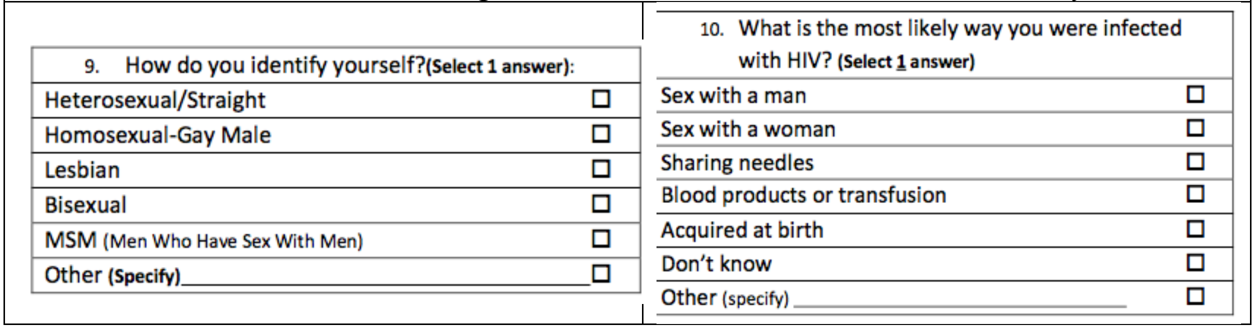
Similarly, using underlying technological standards that do not exactly match the front-end display and/or the data that are collected during data workflows is a strategy that is employed in other health IT contexts. Whether particular kinds of categorical equivocation are epistemologically legitimate is a matter of ongoing contestation and debate among practitioners that unfolds as specific cases arise and in the general discursive field of HIV/AIDS practice, epidemiology, and LGBTQ health. When a "difference in degree" turns into a "difference in kind" between two different classifications is not given or apparent in a specific state of affairs; rather, it must be determined during the course of practice or contested when and if an actor decides to do so.[37]

For now, the technical guidance in health IT related to the storage and exchange of HIV risk hierarchy data operates on the logics of approximation, equivalence, and inference that rely on categories' difference from each other being ones of degree, rather than kind, despite the fact that these same logics do not hold or apply in other areas of HIV practice, such as public health programming, where "homosexual" is generally not acceptable speech. To test this hypothesis, one need only begin talking about "male homosexuals" in a room of U.S. HIV/AIDS or LGBTQ health activists. The speaker is almost certain to be corrected and told to use the language "gay and bisexual men" or "men who have sex with men." The episode might even cause a minor scandal.

The Metropolitan Atlanta HIV Health Services Planning Council 2015 Consumer Needs Assessment Survey: Intermingling and Differentiating Sexual Orientation and Hierarchy

In this example, I explore a different phenomenon of HIV risk hierarchy data and proximate taxonomies coming into strange coexistence. I consider the co-materialization of identity-based sexual orientation categories and an HIV risk hierarchy classification ("MSM") in a single question on a survey where both sexual orientation and HIV transmission category questions are asked. This occurs on the 2015 *Consumer Needs Assessment Survey* of the Atlanta Ryan White Planning Council, shown below. The presentation of both of these questions side-by-side, and the inclusion of “MSM” in the “sexual orientation” question constitutes both an intermingling and a differentiation of “sexual orientation” and “HIV risk hierarchy” in this survey instrument.

Figure 1.6. Questions Nine and 10 on the 2015 Metropolitan Atlanta HIV Health Services Planning Council Consumer Needs Assessment Survey



9. How do you identify yourself?**(Select 1 answer):**	
Heterosexual/Straight	☐
Homosexual-Gay Male	☐
Lesbian	☐
Bisexual	☐
MSM (Men Who Have Sex With Men)	☐
Other **(Specify)**____________________	☐

10. What is the most likely way you were infected with HIV? **(Select 1 answer)**	
Sex with a man	☐
Sex with a woman	☐
Sharing needles	☐
Blood products or transfusion	☐
Acquired at birth	☐
Don’t know	☐
Other (specify) ____________________	☐

Question nine is clearly recognizable as a sexual orientation question, and question 10 as an HIV risk hierarchy question. However, question nine includes “MSM (Men Who Have Sex With Men),” a clear aberration in the sexual orientation taxonomy that was imported from the HIV risk hierarchy.

No one on the Planning Council’s Assessment Committee could tell me why MSM was included in the sexual orientation question of the 2015 assessment mechanism. An educated guess could be ventured: someone on this committee likely believed that there are men in Atlanta who identify as MSM – and there are, although the proportion of men who do is unknown and likely very small. This is a multifaceted issue that I explore later in this chapter. It was not possible for me to review the results of the survey to discern how many respondents selected “MSM” in reply to question nine. This was because of a complicated saga of issues involving the transfer of the data by the Planning Council between different institutions and consultants after the data were collected, which ultimately led to the Planning Council losing the data entirely.

Further, the issue of “MSM” being present in the sexual orientation question was not raised during meetings of this committee in 2017 where the 2015 instrument was systematically reviewed over the course of several months in anticipation of the administration of a 2018 or 2019 assessment survey. As I explore later, the presence of MSM in the sexual orientation question of this survey is not to be taken as an indicator that MSM functions widely as an identity category among gay, bisexual, same-gender loving, or any other group of men in Atlanta. Rather, this Planning Council Assessment survey instrument serves to demonstrate – in another context – how sexual orientation and HIV risk hierarchy taxonomies become intermingled, co-constitutive, and productive of biomedical sexualities and sexual realities that that only manifest because of the particular (sometimes strange and unforeseeable) ways in which these competing frameworks come into coexistence.

This survey stages a specific conceptualization of "MSM," and thus HIV transmission factor and sexual orientation: one in which "MSM" is also "sexual orientation," not just because sexual orientation data are often inferred from MSM data (when "MSM" data are used to speak about "gay and bisexual men"), but because this inference of MSM as a sexual orientation is written into the survey instrument itself. Further, it is written into the instrument in such a way that both differentiates and equivocates between "MSM" as a hierarchy category and a sexual orientation category. This is because questions used to determine whether a respondent was "an MSM" is part of two separate questions on the survey.

The Underlying Database of Fulton County's Build of CAREWare: "Male who has sex with male(s)" as "homo_male"

In some infrastructures, male homosexuality is written into the undergirding of "MSM" at the technical level in yet another way. This is the case in CAREWare. As a reminder to readers, CAREWare is software developed by the Health Resources and Services Administration (HRSA) to assist Ryan White grantees in assembling required reports. All Ryan White-funded agencies in metro Atlanta are required to use the software, the local and customized deployment of which is managed by Fulton County.

Much in the way that the HL7 technical guidance document excerpted in Figure 1.5 associates “male-to-male sexual contact” with the proximate SNOMED CT code “male homosexual (finding)” so that data captured in health IT systems can be used to produce required annual Ryan White Service Reports (RSRs), the classification “Male who has sex with male(s)” displays as “cln_hiv_risk_1_homo_male” in Fulton County’s CAREWare database, from the perspective of the CAREWare managers and informaticists employed by the county. Notably, this is only a feature of the Fulton County CAREWare database. It does not reflect a use of SNOMED CT standards per the HL7 technical guidance document or any other health IT standard or set of specifications. It is a feature of the local Fulton County CAREWare database, and is essentially the header of a column in a large spreadsheet (also called a relational database) that is assigned a positive or negative (yes/no) value.

An affirmative “cln_hiv_risk_1_homo_male” designation indicates that the individual client’s (cln) “HIV Risk Factor” (hiv_risk) has the highest value (1), which is presented as male homosexuality (“homo_male”) in the database. This does not match the on-screen display of “Male who has sex with male(s)” that front-end users of CAREWare see when they work with the software. “Cln_hiv_risk_1_homo_male” is only visible to CAREWare managers at Fulton County who work with the underlying database, such as Greg Nowitzki. I interviewed Greg several times, interacted with him as he worked with CAREWare and queried the database, participated alongside him in quality management workshops, and saw him give data reports and technical assistance presentations during my two-plus years of fieldwork in Atlanta.

I discovered the “homo_male” category in the CAREWare database during one of several interviews with Greg, when he was showing me the “back end” of the system and the classifications used in the underlying database, which he could interact with directly using Structured Query Language (SQL). Other individuals who work with CAREWare in Atlanta – for example, at funded social service agencies – cannot interact with the software or CAREWare data in this way. Most users – even network administrators and IT staff at large organizations such as a local public hospital’s Infectious Disease Clinic – are limited to the report functionalities provided by the software. The direct interface with the CAREWare database through SQL is normally only visible to staff who manage CAREWare data at the County, and is used to aggregate data from multiple providers to aid in county-wide or multi-agency quality assessments. The “cln_hiv_risk_1_homo_male” field – like the underlying CAREWare database itself – is therefore largely invisible and truly “in the guts” of the CAREWare and Fulton County Ryan White infrastructures.

When I saw that “Male who has sex with male(s)” was displayed as “cln_hiv_risk_1_homo_male,” I asked Greg the IT manager: “Why would they [the HRSA employees and contractors that built CAREWare] call it that?” He responded, “you wanna know, honestly?...'Cause it was probably done in 1990 [chuckle]…and it's really difficult to change it in the database, so they had to leave it.”[38]

This interaction was special for several reasons. It provided the rare chance to hear a technical health IT professional reflect on the history of the software they regularly work with against the broader historiography of a specific disease that the software was specifically built to manage, and which is associated with particular social categories. It also indicated that such professionals are often ignorant of the complex relations between software’s history, the politics of biomedicine, and the history of epidemiology – in this case, the very specific histories of HIV/AIDS science, cultural politics, and epidemiology. Greg the IT manager's remark about "homo_male" being an artifact from 1990 was actually not possible, temporally speaking. CAREWare was released in 2000. However, he was correct in some sense (even if inadvertently).

Recall the genealogical chart in Figure 1.4. "Male homosexual" was still part of the official risk hierarchy in 1990. Greg placing the origin of the "homo_male" CAREWare data base classification in 1990 is therefore an astute guess about the genealogy of "male-to-male sexual contact" – which exists in Fulton County CAREWare as both "Male who has sex with male(s)" (on the front-end) and "homo_male" (in the underlying database). While Greg was not (to my knowledge) an AIDS activist and seemed to have basic gained knowledge about the history of the AIDS crisis only because he happened to be employed by a Ryan White program (he had previously worked in shipping logistics), he still understood that male homosexuality was dated terminology in practice – even though he probably did not know the particulars about why this was the case.

The "cln_hiv_risk_1_homo_male" example shows (in another context) that while misalignments between the back-ends of systems visible to network administrators and the front-end display visible to end-users are highly meaningful and instructive from the perspective of infrastructure studies or a deep epistemological interrogation of what the conceptual undergirding of a category is in biomedical practice, these distinctions often simply do not matter to technical professionals, and likely do not matter (or are imperceptible) to other health practitioners. In the health IT context and in the HIV context, the logic of conceptual approximation or inference often functions as the logic of conceptual equivalence. This plays out in social, biomedical, and technical settings whenever professionals use certain categories to stand in for or express data about others (e.g. data about "male-to-male sexual contact" as cause of HIV transmission being used to report out data about "gay and bisexual men). This case reinforces the larger point about the ongoing significance of the genealogy of the HIV risk hierarchy in contemporary practice. As late as 2000 (the year CAREWare was released) and potentially later (depending on the year that Fulton County built its underlying CAREWare database – which I could not determine), male homosexuality remained part of the underlying content of "male who has sex with male(s)" in the information architecture, in the form of "homo_male." As much as categories like "male-to-male sexual contact" or "men who have sex with men" might be developed and deployed with the intent of divorcing sexual identities like "homosexual/gay" or "bisexual" from behavioral metrics in HIV practice, the infrastructures that are used to administer HIV services themselves show – even and especially at the most technical levels of analysis – that behavioral classifications will always be haunted, materially co-constituted, and conceptually held up by their identitarian antecedents.

V. An Ethnographic Account of the HIV Risk Hierarchy in Policy and Practice

This section offers an account of the HIV risk hierarchy as it appears in federal, state, and local health policy documents and ethnographic encounters in Atlanta. I describe how the many different versions of the hierarchy and expressions of hierarchy data that I observed during fieldwork paradoxically produce a hierarchy that is imagined as singular and monolithic. I also analyze the styles of managing data about sexuality, gender, and risk that the hierarchy helps to stage across *macro*, *meso*, and *micro* scales in the course of HIV planning and service provision in the United States. The analyses herein focus on the *National HIV/AIDS Strategy of the United States* and AID Atlanta, a large and longstanding HIV/AIDS Service Organization (ASO) that is an affiliate of the international AIDS Healthcare Foundation (AHF). AID Atlanta utilizes AHF's electronic health record (EHR) system, which is also used in other AHF clinics in and beyond metro Atlanta.

The Absent Hierarchy: The National HIV/AIDS Strategy of the United States

Knowledge of the hierarchy of HIV transmission is generally taken for granted among practitioners who have worked in HIV for even brief periods. However, if one were to read *The National HIV/AIDS Strategy of the United States* (*NHAS*) or *NHAS: Updated to 2020* (*NHAS 2020*) with no prior knowledge of the epidemic or how it had been monitored since 1981, one would have to be very perceptive to realize that a hierarchy of HIV transmission risk even existed (let alone that it had been a key metric for assessing the HIV epidemics since the early years of the crisis). One would, however, know that "the HIV epidemic is concentrated in key populations and geographic areas."[39] With this being said, many of the key populations discussed in the strategy – while determined using hierarchy data from the National HIV Surveillance System (NHSS) – are not framed using language from the hierarchy's categories. As part of framing the populations "at risk," the *Strategy* oscillates between making the epidemic a problem that is distributed equally among all members of the national community, and one that is only a concern for specific groups at elevated "risk."[40]

Cutting in the first direction, the "Vision Statement" of *NHAS* and *NHAS* 2020 is quite sweeping and deploys the notion of a national community as well as specific groups with particular needs: "The United States will become a place where new HIV infections are rare, and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination."[41] Cutting in the other direction, the languages of “risk,” “transmission risk,” “high-risk groups,” “target population,” and “communities where HIV is most heavily concentrated” are emphasized throughout *NHAS*, over and above the generalized (and liberal-humanist) notion of “every person.” Such a targeted approach to HIV prevention and care is, of course, necessary for an effective response to epidemics, which are highly localized. “Know your epidemic” is a common refrain in contemporary HIV practice and activist discourse. This mantra is a way of encouraging local institutions to attend to the specific dynamics of the epidemic in their jurisdictions and to build responses catered to it. There is no uniform template for building a response. However, the discussion of specific LGBTQ groups in *NHAS* is also reflective of an increased openness on the part of the Obama administration to name these groups in official policy discourse. I discuss this in chapter three as part of “the new consensus in LGBTQ health” and processes of “LGBTQ incorporation” into federal health policy.[42]

Portions of the *Strategy* reproduce heteronormative discourses long critiqued by both the LGBTQ health and HIV movements that are designed to position heterosexuals as “the general population,” thus discursively insulating them from the epidemic. These same discourses also tend to reproduce American exceptionalism, highlighting the relative non-severity of the HIV/AIDS epidemic in the United States compared to those of some countries in the developing world, whose HIV epidemics are generalized pandemics. This style of comparison – which dubiously frames the United States response as at least something of a success story in need of improvement – are far more frequent than comparisons of the U.S. HIV epidemic to the epidemics of “peer” nations in the developed world. These other countries in “the Global North” generally have much higher rates of viral suppression than those in the United States, owing to the existence of more robust healthcare systems.[43] For example, a portion of *NHAS* says:

> In the beginning of the HIV epidemic, there was widespread fear that the epidemic would spread to the general population. **The public** heard about growing infection rates and that HIV had spread to all parts of the country. While this is true, nearly three decades later**, the U.S. epidemic has not run the course that was previously feared**. **In contrast to HIV epidemics in sub-Saharan Africa and parts of Asia** where nearly all sexually active adults are at high risk of becoming infected, **HIV cases in the United States are concentrated in specific locations and populations**.
>
> (emphasis mine**)**

The language of containment of HIV from "the public" is striking. This is particularly true in light of sustained activism by people living with HIV, CDC, and other HIV advocates and practitioners to avoid framing the epidemic as only relevant for specific groups of people, and to promote framing HIV as something that "all sexually active adults" should be aware of and attentive to in making personal sexual decisions.[44]

However, more to this chapter's point, while the language of "risk" is used throughout the *Strategy*, discussions of target populations who are at risk of HIV because of reasons related to sexuality are never filtered through categories from the HIV risk hierarchy. Rather, hierarchy data are used to express data through other categories via logics of conceptual inference that employ social categories like "gay and bisexual men" or "gay men." This is the best practice adopted by CDC and *NHAS*, as public-facing documents, even though the data used to gather this information are HIV risk hierarchy data – and specifically "male-to-male sexual contact" data.

NHAS frames its target populations in demographic and geographic terms: "…gay and bisexual men of all races and ethnicities, Black men and women, Latinos and Latinas, people struggling with addiction, including injection drug users, and people in geographic hot spots, including the United States South and Northeast, as well as Puerto Rico and the U.S. Virgin Islands." *NHAS 2020* modifies this slightly, to "gay, bisexual, and other men who have sex with men of all races and ethnicities (noting the particularly high burden of HIV among Black gay and bisexual men), Black women and men, Latino men and women, People who inject drugs, Youth aged 13 to 24 years (noting the particularly high burden of HIV among young Black gay and bisexual men), People in the Southern United States, [and] Transgender women (noting the particularly high burden of HIV among Black transgender women)."

The inclusion of transgender women is the most notable change in *NHAS 2020*, released in 2015, versus the original *NHAS*, released in 2010. This is mainly attributable to the Obama administration's efforts to incorporate LGBTQ health actors' interests into the federal health policy apparatus during this time. However, it is also likely partly because of the increased availability of transgender-inclusive surveillance data during the 2010s, given the greater inclusion of gender identity demographic fields in HIV surveillance case report forms. I return to this topic later in the chapter.

To reiterate, much of the data about the "risk" or "target" groups referred to throughout *NHAS 2020* come almost entirely from the National HIV Surveillance System. So, the hierarchy is present everywhere in the *Strategy*. It is simply not present *as the hierarchy*, but as categories that are inferred from hierarchy data – "male-to-male sexual contact" appears as "gay and bisexual men" or "gay men," and data about "heterosexual contact with a person known to have, or to be at high risk for, HIV infection" are expressed as data about "heterosexuals." "Injecting drug users" are often called "people who inject drugs," reflecting "person-first" language in healthcare long championed by groups of people living with HIV.

This is a common strategy and reflects best practice in public-facing, "non-scientific" communications by CDC, per a CDC interlocutor. This is particularly true in regard to the expression of "male-to-male sexual contact" data as data about "gay and bisexual men." In an interview, one high-level career scientist at HHS who was involved in writing *NHAS* even asserted that the issue regarding the use of "male-to-male sexual contact" data to infer "gay and bisexual men" had been "resolved." This is, of course, a claim that many activists, epidemiologists, service providers, and scholars who prefer different terminology regularly contest.[45]

Additionally, despite never appearing in the body text of the *Strategy*, the hierarchy does make select appearances in both *NHAS* and *NHAS 2020*, in several graphs and pie charts. Therefore, in *NHAS*, the hierarchy is absent until it isn't – or, rather, data from the hierarchy are everywhere in the strategy, but the hierarchy itself only appears as the hierarchy when the authors deem it necessary for purposes of graphical representation, and even then, in a very limited way. Further, even in the case where categories from the hierarchy appear in graphical representations, they are not expressed in a hierarchical arrangement. A histogram from *NHAS*, for example, refers to "MSM" and "heterosexual" men and women in an idiosyncratic order – not in a hierarchical arrangement according to degrees of risk or even by disease burden.[46] A pie chart of the hierarchy included in *NHAS 2020* is ordered by disease burden per risk group, not probability of transmission risk.[47]

The "HIV Risk Group" Field at AID Atlanta and the AIDS Healthcare Foundation

The AIDS Healthcare Foundation (AHF) is the largest HIV/AIDS Service Organization (ASO) in the world. It is a cash-rich multi-billion-dollar firm that has pioneered new models for financing HIV/AIDS care domestically and transnationally, in part by maximizing reimbursements from pharmaceutical companies through a federal pharmacy program called "340b" that is designed to support safety net healthcare providers in the United States with an alternative revenue stream in addition to fundraising and billing payers such as Ryan White, Medicaid, Medicare, and private insurers.[48] In 2015, AID Atlanta, one of the largest ASOs in the Southeast, affiliated with AHF.[49]

During the affiliation process, AID Atlanta (which maintains relative autonomy from AHF) adopted AHF's Electronic Health Record (EHR) and clinical intake documentation for all of its clinical services. Figure 1.7, below shows the HIV risk hierarchy as displayed in the CAREWare manual developed and used by AHF, and below that, the "HIV Risk Factors" field in CAREWare. The AHF CAREWare manual offers technical guidance to health IT professionals to help them use EHR data to populate CAREWare and produce required annual and periodic reports.

I conducted many interviews at AID Atlanta, and discuss the organization in other parts of this dissertation. AID Atlanta-based interlocutors who interacted with this EHR – and this "HIV Risk Groups" field – included a regional manager, physician, Nurse Practitioner, Registered Nurse, clinic manager, a quality manager, and a member of the AHF health informatics staff based in Los Angeles where the international organization is headquartered.

[figure appears on the following page]

Figure 1.7a Hierarchy in EHR Used by AHF and AID Atlanta, Mapped onto CAREWare Fields

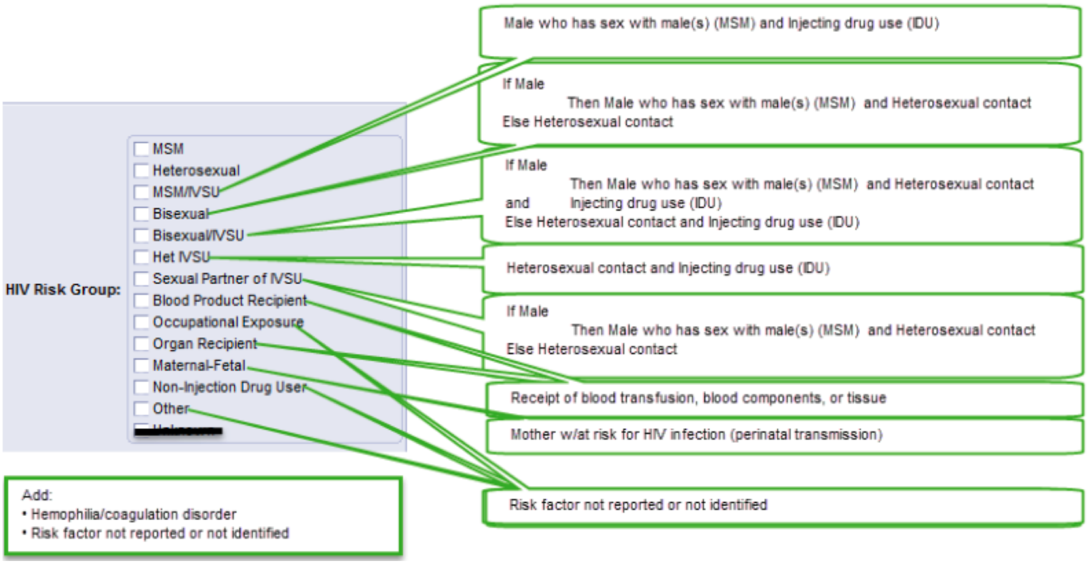
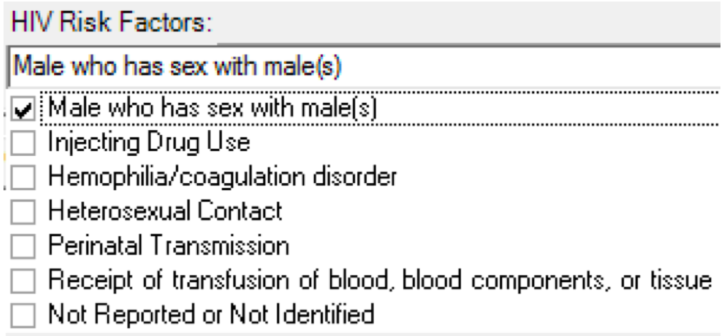


Figure 1.7b The CAREWare "HIV Risk Factors" Hierarchy


HIV Risk Factors:

Male who has sex with male(s)

☑ Male who has sex with male(s)
☐ Injecting Drug Use
☐ Hemophilia/coagulation disorder
☐ Heterosexual Contact
☐ Perinatal Transmission
☐ Receipt of transfusion of blood, blood components, or tissue
☐ Not Reported or Not Identified

On the left of Figure 1.7a, the hierarchy appears as it is displayed on the EHR screen (called "HIV Risk Groups"). The green bubbles stemming out from each field showing how the fields from the EHR's version of the hierarchy are used to populate corresponding fields in CAREWare. The CAREWare hierarchy (called "HIV Risk Factors") is presented independently, below, in Figure 1.7b.

Data collected using the EHR's taxonomy (a version of the HIV risk hierarchy) must be translated using health IT standards into another, different taxonomy: the HIV Risk Factors field in CAREWare. Notably, neither of these iterations of the hierarchy match the CDC gold standard exactly. The CAREWare taxonomy contains fewer categories than the EHR “HIV Risk Groups” field. Therefore, some categories in the EHR are translated (or, in technical terms, “rolled up into”) a single field in CAREWare. For example, “MSM” and “Bisexual” in the EHR are both fed into the “Male who has sex with male(s)” field in CAREWare.

AID Atlanta is a demonstrative case that shows how a hierarchy that is conceptualized as a monolithic set of rigid “transmission categories” only achieves its singularity by manifesting as many different and inexactly reproduced versions of itself (and, in some cases, even layered onto or interconnect with one another at the technical level). While the “HIV Risk Group” taxonomy in the EHR used by AHF and AID Atlanta is an HIV risk hierarchy, it deviates significantly from the gold standard hierarchy in *HIV Surveillance Reports*. As noted, the hierarchy in CAREWare is not in alignment with the gold standard. “Male who has sex with male(s)” has never appeared in any iteration of the HIV risk hierarchy as used in surveillance contexts; it is a kind of hybrid between “men who have sex with men” and “male-to-male sexual contact,” primarily because of the parentheses around the final “s” in “male(s),” denoting that “sex with men” only had to occur one time for HIV transmission to occur. This is the most distinct feature of CAREWare’s hierarchy, which is called “HIV Risk Factors.”

These various misalignments precipitate the need for an organization-specific CAREWare Manual (also called a “Data Dictionary”) that can be used to translate data between these two pieces of software, the risk hierarchy taxonomies of which deviate significantly from one another. For example, “bisexual” is in a category of its own in the EHR, and the category “heterosexual” appears without the additional word “contact” as a qualifier, as it does in the formal definition of the hierarchy in the surveillance gold standard as well as in CAREWare.

While “lesbian” is not present in the EHR’s taxonomy (potentially owing to the fact that HIV organizations serve very few lesbians), the presence in the EHR interface of “MSM” (an acronym without corresponding words on-screen), “heterosexual,” and “bisexual” in sequence (in the context of frequent equivocation between “MSM” and “gay”) makes this EHR’s HIV risk hierarchy appear nearly as sexual orientation-like as it does HIV risk hierarchy-like. This produces some interesting conditions and sexual realities that are unique to the particular build of the hierarchy in the AHF/AID Atlanta EHR.

In clinical practice at AID Atlanta, the “HIV Risk Groups” field in the EHR functions in at least four distinct ways: (1) as a means of recording the reason that one became HIV-positive (their “transmission category” at time of diagnosis), (2) as an up-to-date sexual history, (3) as a more general risk assessment related to HIV and substance use (it includes the fields “IVSU,” presumably for “intravenous substance use” and the even stranger field of “non-injection drug user”), and, (4) as a sexual orientation field. These varied uses makes this particular hierarchy (a single field) appear as multiple different things in practice, at different times. It is what Geoffrey Bowker and Susan Leigh Star call a “boundary object” that “inhabit[s] several intersecting social worlds…and satisf[ies] the informational requirements of each of them.”[50] In this case, the “worlds” this hierarchy must “satisfy the informational requirements of” include clinicians, data staff, executive leadership at AID Atlanta, local and federal funders, and AID Atlanta’s functional parent organization AHF. However, because the EHR field takes on so many different meanings and functions – as HIV risk factor, as recent sexual history, as risk assessment, and as sexual orientation data – it also presents a wild array of ontological misalignments, paradoxes, and unforeseen outcomes.

For example, if a male-identified individual with "MSM" and "bisexual" risk factors was receiving care at AID Atlanta since he began receiving HIV-related medical care in 2003 (and would therefore be classified only as MSM in CAREWare), and then started injecting drugs a decade later and reported this to their provider at AID Atlanta (a perfectly plausible scenario), the *reason that this person became HIV-positive* – his "transmission category" – would change from "MSM" to "MSM/IDU" in CAREWare. This would occur despite the fact that – temporally speaking – this could not be the case, because he only started injecting drugs a full decade after he became HIV-positive via sexual transmission. This man's MSM/IDU risk factor in the EHR and in CAREWare is a situated reality that is only possible in the realm of data and informatics (and thus also in clinical practice). It could not correspond to the reality of this person's actual seroconversion event.

Confusion abounds among practitioners about whether the CAREWare "HIV Risk Factors" field is intended to refer to the reason one became HIV-positive or is meant to function as an inventory of current risk factors. One surveillance official at the Georgia Department of Public Health (GDPH) HIV/AIDS Epidemiology Section, when asked if Ryan White providers collected current risk factors or reason for transmission in this field, said that "I think they collect both," whereas a member of AID Atlanta's leadership team insisted that the field was just "transmission factor" at time of initial diagnosis. The truth is somewhere in between. It varies depending on the agency in question, the systems and protocols they use to collect and report data the individuals doing the work, and methods assemblages they build up and sustain to utilize data.[51] At AID Atlanta and AHF, it is "all of the above" – and then some.

As mentioned, some providers and clinical administrators at AID Atlanta use the "HIV Risk Group" field to collect and express sexual orientation data. This is often not just through inferential logics. Rather, these individuals understand the question to be a sexual orientation data collection instrument that captures sexual identity categories. I repeatedly asked one person involved in the management of the clinic if the organization collected sexual orientation data in the EHR, and was directed to the “HIV Risk Group” field. When I asked “[is] sexual orientation collected anywhere to your knowledge here [at AID Atlanta]?,” he responded in the affirmative: “the risk, Where is it? Yeah, HIV risk group. It's got MSM, heterosexual, MSM, IVSU, bisexual.”

Similarly, a provider referred to checking the “gay” box in the EHR, when in fact no such box exists in the EHR – although sexual orientation data are collected on a paper intake form that travels with the patient during their clinical visits. In the EHR, he was referring to the “MSM” box. Another provider (a nurse) told me that she collects “sexual orientation” data, but only about behaviors, and that those data are recorded in free-text narrative form in progress notes associated with individual visits as well as in the HIV Risk Group field as structured data.

None of these answers indicate some wild deviation from normal practice. Rather, they all emerge from within the bounds of acceptable practice in clinical HIV care. HIV risk hierarchy data are used to express data about sexual orientation all the time, such as in *NHAS*. What the different uses of this EHR field at AID Atlanta shows are the many ways that the hierarchy materializes as different versions of itself, depending on who is using it – and therefore how it enacts many different sexual realities (even within a single organization). However, this only occurs within a given, spatiotemporally bounded range of uses that are both sanctioned by the institution and (generally speaking) allowable within the broader discursive universes that shape the management of HIV/AIDS as a public health issue and an individual disease-state.

Another question raised by the AID Atlanta example is whether HIV risk hierarchy data are demographic characteristics or some other kind of data. As I detail in chapter three, LGBTQ advocates stake the legitimacy of sexual orientation and gender identity data collection in surveys and in federal EHR certification criteria on arguments that these data are demographic variables.[52] However, the answer to whether hierarchy data are demographic data is more contingent upon the individual interpreting, utilizing, or expressing the data than it is dependent on some broader consensus about this issue.

In AID Atlanta's EHR and other EHRs examined during fieldwork, hierarchy data are generally collected in their own tab, away from the demographics page. However, as in *HIV Surveillance Reports*, in the *Ryan White Annual Report* released by the Health Resources and Services Administration, and in CAREWare reports generated by Ryan White-funded clinics using the software's report-building feature, "HIV Risk Factor" is listed as a demographic characteristic alongside age, sex, gender identity, race, and ethnicity.

When I asked a quality manager at AID Atlanta whether these HIV risk hierarchy data were demographic data, she puzzled over the question, ultimately stating that her organization stratified various data by "demographics" in order to measure outcomes, but that HIV Risk Factor was not one of these variables, and was therefore not a demographic variable. However, she continued to wrestle over this question with me, both that day and in subsequent conversations. After all, in reports generated by CAREWare to help organizations assess their total patient load and improve existing services, HIV risk hierarchy data are presented alongside other demographic attributes. The question of whether the field constitutes a demographic category remained an unresolved and open question. Our meeting that day ended with both of us continuing to ponder it. We were left (like the hierarchy itself) in an ontological limbo – or, perhaps, with a greater appreciation for the hierarchy's ontological multiplicity.

VI. "Male-to-Male Sexual Contact" and the Meanings of "Identify as MSM"

Of all the categories in the HIV risk hierarchy, "male-to-male sexual contact" has by far the most extensive literature reflecting on its meaning; this discourse cuts across public health, social scientific, and humanist literature on HIV/AIDS and sexual and gender minority health.[53] However, this body of scholarship does not actually constitute a historiography or genealogy of "male to male sexual contact." Rather, this work is largely on the classification "men who have sex with men," and actually, even more specifically, about the acronym "MSM" and related terms such as like "BMSM" (Black MSM) or "YMSM" (Young MSM). Scholars have analyzed the term's history, critiqued its use for "erasing" local queer identities in transnational and domestic contexts, promoted its use based on claims that it actually allows for HIV work to take place while honoring local identities and that it allows an epidemiological focus on vectors of transmission that avoids engaging with questions of individual sexual identity or self-definition, and have generally made both compelling cases for the current classification paradigm and for the creation of new ones. In 2016, a full journal issue of *Global Public Health* was dedicated to "The Trouble with 'Categories,'" and MSM took center stage.[54] I also attended a panel devoted to "MSM" at the 2017 American Anthropological Association annual meeting where I, too, presented on "MSM," in a kind of meta-ethnographic engagement with the category.

Despite the gold standard classification being "male-to-male sexual contact" since 2002, many practitioners operate as if "men who have sex with men" is still the official classification. While "men who have sex with men" are framed as a target population in prevention programs, determining actual instances of HIV transmission because of "male-to-male sexual contact" is the focus in the three major domains of care, surveillance, and prevention. However, even many surveillance professionals and epidemiologists continue to use “MSM,” despite the fact that their subfield of HIV practice is the most terminologically precise and definitionally consistent across contexts. Many state and local surveillance reports, such as those produced by the Georgia Department of Public Health (GDPH) HIV/AIDS Epidemiology Section, use “MSM” to abbreviate data about “male-to-male sexual contact,” and provide definitions in presentations and reports saying this. For example, a slide titled “Transmission category definitions” in a publicly available presentation of 2017 HIV data in the includes the entry “MSM = Male to male sexual contact.” This is notable, and odd, because it actually divorces the three-letter acronym “MSM” from any actual sequential arrangement of words that corresponds to the letters “M,” “S,” and “M,” presented in that order.[55]

As of 2008, CDC no longer uses the abbreviation “MSM” in *HIV Surveillance Reports*; it refers only to “male-to-male sexual contact.” In public-facing communication, CDC uses “gay and bisexual men.” In public health messaging, GDPH is mixed, employing both “MSM” (such as in its *MSM Strategic Plan*) and “gay and bisexual men” (which dominates the text of the plan itself).[56] This produces constitutive and substantive misalignments between official classifications, corresponding acronyms, and populations discussed in key documents across domains of practice and jurisdictions. For example, a 2017 Fulton County HIV prevention Request for Proposals (RFP) contains the sentence: “Among cis-gender males, 83% of new HIV diagnoses were attributed to male to male (MSM) sexual contact,” which is in line with the GDPH surveillance unit’s official designation of “male-to-male sexual contact as “MSM,” despite the evident acronymic mismatch.[57] As different classifications vis-à-vis “MSM” have accumulated over decades, been layered on top of one another, and been co-deployed, a mangle of terminologies have come to be used in practice, often together, and often in ways that do not make logical sense, but which nonetheless function in practice.

In what follows, I chart the history and material existence of "male to male sexual contact" in the same fashion that I do with the hierarchy and its taxonomy in the previous sections. However, here, I combine historical, technical, and ethnographic analyses into a single narrative about the development and use of the category in practice.

MSM

The history of the "male-to-male sexual contact" classification and its technical definition in *HIV Surveillance Reports* is notable for two main reasons. First, the category stands out for its definitional consistency across time, even through multiple transformations. Its formal definition has remained relatively unchanged since 2002, when it changed from "men who have sex with men" to "male-to-male sexual contact." Second, it is notable for its continued inclusion of the terms "homosexual" and "bisexual" in its technical definition, even after those terms were jettisoned from the official taxonomy in 1991. Even today, the category is conceptually haunted and shaped by homosexual identity, and bisexuality, and sexual orientation at the most technical level. The category's definition in the 2016 *Report* is as follows: "Persons whose transmission category is classified as male-to-male sexual contact include men who have ever had sexual contact with other men (i.e., homosexual contact) and men who have ever had sexual contact with both men and women (i.e., bisexual contact)."[58]

During fieldwork, an interdisciplinary range of practitioners across domains of HIV practice – and particularly in HIV surveillance – overwhelmingly emphasized that their main interest is in understanding sexual behaviors that can transmit HIV, and that they had little or no interest in sexual identities or attractions. This did not include *all* interlocutors in the HIV world (particularly those in prevention), but was a substantial proportion. This can be contrasted to practitioners and advocates in LGBTQ health, who tend to promote the collection of identity-based sexual orientation data because they want providers and population health professionals to structure interventions around disparities that are driven by sexual identity rather than behaviors (or at least for practitioners to create behavioral interventions that are informed by data about identity). That is a major topic in this dissertation's third chapter.[59] The focus on behaviors in HIV is in part a function of how all HIV transmission categories and collection instruments are geared toward measuring behaviors that are likely to cause transmission of HIV. However, the continued presence of "homosexual" and "bisexual" in the technical definition of surveillance reports, which are terms that are primarily about *identity*, show that the question of sexual identification remains somewhat central to the "male-to-male sexual contact" category, even as practitioners insist that the category is strictly behavioral and often work purposefully to abject the question of identity from the classification. This means that, even if the category is primarily a reference to behaviors, sexual identity categories are likely to remain central to the category's undergirding for the duration of its use in public health practice. The relation of sexual identity categories to "male-to-male sexual contact" does not only exist where hierarchy data are *expressed* as data about "gay and bisexual men" (as in the *National HIV/AIDS Strategy*) but also at the technical and definitional level in CDC's formal gold standard in the *HIV Surveillance Report*.

"Identify as MSM" and Responding to Boellstorff (2009)

There is considerable anxiety in the public health workforce, communities of researchers, and among some gay activists (and, in Atlanta, a cohort of Black gay men's health activists) about individuals – and particularly young Black gay men – taking up "MSM" as a category of self-identification or a sexual orientation. This is accompanied by (and has produced) numerous competing discourses about the term "MSM." Some activists and advocates (white and Black, gay and otherwise) have told me that they want to jettison it from the HIV and LGBTQ health lexicon entirely, and believe it to be in the process of replacing or erasing local Black gay identities. Anxieties about – and contestations over – the term generally coalesce around the use of the phrase "identify as MSM."

My ethnography in Atlanta suggests that MSM does in fact exist as an identity of subjective self-identification among a very small segment of people. However, I have also found that fears among queer HIV activists and others about MSM overriding existing or dominant sexual minority identities such as gay, bisexual, or same-gender loving (et cetera) ought to be tempered. The practice of individual people identifying as MSM is not at all widespread; when epidemiologists, healthcare providers, and prevention workers say "identify as MSM" or related phrases, they are not saying or assuming that the clients or populations they are discussing possess "MSM identities" in the same way that an individual might possess a "gay," "bisexual," or "pansexual" (et cetera) identity in the mode of sexual orientation (an internalized sense of self). Overwhelmingly, MSM remains a biomedical classification used by providers, researchers, and client/respondents for the purposes of providing or receiving services. Even when the language of "identification" is used, it almost always a context-bound "identification" that is particular to the healthcare environment.

While using the category "MSM" rather than "gay and bisexual men" does enact some degree of erasure – what one prominent Black gay health activist described to me, in a common refrain, as ignoring the "whole person" and "reducing someone to a sex act" – the *vast* majority of scholarly and community-level deployments of phrases like "identify as MSM" usually do not refer to people who possess “MSM identities,” nor do they constitute the projection of “MSM identities” onto people by researchers, public health practitioners, and epidemiologists. In the vast majority of instances, these are provisional and strategic biomedical classifications.

My response to MSM-related anxieties cuts in two directions. Firstly, I respond to anthropologist Tom Boelstorff’s interpretation of the phrases such as “identify as MSM” and “MSM identities” in the global public health grey literature. I take Boellstorff’s framing of the issue – that MSM identities are emergent forms of sexual self-identification and subjectivity – to be representative of broader anxieties in the HIV workforce about “MSM’s” rumored mutation into a category of self-identification equivalent to “gay,” “bisexual,” “same-gender loving,” or some other category of identity akin to sexual orientation. Secondly, I draw examples from fieldwork in Atlanta to demonstrate that when practitioners use phrases such as “identify as MSM,” they are not referring to “MSM identities,” but to people identifying with the term in order to complete forms, answer questionnaires, receive services, or participate in programmatic interventions or research studies.

In a 2009 article that is the most astute extant assessment of the category’s evolution, Boellstorff claims that MSM has undergone several sequential mutations. The first of these was the conversion of MSM from being a descriptor of “men who have sex with men but do not identify as gay” at its genesis in the 1980s to a catchall term encompassing all “men who have sex with men” – regardless of sexual identity – during the 1990s and 2000s. This second “broad umbrella” understanding of MSM – where MSM functions as what a high-ranking HIV/AIDS official at HHS described to me in an interview as a “super-category” encompassing all queer men who engage in sexual practices with other men – is how the term is most commonly used.[60]

However, using the framework of "prolepsis" – or rhetorical anticipation – Boellstorff claims to document a third, more recent, and growing shift: MSM's emergence as an identity category that exists alongside more recognizable categories of sexual self-identification such as gay, bisexual, same-gender loving, or indigenous sexualities (in his case, in Southeast Asia). These are the aforementioned "MSM identities" that are the source of so much anxiety in the public health workforce: fears that the use of the term "MSM" has so proliferated into public health discourses aimed at marginalized communities that it is in the process of replacing local sexual minority identities that emerge from queer cultures (both domestically and transnationally).

Boellstorff interprets phrases such as "self-identified MSM," "identify as MSM," "out MSM," and "closeted MSM," as they are used by HIV researchers and in documents published by international non-governmental organizations (NGOs) to mean that these entities are referring to individuals who experience MSM as a personally-held identity category in the same way that gay men experience a gay identity. That is to say, as a label describing an indelible and potentially immutable characteristic inherent in one's sense of self (MSM as a "sexual orientation" defined by self-identification with a category or label).

Boellstorff's central claim about MSM's transmutation into a category of subjective self-identification (which reflects comments from many of my interlocutors) is not exactly incorrect. However, it is overstated and somewhat simplified, both in regard to some of his own primary source data and my own findings in the field. In Atlanta and transnationally, MSM does indeed function as an identity category for some (likely very small) number of people. There is limited evidence to support this claim in the public health literature,[61] and I have met two self-identified MSM who equate it with sexual orientation – as parallel to gay identity and as a self-descriptor that reflects an internalized sense of self. Both are African American men who themselves work in HIV. One is young and primarily identifies as MSM as a disidentification with white gay identity and what he characterized as “the down-low category” (a category that I never bring up in interviews, owing to its racist history, and which in fact only came up in my fieldwork a handful of times).[62]

The other man (Steven Jones) is in his 60s, and is a substance use counselor and case manager at a small agency in Southwest Atlanta. He identified himself to me as “gay or…an MSM,” treating the two as conceptually equivalent and weaving it in with the categories he uses in his work. He was one of several interlocutors in Atlanta who compared the two terms (“gay” and “MSM”) to changing racial classifications in 20th century U.S. history:

> **Me**: Do you have any clients who prefer to be labeled or self-identify as MSM?
>
> **Steven Jones, Interlocutor and HIV Substance Use Counselor**: Yeah. And I think they have adapted to the status quo, cause 20 years ago it was, "I'm gay." Same people 20 years later: "I'm MSM." It's just like 40 years ago, "I'm a Negro," today is, "I'm black." It's just like Negro, African-American, Black, has evolved. I think that trying to find true sexual identity or sexual identity references will continue to evolve.

This gentleman (in this statement) and other HIV personnel have told me that that they regularly work with men who personally “identify as MSM” in essentially the mode of sexual orientation rooted in identity categories. Therefore, regardless of how widespread the phenomenon is, MSM’s emergence as an identity category is definitely real. However, what that phrase means is often ambiguous, difficult to discern, multiply-signifying, bounded by context, and is usually confined to “identification as” only for the duration of a healthcare-related encounter of some kind.

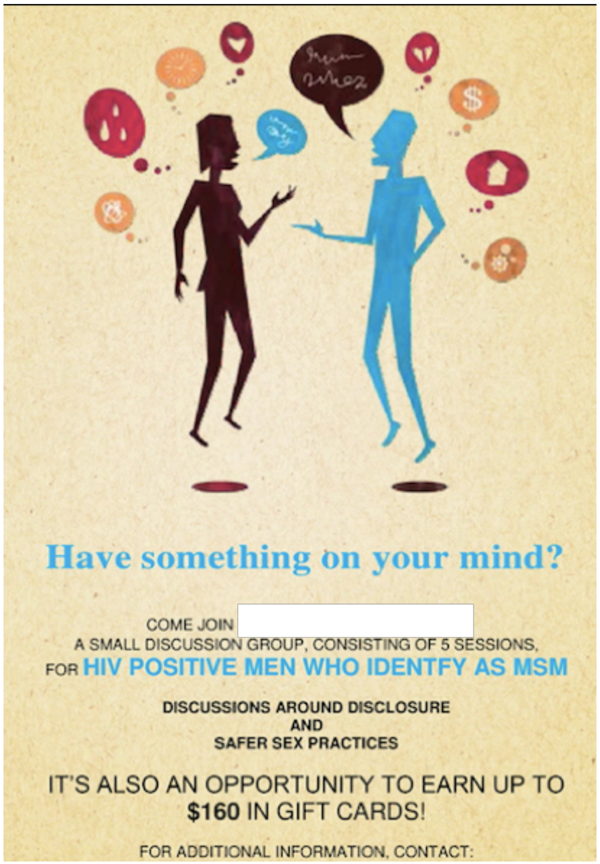
In sum, the story of MSM’s emergence as an identity category is not as neatly straightforward as Boellstorff’s narrative implies. Further, as I will show, upon closer examination, his own primary sources demonstrate my claim of greater complexity. In my fieldwork, most of the time, when health workers employ phrases such as “identify as MSM,” they are not speaking about an individual possessing an identity *as* “an MSM” or who has “an MSM identity” akin to a more recognizable “gay” or “bisexual” identity, or even ones more specific to African American culture such as “same-gender loving” or “butch queen.”[63] Rather, interlocutors who uses phrases such as a client “identifying as MSM” are referring to a male client simply acknowledging that they have sex with other men, either generally (such as for the purposes of recruitment for a research study or public health intervention) or during the battery of questions that are asked during testing events, interviews, clinical intake processes, or for some other purpose. This can take the form of identifying as “MSM” (as in, identification with the acronym outside of a formal definition) or as someone who identifies as a man and as someone who “has sex with men,” with the practitioner or health worker using this acknowledgment of behavior to say that someone has “identified” themselves “as MSM.” To “identify as,” in this context, usually means simply “acknowledge” or “declare” that one engages in a behavior or recognizes oneself in the acronym “MSM.”

This mode of “identifying” with the acronym “MSM” or the term “men who has sex with men” also extends to participation in public health programs that require individuals to openly identify themselves as such to participate. One example is the GDPH and Kaiser Permanente Foundation’s Speak Out Ambassador program, which is a platform for queer men of color to publicly share their experiences living with HIV. Another is the representation matrix for voting member slots of the Georgia Prevention and Care Council (GPACC), a statewide planning body that reserves four slots for “MSM” of different races.

In all these examples, “identifying as” MSM refers to acknowledging a behavior, not a personal or social identity, and this is true in the *vast majority* of cases when the language of “identification” is used in juxtaposition with “MSM.” I came to this conclusion by asking dozens of participants many variations of questions regarding what it might mean to “identify as MSM,” whether MSM is an identity, if they have encountered MSM functioning as an identity in their work, and how the category shapes the way they engage clients.

But the story is still more complex. One of the stranger sexual realities that I have encountered in Atlanta is the appearance of “identify as MSM” and related terms on recruitment materials for studies or public health interventions, without reference to the actual phrase “men who have sex with men” or any definition at all. Figure 1.8 shows one such example.

Figure 1.8. “MSM” in a Health Intervention Advertisement with no Accompanying Definition



Have something on your mind?

COME JOIN [redacted]
A SMALL DISCUSSION GROUP, CONSISTING OF 5 SESSIONS,
FOR HIV POSITIVE MEN WHO IDENTFY AS MSM

DISCUSSIONS AROUND DISCLOSURE
AND
SAFER SEX PRACTICES

IT'S ALSO AN OPPORTUNITY TO EARN UP TO
$160 IN GIFT CARDS!

FOR ADDITIONAL INFORMATION, CONTACT:

Because “MSM” is not defined in this ad, its legibility (and therefore, one would presume, the ability to effectively recruit for the intervention) is entirely contingent on the recipient of the message knowing what “MSM” means and “identify[ing] as MSM,” at least in the case of the need to respond to this specific public health intervention ad. However, per the program manager (a key interlocutor), this identification “as MSM” is in no way intended to refer to a sense of interiority *as an MSM*, but to the recipient’s identification as gay, bisexual, or same-gender loving, or to the fact that they have sex with other men for whatever reason (such as for food, housing, are in the closet, or because they are straight-identified but enjoy sex with men).

However, the fact remains that participants must know what “MSM” means in order for the recruitment flyer to signify. They must recognize themselves in the phrase “HIV POSITIVE MEN WHO IDENTIFY AS MSM.” The fact that the intervention is, per the individual who ran it during a portion of my fieldwork, well-utilized by gay and bi identified men as well as men who do not identify as such means that at least some respondents saw the acronym “MSM” along with “IDENTIFY AS” and recognized themselves in that discourse absent any need for additional definition or clarification. Suffice to say, while interlocutors with whom I work frequently use language of “identification” or “identifying as” in juxtaposition with MSM, the biomedical sexualities and sexual realities that these phrases refer to are generally not referring to men who possess “MSM identities,” as Boellstorff suggests and as no small number of my interlocutors fear.

Yet the fact remains that the phrase “identify as MSM” and similar ones are ubiquitous, and opinions about what they mean vary substantially within the HIV workforce in Atlanta and among advocates for LGBTQ health. For many, the issue is straightforward. Some express incredulity at the idea that someone would - or even *could* – “identify as MSM.” These interlocutors range from white queer HIV and LGBTQ health policy leaders to queer and trans African American public health practitioners. However, as I have indicated, equally as many interlocutors are quick to emphasize that MSM is a legitimate identity and must be honored if a client self-identifies as such, even if they themselves have never personally met or heard of someone who possesses such an identity.

However, to reiterate, the vast majority of the time, "identifying as" MSM simply means identifying as a man who engages in sexual acts with other men, for some health-related purpose. One interlocutor whom I will call Maurice – a young, HIV-positive African American man who runs his own nonprofit and does peer education and recruitment work for other HIV organizations in Atlanta – told me that many men will not "identify as MSM" during testing events, group therapy sessions, or one-on-one sessions – although most will. It took me some time, several conversations, and rephrasing the question in different ways to discern exactly what Maurice was saying. What he meant was that those who *do* "identify as MSM" have acknowledged that they have sex with men on a form, or that a client has indicated they have sex with men or became seropositive through "male-to-male sexual contact." In the vernacular of many HIV workers in Atlanta, stating this means that an individual client has "identified as MSM." But it does not mean that these individuals possess MSM identities in the mode of a sexual orientation that reflects an indelible interiority or identity. Those who refuse to "identify as MSM," in Maurice's discourse, have opted not to share the fact that that they have sex with men with a health educator. It usually has nothing to do with "MSM" functioning as an internalized identity category for the client.

Consider another example. Colette Clinton – a Physician Assistant who works primarily with HIV-positive and trans patients in a prominent private practice in Atlanta – told me that "most of my patients probably identity as MSM." Informed by my previous conversations with Maurice and other interlocutors, I followed up, asking "so, what do you mean by 'identify as MSM?'" After some back and forth, Colette said that she believes MSM is a term that her patients use only when interacting with medical providers. She said:

> they identify as being men who sleep with men. They may not say that they are "gay" or "bisexual" or "poly[amorous]" or "pan[sexual]," they will say "MSM"…I just don't think they use the terminology "MSM" outside of a medical visit...in everyday vernacular, they're not saying or identifying as MSM...If it's on a form, they'll say so. Yeah. They'll make a relation to that but not just, "Yes, I'm MSM."

When Colette claims her patients identify as MSM, she is actually saying that they check the "MSM" box on a form (or say the equivalent when speaking to her, and then she fills in the data in her EHR), not that they actually "identity as MSM" as in possessing internalized identifications as MSM. Rather, they would identify outside of the clinical context as "'gay' or 'bisexual' or 'poly[amorous]' or 'pan[sexual],'" but will say "MSM" or "I sleep with men" or "I have sex with men" to Collette during the clinical visit. It refers to a specific, situated, biomedical sexuality.

An administrator of the GDPH Speak Out program made a similar claim about Speak Out Ambassadors' identification "as MSM" to participate in the program. Further, the entire program of GDPH's annual "MSM Symposium," coordinated by GDPH's two "MSM Coordinators," is not focused on the MSM category (it rarely comes up, except when the conference itself is referred to by name) but on affirming gay, bi, and queer men of color's experiences as well as those of transgender and gender nonconforming Georgians. "MSM" is, in this case, coded language for "LGBTQ."

"God forbid we put 'gay' on anything," one GDPH employee told me in an interview, rolling their eyes, in a tacit reference to the limitations of working in the southeastern U.S., which many interlocutors reflexively called "the Bible Belt" (a category I never brought up proactively so as not to map Northern stereotypes onto the region). In the Bible Belt, public health officials must use strategic language in official communications that does not highlight LGBTQ social categories. Although never explicitly stated, this is often clearly done to avoid drawing attention to the fact that state dollars are being used specifically for LGBTQ health purposes, which could potentially ignite a political firestorm.[64]

However, if I had used Boellstorff's logic to interpret my data, Maurice, Collette, and other interlocutors' use of phrases like "identify as MSM" would mean that these practitioners were referring to clients with internalized "MSM identities" akin to "gay," "bisexual," or "same-gender loving." But that is not at all what my interlocutors (or a vast majority of their clients) are saying. In fact, it is not what Boellstorff's own primary sources are saying. In his 2009 article on the subject, Boellstorff reads report authors' uses of phrases such as "identified as MSM" as referring to personally-held MSM identities. However, a re-examination of Boellstorff's primary sources shows a different logic at work – one that is more in line with the way that practitioners in Atlanta most commonly employ phrases such as "identify as MSM."

Boellstorff says that, in a 2006 report from the Vietnamese Ministry of Health, the use of the phrase "consensual male partners" of MSM, rather than simply "MSM," means that MSM is functioning as a personally-held identity category for some in the study sample (the "MSM"), and *not* for others (those MSM's "consensual partners").[65] In Boellstorff's words, "The only intelligible way to understand such a 'consensual male partner' as something other than an 'MSM' is that they are distinguished by lack of an MSM identity."[66]

However, upon closer examination of the Vietnamese report and its technical notes, the document in question uses the term "consensual male partners" of MSM not to distinguish those in the sample with “MSM identities” from a different class of men who have sex with men but who do not possess an “MSM identity,” but in order to separate men in the sample who had sex with “consensual male partners” from men who engaged in “commercial sex” with other men. The authors place “consensual partners” into a different category than both “clients” of sex workers and “male sex workers.” The researchers Boellstorff cites do not indicate that the consensual male partners referred to in the study would not also be classified as MSM if they were included in the study sample. Further, the authors discuss the Vietnamese identities “Bong lo,” “Bong kin,” and “straight men” (who identify as straight men and are included in the sample because they reported sex with other men) collectively under the behavioral umbrella of “MSM.” These three identity categories together make up 99.8% of the sample.[67] This leaves very little room for “MSM identities” beyond subjects “identifying” to surveyors that they engage in sex acts with other men, not that they have internalized “MSM identities.”

Boellstorff makes similar claims when he considers the MSM Initiative of the American Foundation for AIDS Research (amfAR), which launched in 2008. Boellstorff says, “I was fascinated to see that the sample application suggested that ‘out and closeted MSM in three districts of my city’ might be the target of an HIV prevention program.” He continues, writing that

> This distinction between “out MSM” and “closeted MSM” is more than the paradoxical returning of the MSM category full circle to the kind of identity category it was coined to avoid. It is indicative of a broader recursion in which the transformation of “MSM” into a sexual identity has spawned a new binarism - not between “gay” and “MSM,” but between men who identify as “MSM” (“out MSM”) and those who do not, but still have sex with men (“closeted MSM”).[68]

However, this is not what the MSM Initiative staff mean by “out” and “closeted” MSM. The introduction of a 2008 MSM Initiative document emphasizes that individuals may “fail to identify as MSM because of the stigma associated with male-male sex.”[69] This suggests that the

MSM Initiative is deploying the phrase “identify as MSM” in the way that I have observed it being used most prominently by health workers in metro Atlanta: not as an identity in the mode of gay or bisexual, but as a way of indicating whether a man will disclose same-sex sexual behavior to a surveyor *or* whether they will take on a more recognizable sexual minority identity which implies that they have sex with or experience sexual attraction to other men. The authors say as much in the MSM Initiative report cited by Boellstorff, writing that “denial of male-male sexual activity is high,” not that the denial of “MSM identities” is high.[70]

I draw attention to these issues with the article out of deep appreciation for Boellstorff and his work. His article, in fact, formed the basis for many of my research questions and investigatory starting points in this area. However, the fact remains that the MSM identities he purports to have identified as emergent in the everyday vernacular of sexual identity likely do exist in the world as such, but only rarely so. Far more often, “MSM identities” are strategic biomedical identifications by individual clients or patients in health contexts that do not extend outward into everyday life, or are disclosures about sexual behaviors that practitioners discuss as “identifications” as MSM.

While there are nearly as many uses of “MSM” in my study data as there are organizations and interlocutors, the use of MSM as a category of self-identification – while a real phenomenon – is relatively rare. The notion of an “MSM identity” equivalent to “gay” or “bisexual” corresponds to some sexual realities, but to ones that are very limited in their existence if that “identification” is taken to mean that individuals possess a sense of indelible interiority as “an MSM.” Much more commonly, MSM is a *provisional identification* that takes the form of acknowledging oneself as being “an MSM,” or as a man who has sex with other men on a form or for some other purpose related to interacting with the healthcare system.

These acts produce sexual realities that largely evaporate once the box has been ticked, the form has been filled out, or the encounter with the provider concludes. Or, alternatively, health educators, clinicians, and other practitioners record a client as "MSM" and then speak about this as an "identification." Widespread discussions about "MSM identities" therefore reflect ambiguity and multiplicity around the meaning of what it means "to identify" as MSM more than they reflect actual rapid emergence of populations that possess internalized "MSM identities."

VII. Transgender Data in HIV Surveillance: Toward a More Inclusive Hierarchy

In this conclusion, I flirt with a concept that I quite dislike, but which has a great deal of currency in contemporary queer and trans theory: futurity.[71] Predicting the future is not a business that sets one up for success. However, given the acknowledged need for high quality HIV surveillance data on transgender people to secure public health funding for this population, and given the existence of an emergent set of evidence-based methodologies that are being used to collect, "clean up," and report trans-inclusive HIV surveillance data and transgender-inclusive HIV risk hierarchy data, I find it appropriate to speculate on the likely futures of transgender data reporting in HIV surveillance and to put forward some concrete proposals to actualize those and other futures.

Therefore, herein, I discuss how the reporting of trans data is likely to change in HIV surveillance in the near future and how this will affect how HIV risk hierarchy data materialize in practice. In doing this, I also advocate for an approach that will be both more inclusive of trans people and more reflective of the diverse range of sexual practices that can potentially transmit HIV and are, therefore, worth measuring in their specificity.

Transgender Data in the HIV Assemblage

Trans data collection and reporting in the HIV context is somewhat more complicated than simply collecting and reporting gender identity data on a normal survey instrument. This is because the categories in the HIV risk hierarchy that are used to collect and report data about sexual "risk factors" for HIV transmission contain references to the sex/gender system ("**male**-to-**male** sexual contact") and/or sexual orientation ("**heterosexual** contact with a person known to have, or to be at high risk for, HIV infection," emphasis mine**)**. Therefore, even in the case where a separate, transgender-inclusive "gender identity" field is captured, which is the case in federally-recommended HIV surveillance, care, and prevention data collection instruments in the United States as of 2018, data about sex/gender (and, sometimes, sexual orientation) are also collected as "HIV risk hierarchy" data. Transgender data collection in HIV surveillance is a phenomenon of the mid-late 2010s. Below, I document an effort by the Georgia Department of Public Health (GDPH) to identify transgender cases of HIV in the state's HIV surveillance system retroactively, in consultation with CDC.

However, historically, the lack of gender identity data – and reliance on a binary "sex" field – has led to transgender women being coded as "MSM" and transgender men being coded as women whose transmission factor is "heterosexual contact." This is because the "male" in "male-to-male sexual contact" refers to sex assigned at birth in HIV surveillance contexts, not to gender identity. This has led to a great deal of public health programming targeted at "MSM" also including transgender women; this is the case, for example, in GDPH's *MSM Strategic Plan*, which includes "Addressing HIV/AIDS among transgender and gender non-conforming community" as a goal and references to "the LGBT community" and "transgender/MSM community."[72]

Prominent Black trans health and HIV activist Tori Cooper, explained this to me during an interview in Atlanta, as part of a disquisition on the need for more and better trans health data to fund more robust services for trans and gender-nonconforming populations:

> **Tori Cooper, Atlanta-based HIV/AIDS professional, trans health advocate, and Black trans woman**: So, at an agency level…on a state level, there needs to be paperwork that'll capture that data. And, of course, on a federal level…You can get a lot of money if you say that you deal with a lot of MSM: get a whole bunch of money. You don't get a whole bunch of money if you say you deal with a lot of trans folks. And so, by adding trans numbers to MSM numbers – which has been done historically for a long, long time – if you add in those numbers, then you get more money for your MSM communities and you can trickle some funds off to our trans communities. That's what happens…
>
> **SM**: It all goes back to the data.
>
> **Tori**: Of course! And data is what?
>
> **Me**: It is money.
>
> **Tori**: Data is money![73]

Tori is well-known for the multiply-signifying mantra "Data is Money!" in Atlanta's HIV world. It is a slogan of sorts in her longstanding demand – made collectively with other activists and researchers – for better data collection on transgender individuals and basic research on transgender health. In our conversations, social media interactions, and in large group presentations where I saw her present, Ms. Cooper introduces the phrase and then asks for a response, as in our interaction quoted above: Tori asks, "Data is what?," and the respondents reply "Data is money!," or simply "money!"

To this point, the majority of U.S. states and jurisdictions now collect transgender-inclusive data on their HIV case report forms, the CDC recommends doing so, and gender identity was included in the new HIV case report form released to states in 2018. However, how these data are utilized is largely limited to the jurisdictions in which the data are collected, or to researchers and practitioners in public health who are granted access to CDC HIV surveillance data. Transgender data are not included in *HIV Surveillance Reports*, owing to claims that the data are incomplete and of low quality compared to other data classes that have consistently been collected in the same way using validated instruments for nearly two decades.

To wit, recent *HIV Surveillance Reports* have included the following note in the "Technical Notes" section, which I excerpt from the 2017 *Report*:

> **Sex**
>
> Sex designations in this report are based on a person's sex at birth. Transgender is an umbrella term that is used to identify persons whose sex assigned at birth does not match current gender identity or expression. **Data for transgender persons are not presented in this report because information on gender identity (a person's internal understanding of his or her gender or the gender with which a person identifies) is not consistently collected or documented in the data sources used by HIV reporting jurisdictions**. HIV surveillance personnel collect data on gender identity, when available, from sources such as case report forms submitted by health care or HIV testing providers and medical records, or by matching with other health department databases (e.g., Ryan White program data). In May 2012, CDC issued guidance to state and local programs on methods for collecting data on transgender persons and working with transgender-specific data. However, characterization of HIV infection among transgender persons may require supplemental data from special studies.
>
> (emphasis mine**)**

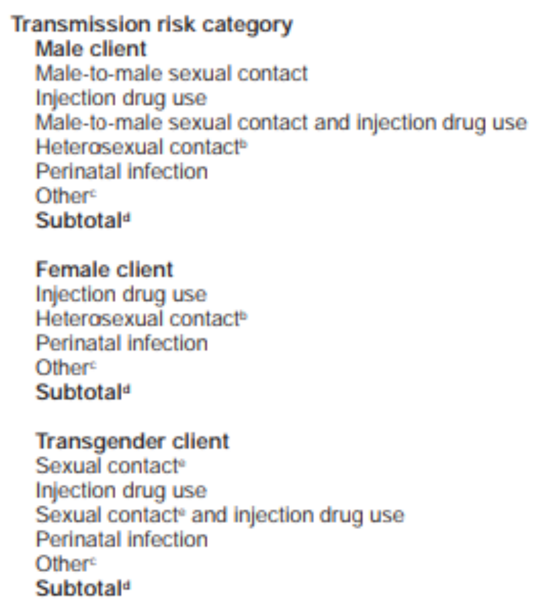
The complexity referred to in this technical note and the incompleteness of existing trans data are not legitimate reasons for the ongoing exclusion of available data about transgender people living with HIV in the *HIV Surveillance Report*. It is imperative for CDC to begin including these data in *Reports* in order to better allocate resources to transgender populations specifically. This is the consensus among LGBTQ and trans health professionals and is the basis for my position.[74]

To this end, a method exists for reporting trans-inclusive HIV data that is endorsed by HHS. However, this method emerges from the care context, not surveillance. While gender identity data collection is relatively new in surveillance, and was only added to recommended HIV case report forms in 2018, Ryan White providers have had to collect and report gender identity data in their annual Ryan White Service Reports (RSRs) to the Health Services and Resources Administration (HRSA) since the early 2000s. This has produced a relatively "clean" clinical gender identity dataset that is probably the highest quality such dataset in existence in the United States (although my fieldwork suggests that trans patients are still likely undercounted in Ryan White data). Because of the high quality of the Ryan White gender identity data, the authors of the 2016 *Ryan White HIV/AIDS Program Annual Client-Level Data Report* published by HRSA contains a model for reporting trans-inclusive risk hierarchy data using the current hierarchy.

This data reporting method creates the single transmission category of "sexual contact" for transgender people living with HIV who most likely acquired HIV sexually. In these reports, a standard hierarchy for cisgender individuals and a trans-specific hierarchy appear together, with trans cases owing to sexual transmission reported out simply as "sexual contact." However, producing this model required back-coding HIV transmission risk factor data that systematically misgender transfolk by reporting trans women's risk factor as "male to male sexual contact" (based on sex at birth) and classify most transgender men as "heterosexual contact."

[figure appears on the following page]

Figure 1.9. Transgender-Inclusive HIV Risk Hierarchy data as reported in the 2016 *Ryan White HIV/AIDS Program Annual Client-Level Data Report*



Transmission risk category

Male client
Male-to-male sexual contact
Injection drug use
Male-to-male sexual contact and injection drug use
Heterosexual contact[b]
Perinatal infection
Other[c]
Subtotal[d]

Female client
Injection drug use
Heterosexual contact[b]
Perinatal infection
Other[c]
Subtotal[d]

Transgender client
Sexual contact[e]
Injection drug use
Sexual contact[e] and injection drug use
Perinatal infection
Other[c]
Subtotal[d]

Given that this method is endorsed by HRSA (a branch of HHS with purview over federal HIV programming in the domain of care), it is likely – but not a guaranteed outcome – that this will eventually become the normative mode of HIV risk hierarchy reporting in the surveillance domain in years to come. This is especially likely given the mainstreaming of LGBTQ health and the new consensus in LGBTQ health that I discuss in chapter three, and that better HIV data collection and reporting is a consistent demand of LGBTQ health, transgender health, and HIV activists.

However, I go one step further than the current consensus, which is simply to report available transgender data where it exists, in the manner that HRSA chose to do for the 2016 report excerpted above. I argue that it is not just time for CDC to start reporting transgender data, but also for the HIV risk hierarchy itself to be changed so that its sexual transmission categories are not gendered (e.g. "male-to-male sexual contact") or heteronormative ("heterosexual contact”) whenever they are reported. The infrastructures, models, and methods exist to implement the necessary changes to remove reference to sex, gender, and orientation when hierarchy data are reported. This is also the method used for reporting transgender cases by GDPH. These efforts could, and should, be expanded and move forward immediately in the states and at CDC.

The main objection to reporting trans data in the surveillance context is that gender identity data collection is a relatively new practice in HIV surveillance. The fact that these data collection practices are relatively new means that, in surveillance, where vital demographic information about individual cases is usually only collected upon the initial report that an individual has seroconverted, many existing cases of HIV among transfolk are likely to be coded as cisgender cases. This potentially results in the systematic under-counting of transgender cases even when “trans-inclusive” surveillance numbers are reported.

However, as indicated in the quotation from the CDC’s technical note on transgender data under the heading “Sex,” methods do exist to guard against this and to systematically examine surveillance data in order to identify and count existing transgender cases that were reported before gender identity data collection began in the 2010s. These methods include, per CDC (in the quote above), consulting “sources such as case report forms submitted by health care or HIV testing providers and medical records, or by matching with other health department databases.”

Such a project was undertaken in Georgia, in direct consultation with CDC, owing in part to the proximity of CDC to GDPH. The project was also a direct response to the demands of Black trans women in Georgia that they be counted in HIV surveillance. In a research interview, one GDPH HIV epidemiologist recounted a story in which Cheryl Courtney-Evans, a highly-regarded and legendary-even-in-her-time Black trans activist in the city who co-founded a prominent grassroots organization and was omnipresent at HIV and LGBTQ-health related events in the state and city, confronted public health officials at a public meeting:

> **GDPH HIV Epidemiologist**: Oh, man, do I remember the day when I presented some HIV statistics, and she came up to the mic, and said, "Do you see me?"…a hush descends across the room. She says, "Do you see me? I'm standing right here, but I don't see myself represented on your slides."
>
> It was like: "Whoa." We were really called out - and that moment, more than any one I think, sealed the commitment of "We need to figure this out. We need to be better at providing HIV data with regards to the trans community."[75]

This is one of many stories that I heard about Cheryl Courtney-Evans confronting local, state, and federal officials in public meetings about the issue of transgender HIV surveillance numbers in the state. Unfortunately, Ms. Evans died very shortly after my arrival in Atlanta in August of 2016, and we never had a chance to speak.[76]

However, following the activism of Cheryl Courtney-Evans and other Atlanta-based trans activists, in 2015, GDPH convened a transgender data workgroup which included several MPHs from local universities, and included input and participation from CDC, to undertake a review of their surveillance data to identify transgender cases. This project involved going through surveillance data in a systematic fashion (using algorithms applied to data sets in automated and manual fashions), matching state surveillance data to CAREWare, other health department databases, and direct outreach to healthcare providers to undertake chart reviews.[77] If all states were to undertake such projects, and if CDC were to report these data, a much more accurate picture of the HIV/AIDS crisis among transfolk in the United States would emerge.

While Georgia is hardly a model for how a state should respond to the AIDS crisis, the epidemiology staff at GDPH deserve credit for being responsive to the demands of local trans activists, and their model for increasing core surveillance numbers can be used as a basis for similar work in other jurisdictions. Further, if this course of action were to be pursued, it would strengthen the case for a new HIV risk hierarchy that would focus on the question of sexual transmission, rather than using categories that require reference to the sexes, genders, or sexual orientations of those doing the transmitting or seroconverting. Such a revised HIV risk hierarchy would open up the door to building transnational, national, and local responses to the HIV/AIDS epidemic that could be shaped by more inclusive, capacious, and malleable conditions of sexual possibility than current ones (bounded by cisheteronormative classifications) can provide.

It is precisely because the various domains I have considered in this chapter permit, encourage, and even systematize semblances between competing classifications and frameworks for understanding sexuality that these taxonomies come to produce an infinite range of conditions of sexual possibility, but only within effectively constraining parameters. However, as this conclusion on trans futurities in HIV surveillance demonstrates, these parameters are themselves constantly becoming-different and can even be entirely remade without the need to fundamentally change the underlying infrastructures. Permissible uses of specific data classes or categories change, and as they change, new ways of managing queer health emerge. This occurs as individuals and institutions reflect upon what categories mean (such as when an ethnographer asks them to, when they are confronted by an activist, or in special journal issues), when experts revise technical definitions, as individual and institutional habits shift, or as existing datasets are systematically “cleaned up” or revisited and improved. While possibilities for working with and creating biomedical sexualities are always bounded by organizational will, resources, and available best practices, the burden of infrastructural histories, and the IT systems and data that are available to practitioners, modes of managing the health of queers and people living with

HIV that emerge from these milieus remain open to creative deployments and are constantly in flux.

In the right hands, some such styles can even raise the potential of extending to their absolute limit, raising the possibility of unmaking or fundamentally reorienting the logics of the modern sexual system itself.[78] Nothing less than this is at stake in determining the future of the HIV risk hierarchy and its individual classifications, just as the history and future of HIV/AIDS and responses to it continue to shape and reshape the histories and futures of sexuality.

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References for Chapter 1

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[1] Since 2008, this has been the most common presentation of the hierarchy in tables in the *HIV Surveillance Report*.

[2] This method of tracing the emergence of seemingly singular realities or entities through an attention to their underlying multiplicity builds upon constructivist and new materialist STS. In the case of the HIV risk hierarchy, see especially: Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002), *passim*, on "enactment."

[3] Foucault, Michel. *The Archaeology of Knowledge and The Discourse on Language*. New York: Pantheon Books, 1972, 41.

[4] On "recursive origami" as a practice or method for analyzing historical materials in the history of biomedicine and health, Michelle Murphy writes about drawing inspiration and insight from the artistic practice of "crumpled origami," which begins with paper that has already been folded, rather than traditional origami, which beings with crisp pieces of paper:

> I am inspired not by the precise, rule-bound techniques of conventional origami, but the textured shapes produced by what practitioners call 'crumpled origami.' In turn, the method I am calling recursive origami does not begin with a smooth flat plane, but always enters the archive of the past as already refolded, always crumpled, unavoidably uneven – the world already complexly articulated through race, sex, capital, and nation. Analytical acts of unfolding chart how practices and phenomena (such as Pap smears and cervical cancer) are already made up of many other folds stretching far beyond the object itself.

Seizing the Means of Reproduction: Entanglements of Feminism, Health, and Technoscience, (Durham, NC: Duke University Press, 2012), 186-7. My own method of textual reassemblage as a form of diagrammatic analysis is informed by Murphy's approach.

[5] See also, Centers for Disease Control and Prevention (CDC). "Terms, Definitions, and Calculations Used in CDC HIV Surveillance Publications." Centers for Disease Control and Prevention (CDC), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Division of HIV/AIDS Prevention (DHAP), December 12, 2016. https://www.cdc.gov/hiv/statistics/surveillance/terms.html.

[6] Sociologist Martin French defines "informatic practice" as

> the sum of everyday activity, by assemblages of humans and non-humans, that makes information a material reality in quotidian life…the work of scrawling a pencil across paper, the function of booting up a laptop, the artful composition of characters in a free-text field, the writing of data to discs, the transit of signals through a network, and a great deal of other everyday practices that cause information to manifest.

"Gaps in the Gaze: Informatic Practice and the Work of Public Health Surveillance," *Surveillance and Society* 12, no. 2 (2014): 227.

[7] The Office of the National Coordinator for Health IT (ONC) defines "interoperability" by referring to statute:

> According to section 4003 of the 21st Century Cures Act, the term 'interoperability,' with respect to health information technology, means such health information technology that— "(A) enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the user; "(B) allows for complete access, exchange, and use of all electronically accessible health information for authorized use under applicable State or Federal law; and "(C) does not constitute information blocking as defined in section 3022(a)."

Office of the National Coordinator for Health Information Technology (ONC). "Interoperability," April 10, 2018. https://www.healthit.gov/topic/interoperability.

[8] Staff, "Reuben Sandwich History and Recipe." *What's Cooking America: America's Most Trusted Culinary Resource Since 1977*, November 2016; Elizabeth Weil, "My Grandfather Invented the Reuben Sandwich. Right? (Print Title: The Midnight Lunch)," *The New York Times Magazine*, June 7, 2013.

[9] To appropriate Spinoza: we still don't know what a Reuben might be.

[10] Pride in high data quality reporting was an observation made during fieldwork with some organizations in Atlanta.

[11] Sources: Quadrant one: Zingerman's Delicatessen, "Corned Beef Sandwiches," n.d., https://www.zingermansdeli.com/menus/corned-beef-sandwiches/; Quadrant two: Scott Baker, "Best Reuben Sandwiches Around Orlando Featuring Jason's Deli, Toojay's Gourmet Deli, Pickles NY Deli, and C&S Brisket Bus," *Orlando Local Guide: A Travel and Entertainment Guide*, July 19, 2013, http://orlandolocalguide.com/best-reuben-sandwich-orlando/; Quadrant three: Dan, "REVIEW: Subway Corned Beef Reuben Sandwich," *The Impulsive Buy*, November 30, 2016, https://www.theimpulsivebuy.com/wordpress/2016/11/30/review-subway-corned-beef-reuben-sandwich/; Quadrant four: Rachael Ray Every Day, "Reuben Wraps," *Rachael Ray Magazine*, December 28, 2011, https://www.rachaelraymag.com/recipe/reuben-wraps.

[12] In this technical use of "coming into presence," I borrow from the Heideggerian notion of "presencing" or "bringing-forth," which he characterizes in "The Question Concerning Technology" as "the arising of something from out of itself." as in "[the] bursting of a blossom into a bloom," or as in "what is brought forth by the artisan, or the artist." See, Martin Heidegger, *The Question Concerning Technology and Other Essays*, trans. William Lovitt (New York: Harper & Row, 1977), 10-11. See also, Hannah Arendt, *The Life of the Mind* (San Diego: Harcourt, 1981).

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[13] On "event-process," see, Kane Race, "Reluctant Objects: Sexual Pleasure as a Problem for Biomedical HIV Prevention," *GLQ: A Journal of Lesbian and Gay Studies* 22, no. 1 (2016): 1–31, https://doi.org/10.1215/10642684-3315217, 5-6.

[14] Interview, January 10th, 2017.

[15] I follow Chantal Mouffe in defining agonism as the "struggle against adversaries" who seek to understand each other versus the "struggle against enemies." Adversaries do not seek to totally destroy each other, while this is the definition of "the enemy" in Mouffe's Schmittian usage of the term. See, Chantal Mouffe, "Deliberative Democracy or Agonistic Pluralism," *Social Research* 66, no. 3 (Fall 1999): 745–58. See also, Carl Schmitt, "The Concept of the Political," in *The Concept of the Political*, Expanded ed (Chicago: University of Chicago Press, 2007), 19–79.

[16] CDC. "Pneumocystis Pneumonia --- Los Angeles." *Morbidity and Mortality Weekly Report* 30, no. 21 (June 5, 1981): 1–3.

[17] Gilles Deleuze, *Foucault*, trans. Seán Hand (Minneapolis: University of Minnesota Press, 1988), 1-69; Michel Foucault, "Nietzsche, Genealogy, History," in *The Essential Foucault: Selections from Essential Works of Foucault, 1954-1984*, ed. Paul Rabinow and Nikolas S. Rose (New York: New Press, 2003), 351–69; David M. Halperin, "How to Do the History of Male Homosexuality," in *How to Do the History of Homosexuality* (Chicago: University of Chicago Press, 2002), 104–37.

To download copies of *HIV Surveillance Reports* and predecessor documents, see, Centers for Disease Control and Prevention, National Center for HIV/AIDS, Viral Hepatitis, and TB Prevention, Division of HIV/AIDS Prevention, "HIV Surveillance Reports Archive," https://www.cdc.gov/hiv/library/reports/hiv-surveillance-archive.html.

[18] I draw on Clifford Geertz's framing of thick description as the task of ethnographic research, and treat this genealogy of HIV surveillance – an historical investigation – as part of my larger project in this dissertation, which is primarily ethnographic:

> Ethnography is thick description. What the ethnographer is in fact faced with…is a multiplicity of complex conceptual structures, many of the superimposed upon or knotted into one another, which are at once strange, irregular, and inexplicit, and which he must contrive somehow first to grasp and then to render.

"Thick Description: Toward an Interpretive Theory of Culture," in *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973), 9-10.

As Geertz notes in the essay, ethnography generates its own archives, and the employment of the CDC's archive of HIV surveillance in my work is not outside of my construction of an ethnographic archive particular to this project. As he says, "doing ethnography is establishing rapport, selecting informants, transcribing texts, taking genealogies, mapping fields, keeping a diary, and so on," 6. Historical investigation is a part of ethnographic practice – at least in my case – not merely an additional method that I employ in addition to ethnography and other forms of fieldwork.

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[19] Per Deleuze, in a new cartography, "analysis becomes increasingly microphysical and the illustrations increasingly physical, expressing the 'effects' of analysis…Analysis and illustration go hand in hand, offering us a microphysics of power and a political investment in the body," see, *Foucault*, 24.

By providing a chart that expounds upon minute changes in definitions over time, and by showing how these are connected to the analog and digital technologies that practitioners use to collect hierarchy data, I aim to paint a picture of the relationship between the political investments in gathering these data, as they move through institutional and transnational circuits all the way down to individual client interactions.

[20] Bruno Latour, *An Inquiry into Modes of Existence: An Anthropology of the Moderns* (Cambridge, Massachusetts: Harvard University Press, 2013), 8-9.

[21] Lucia Torian et al., "HIV Surveillance -- United States, 1981-2008," *Morbidity and Mortality Weekly Report* 60, no. 21 (June 3, 2011): 689–93.

[22] Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley, CA: University of California Press, 1996), 45-104 *passim*; For a primary source from the late 1980s, see also, Michael M. Jacobs, "HIV or HTLV-III?," *Archives of Surgery* 122, no. 8 (August 1, 1987): 959, https://doi.org/10.1001/archsurg.1987.01400200109031.

[23] Stacy M. Cohen et al., "The Status of the National HIV Surveillance System, United States, 2013," *Public Health Reports* 129, no. 4 (July 2014): 335–41, https://doi.org/10.1177/003335491412900408.

[24] See, Alexander McClelland, Adrian Guta, and Marilou Gagnon, "The Rise of Molecular HIV Surveillance: Implications on Consent and Criminalization," *Critical Public Health*, February 20, 2019, 1–7, https://doi.org/10.1080/09581596.2019.1582755; Manon Ragonnet-Cronin et al., "HIV Transmission Networks among Transgender Women in Los Angeles County, CA, USA: A Phylogenetic Analysis of Surveillance Data," *The Lancet HIV*, February 2019, https://doi.org/10.1016/S2352-3018(18)30359-X.

[25] Cohen et al., "The Status of the National HIV Surveillance System."

[26] Centers for Disease Control and Prevention (CDC), "Terms, Definitions, and Calculations Used in CDC HIV Surveillance Publications" (Centers for Disease Control and Prevention (CDC), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Division of HIV/AIDS Prevention (DHAP), December 12, 2016), https://www.cdc.gov/hiv/statistics/surveillance/terms.html.

[27] This book on multiple imputation methodology is cited in the 2007 *Report*: Donald B. Rubin, ed., *Multiple Imputation for Nonresponse in Surveys*, Wiley Series in Probability and Statistics (Hoboken, NJ, USA: John Wiley & Sons, Inc., 1987), https://doi.org/10.1002/9780470316696. That source, and this article on multiple imputation in HIV surveillance, are both cited in subsequent *Reports*: Kathleen Mc David Harrison et al., "Risk Factor Redistribution of the

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National HIV/AIDS Surveillance Data: An Alternative Approach," *Public Health Reports* 123, no. 5 (September 2008): 618–27, https://doi.org/10.1177/003335490812300512.

[28] See, Cindy Patton, *Inventing AIDS* (New York, NY: Routledge, 1990), 77-89; Cindy Patton, *Globalizing AIDS*, (Minneapolis: University of Minnesota Press, 2002), *passim*; Adia Benton, *HIV Exceptionalism: Development through Disease in Sierra Leone* (Minneapolis: University of Minnesota Press, 2015), *passim*.

[29] CDC, "Adult HIV Confidential Case Report Form," 2018, https://www.cdc.gov/hiv/pdf/guidelines/cdc-hiv-adult-confidential-case-report-form-2018.pdf.

[30] Here, I deliberately set aside the question of biomedical prevention advances such as Pre-Exposure Prophylaxis and Treatment as Prevention, about which *HIV Surveillance Reports* have nothing yet to say, and which have in no way affected the constitution of the HIV transmission risk hierarchy.

[31] Vicki Lynn et al., "HIV #LanguageMatters: Addressing Stigma by Using Preferred Language," January 2016, https://www.hiveonline.org/wp-content/uploads/2016/01/Anti-StigmaSign-Onletter-1.pdf.

[32] After this became apparent to me based on close readings of several documents related to the development of standards for Ryan White Service Reports, I confirmed this finding via an exhaustive search for key terms in the ICD-10 search tool provided by AAPC (formerly the American Association of Professional Coders), a professional association and technical assistance entity for medical coders.

[33] See, Maxim Topaz, Leah Shafran-Topaz, and Kathryn H. Bowles, "ICD-9 to ICD-10: Evolution, Revolution, and Current Debates in the United States," *Perspectives in Health Information Management* 10 (2013): 1d. An 11th edition is, as of 2019, being drafted. However, as with all standards in health IT and healthcare, adoption is uneven. Some interlocutors still referred to "ICD-9" codes in their electronic health records when the topic came up.

[34] Structured Documents Work Group."HL7 Implementation Guide for CDA® Release 2: HIV/AIDS Services Report, Release 1 - US Realm." Health Level 7 International, December 2013, 237.

[35] On "tuning" as an activity undertaken by skilled professionals in science and technology to slightly modify tools they use on an ongoing basis so that they continue to function in practice, see, Andrew Pickering, *The Mangle of Practice: Time, Agency, and Science* (Chicago, IL: University of Chicago Press, 1995),14-15.

[36] Gilles Deleuze and Félix Guattari, *What Is Philosophy?*, trans. Hugh Tomlinson and Graham Burchell (New York: Columbia University Press, 1994), 19-32.

[37] On "difference in degree" as categorical difference that links same-with-similar versus "difference in kind" as a mode of distinguishing same-from-different, see, Gilles Deleuze,

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Difference and Repetition, trans. Paul Patton (New York: Columbia University Press, 1994), 238-47.

[38] Interview with Greg Nowitzki, Fulton County IT Manager, 2017.

[39] White House Office of National AIDS Policy (ONAP). “The National HIV/AIDS Strategy for the United States: Updated to 2020.” The White House, July 2015, 4.

[40] In this framing of the nation-state, I invoke – in general terms – Benedict Anderson’s notion of an “imagined community” in the formation of national identity and nationalist discourse: Benedict R. O’G Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism*, Revised edition (London New York: Verso, 2016).

[41] *NHAS 2020*, n.p.

[42] *NHAS* and *NHAS 2020*, *passim*.

[43] See generally: UNAIDS, “Fast Track: Ending the AIDS Epidemic by 2030” (Geneva, Switzerland: UNAIDS, 2014), http://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf; UNAIDS, “Ending AIDS: Progress Towards the 90-90-90 Targets” (Geneva, Switzerland: UNAIDS, July 20, 2017), http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf. See also, Jane M. Kelly et al., “Achieving NHAS 90/90/80 Objectives by 2020: An Interactive Tool Modeling Local HIV Prevalence Projections,” ed. Rasheed Ahmad, *PLOS ONE* 11, no. 7 (July 26, 2016), https://doi.org/10.1371/journal.pone.0156888.

[44] People with AIDS Advisory Committee. “The Denver Principles,” 1983. http://www.actupny.org/documents/denver_principles.pdf.

[45] Interview with Richard Wolitski, then-Acting Director, Office of HIV/AIDS and Infectious Disease Policy, U.S. Department of Health and Human Services July 3rd, 2017.

[46] ONAP, *NHAS*, 10.

[47] ONAP, *NHAS 2020*, 18.

[48] Christopher Glazek, “The C.E.O. of H.I.V.: Michael Weinstein’s AIDS Healthcare Foundation Treats and Enormous Number of Patients - and Makes an Enormous Amount of Money. Is That Why so Many Activists Hate Him?,” *The New York Times Magazine*, April 26, 2017, https://www.nytimes.com/2017/04/26/magazine/the-ceo-of-hiv.html.

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[71] The preeminent example of queer theory's interest in futurity is Muñoz, José Esteban. *Cruising Utopia: The Then and There of Queer Futurity*. Sexual Cultures. New York: New York University Press, 2009.

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[73] Interview with Tori Cooper, June 15th, 2017.

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[74] Interview with Sean Cahill; Interview and conversations with Tori Cooper and other trans health advocates in Atlanta.

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[76] Matt Hennie, "Atlanta Trans Pioneer Cheryl Courtney-Evans Dies," *Project Q Atlanta: Q Magazine*, October 3, 2016, https://www.projectq.us/atlanta/atlanta_trans_pioneer_cheryl_courtney_evans_dies?gid=18032; Patrick Saunders, "Atlanta Transgender Activist Cheryl Courtney-Evans Dies," *The Georgia Voice: The Premier Media Source for LGBTQ Georgia*, October 3, 2016, https://thegavoice.com/news/georgia/atlanta-transgender-activist-cheryl-courtney-evans-dies/.

[77] Interview and correspondence with GDPH epidemiologist, June 2017.

[78] Deleuze and Guattari write about the "absolute limit" as a kind of total freedom and liberty. Reaching absolute limits, such as the undoing of the modern sexual system in the example I consider, "causes the flows to travel in a free state on a desocialized body without organs," *Anti-Oedipus: Capitalism and Schizophrenia*. Minneapolis: University of Minnesota Press, 1983, 246.

Chapter 2: Assembling the "Nationwide Interoperable Health IT Infrastructure": Programmable Futures and Technical Democracy in U.S. Health IT Policy

I. Promise and Failure in Healthcare's Programmable Futures

"With an eye to the future of artificial intelligence and machine learning, as well as the promise of value-based healthcare, ONC's approach to addressing interoperability is to help make all clinical data, including free text data, liquid and accessible."

-Don Rucker, MD, National Coordinator for Health Information Technology
"Automation in Healthcare is Transforming Medicine," October 1st, 2018
Blog of the Health Information and Management Systems Society (HIMSS)[1]

In this chapter, I describe how the U.S. Department of Health and Human Services (HHS) has pursued the construction of what it characterizes as "a nationwide interoperable health IT infrastructure" since 2009. This process has been led by the Office of National Coordinator for Health Information Technology (ONC) in the Office of the HHS Secretary.[2] The construction of the nationwide health IT infrastructure followed primarily from federal mandates in the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) and the 21st Century Cures Act of 2016 ("21st Century Cures," or "Cures").[3]

ONC has driven and harmonized the process of health IT adoption in the United States, creating strategic visioning and implementation documents such as the *Federal Health IT Strategic Plan*, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*, the *Trusted Exchange Framework and Common* Agreement, and by coordinating programs to certify health IT products and distribute incentive payments for health IT utilization and penalties for non-utilization. ONC has worked with the White House, HHS at the all-agency level, the Centers for Medicare and Medicaid Services (CMS), other federal departments such as Defense and Veterans Administration, the private sector, the public health sector, academia, health IT developers, state governments, and other stakeholder groups to foster shared frameworks and goals in the pursuit of nationwide interoperability.[4]

Financially incentivizing the adoption of clinical electronic health records (EHRs) has been the chief aim of this work to date, with EHRs functioning as the backbone of the nationwide infrastructure. The secondary aims have been to encourage healthcare entities to participate in health information exchanges (HIEs) and to adopt uniform interoperability standards to facilitate the movement of data between systems and the circulation of data in an increasingly "liquid" data ecology, with "liquidity" being one of several metaphors for free flow and movement that are increasingly common in "big data" discourses, along with the metaphor of "cloud."[5]

I do not adopt a definition of interoperability. However, Sabina Leonelli's approach to defining data is a useful starting point for developing an analytical definition of interoperability: one that emphasizes the fungible nature and extreme relativity of the concept as a relational construct having primarily to do with the exchange of data between different health entities using health IT standards and organizational processes.[6] This is because my observations of "interoperability" as a concept used by actors in fieldwork and policy analysis has been that – like "data" – "interoperability" is extremely relational, interchangeable with other concepts such as "data exchange" or "transmission," and deeply shaped by the context in which the concept is used. One actor's deployment of "interoperability" aligns with another's use of "health information exchange" – a category of data transmission which some oppose to interoperability or frame as more primitive than "true interoperability," which is discussed as seamless and automated. For some health actors, however "interoperability" can be achieved via any number of modalities – including manual interoperation performed by human actors, which would be framed by most as an antiquated analog process.

Health IT practitioners generally refer to the 1990 definition of interoperability in the *Standard Computer Dictionary* of the Institute of Electrical and Electronics Engineers (IEEE): "the ability of two or more systems or components to exchange information and to use the information that has been exchanged."[7] Another popular definition is one released in 2013 by the Health Information and Management Systems Society (HIMMS): "the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged" and "the ability of health information systems to work together within and across organizational boundaries in order to advance the health status of, and the effective delivery of healthcare for, individuals and communities."[8] At the core of all of these definitions – whether an analytical one emphasizing the fungible nature and relativity of the concept or a practical definition used by engineers – is the ability of organizations to use systems to exchange information in a mutually-beneficial and useful fashion.

Drawing on digital studies' scholar Wendy Chun's concept of "programmability," I argue that HHS's imagined nationwide infrastructure constitutes a techno-utopian "programmed vision" of total and seamless digital interconnectivity, information accessibility, and data interoperability in U.S. healthcare. HHS's pursuit of a nationwide interoperable health IT infrastructure reflects an all-encompassing view rooted in determinist logics that are typical of the late 20th and early 21st centuries, wherein proponents of digital technology operate on the assumption that computers and their users can literally program future outcomes by manipulating data gathered in the past and on an ongoing basis in the present.[9] Information extracted from available data are then used to build programs of action to solve problems or improve processes.

In healthcare, this is often done with the aim of reducing costs, improving quality of care, "empowering" health IT users (from doctors to patients), and realizing "personalized" medicine and "value-based" care.[10]

The grounding assumption of the vision of total interoperability in U.S. health IT is that access to large amounts of data and the ability to make sense of these data using health IT systems will allow healthcare organizations – even small private providers – to create models of the present and of ideal futures, and therefore to materialize desired outcomes by building plans around the futures they envision. In the eyes of proponents, a transformed "health IT ecosystem" will have the effect of creating a "person-centered" and "learning" health system where resources will be able to be allocated with greater precision and at a lower overall cost to the healthcare system.[11] Per advocates, the new health information ecology will transform clinical medicine, biomedical research, and public health practice by linking databases to one another, creating decision-support systems, and giving organizations the capacity to manipulate their own data in new ways, to receive data from other sources, and to send data to other actors who request or need it – and, critically, to ensure that this can happen "without special effort on the part of the user."[12] This chapter is chiefly focused on illuminating and explaining how this programmed vision has been pursued by HHS – particularly through ONC, which is charged with coordinating the national health IT strategy across federal and non-federal actors in healthcare. In explaining this vision and its effects, the chapter builds bridges between developments in health IT generally in order to provide a foundation to understand transformations in the standardization of sexual orientation and gender identity in federal health IT policy and the governance HIV using new health IT systems, which are the focuses of subsequent dissertation chapters of the dissertation.

The chapter's secondary focus is a consideration of the curious contradictions contained within the all-encompassing vision of a fully interconnected healthcare system. Specifically, nearly every organization or actor that is pursuing, contributing to, or committed to building interoperability – whether they are a visionary policy leader or a local systems administrator or quality manager – does their work with the knowledge that the future they desire and labor continuously to build will never fully materialize. The project of total interconnectivity in healthcare will always remain a work in progress and an ever-deferred collective project. This is because all interoperability projects are localized – situated in what Yanni Alexander Loukissas calls "data settings" made up of institutional and organizational constraints, the existence of which depend on the constant work of individual programmers and IT personnel aimed at debugging, patching, fixing, and keeping technologies functional and operational.[13] The need to constantly be responsive to technological failure is built into the baseline possibility of technological success. This is especially true where automated interoperability is the goal, since interoperation requires different systems – which are often built by different firms, maintained by different teams, and which perform different functions – to exchange information. Maintaining these linkages – when doing so is possible – takes a great deal of labor, time, and other forms of organizational investment. The appearance of smooth interoperability relies on a multiplicity of quotidian failures, and these failures often mean that the futures health IT systems and interoperable infrastructures produce are unexpectedly different than the ones envisioned at the outset.

This is the sociotechnical basis of all programmed visions. Per Chun, they are partially brought forth into existence: actors' labor and the investment of resources to build infrastructures designed to produce particular outcomes do, in fact, yield results that at least resemble actors' intentions. However, the futures actors work to realize also fail to fully be achieved. This is not only because totally achieving pre-planned outcomes is a rare occurrence in the human experience generally, but because of the specific features of the computers, interfaces, servers, and other digital technologies that make everyday failure a central part of the process of achieving any end-goal using these technologies.[14] Programmed futurities, in their failure to materialize fully as the result of both large-scale and everyday technological failures, open doors to unanticipated and unplanned outcomes that partly reflect the future initially conceptualized and partly diverge from that future. This is the double-movement of the programmable futures offered by digital technology: they simultaneously move toward realization and failure.[15] This is not just another way of speaking about human striving or organizational development. Rather, it is specific to contemporary forms of technological governmentality as they find expression in computing technologies. Programmed visions of seamless and total interconnectivity are sustained in practice by a multiplicity of quotidian failures that are specific to computers, interfaces, and the organizations and people who use them. On this, Chun writes:

> By interacting with [digital] interfaces, we are also mapped: data-driven machine learning algorithms process our collective data traces in order to discover underlying patterns (this process reveals that our computers are now more profound programmers than their human counterparts). This logic of programmability…is not limited to computer technology; it also stems from and bleeds everywhere…Crucially, though, this knowledge is also based on a profound ignorance or ambiguity: our computers execute in unforeseen ways, the future opens to the unexpected. Because of this, any programmed vision will always be inadequate, will always give way to another future.[16]

The tone used to communicate programed visions in health IT oscillates wildly. Those high on visionary or administrative ladders tend to set trajectories in broad strokes, glossing over the everyday failures embedded in the pursuit of total interconnectivity, while those situated lower on organizational hierarchies live with the reality of technological failure every day.

In 2015, then-ONC National Coordinator Karen DeSalvo struck a utopian tone in her introductory letter to *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*, released after a year-long "visioning" process. In her opening remarks outlining ONC's programmed vision of national interoperability, DeSalvo acknowledged the ongoing work of programming interoperable futures in healthcare, treating total interoperability as both end-point and endless process. She insists that total nationwide interoperability must be achieved, but also says that this will take constant work from a broad range of stakeholders:

> Public and private stakeholders will need to do more than just address our policies and technical approaches to achieve real, meaningful, seamless interoperability – we will need to change our culture. We will all need to commit to actions that will define how we work together on behalf of the American public to empower them to improve their health. We are committed to helping consumers easily and securely access their electronic health information when and where they need it most; to enabling individual health information to be shared with other providers and refrain from information blocking; and to implementing federally recognized, national interoperability standards and policies so that we are no longer competing between standards, but rather innovating on a set of core standards. We hope the private sector will join us in this pledge…Thank you all in advance for your continued dedication and work on the advancement of nationwide interoperability as a means of creating an open, connected community, best able to serve the health needs of all Americans.[17]

As DeSalvo's statement and the health IT discourse that one encounters when attending industry conferences or working with visionary health IT policy documents or proponents shows, the knowledge that nationwide interoperability will never be a completed project is hard-wired into its dogged pursuit: nationwide interoperability must be achieved, and/but, we will always also always be working to reach it.

The deeper one travels into the guts of a health infrastructure, the more issues related to technological failure and what Martin French calls "informatic practice" arise:

> the sum of everyday activity, by assemblages of humans and non-humans, that makes information a material reality in quotidian life…the work of scrawling a pencil across paper, the function of booting up a laptop, the artful composition of characters in a free-text field, the writing of data to discs, the transit of signals through a network, and a great

deal of other everyday practices that cause information to manifest.[18]

For providers who wrangle with uncooperative interfaces as they key in data, middle-rung IT administrators who struggle constantly to fix bugs and re-establish broken data feeds between systems and organizations, and clerical quality assurance personnel who spend time assessing the validity of clinical EHR data before its quality can be attested to by the organization, the necessary (and continuous) failure of the programmed vision of total information liquidity is more concrete than it is for policy visionaries like DeSalvo whose daily work does not require them to face the quotidian reality of constant technological failure.[19]

Unlike policy professionals or high-level leadership who do not have to work with systems daily, these workers face and deal with technological failure for most of their working hours, as they are forced to clean datasets, debug programs, and deal with the everyday reality of technological failure. It is apparent (often painfully so) to these personnel that any sort of sustained interoperability or functionality of any health IT system – let alone a "nationwide interoperable infrastructure" – will be fleeting, because such infrastructures take so much labor, work, and updated technology to maintain, and because they are ultimately only as strong and robust as the quality and volume of resources (organizational, human, technical, and financial) that are invested into them. This programmed vision is a double-bind: it is unachievable from the start, but lures actors in and compels their participation with local, temporary achievements so as to bind them to the larger program of nationwide interoperability, which is inexorably destined to fail.

Historicizing Total Interoperability, and Who Makes Healthcare Interoperable?

The vision of a totally interconnected health IT infrastructure is hardly new or reducible to an outgrowth of "big data" discourses and other styles of digital utopianism that have dominated the second decade of the 21st century. Rather, like all programmed visions, the pursuit of total interoperability in healthcare is “linked intimately to the past, to computers as capable of being the future because, based on past data, they shape and predict it.”[20] The “dream of programmability” is “a return to a world of Laplacean determinism in which an all-knowing intelligence can comprehend the future by apprehending the past and present.”[21] These sorts of dreams are traceable to the early modern period and patterns of technoscientific development that accelerated in the late 19th century, continued into the 20th, and achieved even further velocity in the 1960s when contemporary computing and associated ideologies calcified.[22]

Electronic medical records have existed in some form since the 1960s. Even in their earliest iterations, these tools were associated with utopian dreams: programmed visions of an interconnected healthcare system where data would move easily between different actors and organizations, therein improving the quality of care, making the healthcare delivery more efficient, and empowering providers and patients.[23] A genealogy of health IT that would draw upon the insights of digital studies, histories of computing, the history of standards, and histories of 20th century biomedicalization would contribute more to the collective understanding of current challenges in health technology and healthcare delivery than any other study of the subject. While that is not my project here, this section historicizes my contributions.

Per health informatics professional Micky Tripathi, “from the moment technological advances moved data entry from punch cards to keyboards, and data display from printed results to video display terminals, innovative physician tinkerers around the country have seized on the opportunity to improve healthcare delivery.”[24] Tripathi says that “the irrepressible Dr. Clem McDonald from the Regenstrief Institute captured it best with his rare gift for combining insight, vision, and straight-talk,” quoting from a 1999 article by McDonald in which he says that:

> Our goal was to solve three problems: (1) to eliminate the logistical problems of the paper records by making clinical data immediately available to authorized users wherever they are – no more unavailable or undecipherable clinical records; (2) to reduce the work of clinical book keeping required to manage patients – no more missed diagnoses when laboratory evidence shouts its existence, no more forgetting about required preventive care; (3) to make the informational "gold" in the medical record accessible to clinical, epidemiological, outcomes and management research.[25]

While these are now the motivating visions of health IT in the United States, Regenstrief – an academic medical research center in Indianapolis that maintains the Logical Observation Identifiers Names and Codes (LOINC) set of health IT standards – has been pursuing its own programmed vision of health data liquidity since in 1972.[26] It is one of several such projects in the history of medical records identified by Tripathi, including a similar project at Massachusetts General Hospital that began in 1968.

Further, like other digital revolutions with roots in early histories of computing, software programming, and hardware manufacture, the contemporary digital health IT revolution is largely enabled workers who toil in obscurity performing repetitive tasks – often on paper, or translating between paper and digital interfaces manually – while health informaticists and policy leaders receive most of the plaudits. This theme cuts across this dissertation, and in this chapter and chapter four, I explore both these tendencies: to emphasize seamless interconnectivity in policy discourses, while healthcare workers closer to the ground experience everyday failures.

The existence of invisible informatic workforces also reflects the ongoing reliance of "digital" revolutions on not only analog processes, but also gendered, racialized, and exploitative labor practices. These issues are longstanding in digital history. Informative examples from computing history include all-female teams of punch-card programmers at the Electronic Numerical Integrator and Computer (ENIAC) project, Fairchild Semiconductor plants in New

Mexico built explicitly to employ indigenous women's craftsmanship in microchip manufacturing, and understandings of computing as "women's work" in England.[27]

The vision and actual project of building nationwide interoperability did not come from a set of visionary policy minds who crafted the HITECH Act of 2009. Rather, the ideas in this law emerged from interwoven genealogies in biomedicalization, the development of computing technologies, and novel data futurities. This programmed vision is at least as old as the concept of electronic medical records. It is ultimately grounded in much more longstanding organizations of the labor market and emerges from systems of thought and logics of scientific progress which Bruno Latour and STS scholars have spent decades articulating as the driving engines of modernity, technoscientific development, and histories of computing and informatics.[28]

II. Legal Bases and Key Metaphors for Visioning and Building the Nationwide Health IT Infrastructure, 2009-2018

The Department of Health and Human Services' (HHS) efforts to build the nationwide health IT infrastructure followed from a mandate in the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH). HITECH was a spending package of over $30 billion that was designed primarily to promote the adoption and utilization of electronic health records (EHRs) and, secondarily, other health IT systems such as health information exchanges (HIEs). Modalities used to achieve this included incentive payments to providers for EHR utilization, the construction of state and regional HIEs and "health IT extension centers," and the fostering of consensus among stakeholders in the national community of health IT stakeholders.[29]

HITECH reconstituted the Office of the National Coordinator for Health Information Technology (ONC), which was first opened in 2004 as a coordinating body with little influence or power to effectuate policy. HITECH vested ONC with a broad array of powers, chief among which was to coordinate “the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information.”[30] HITECH was a major component of the American Recovery and Reinvestment Act of 2009 (ARRA). ARRA was one of the largest and most comprehensive spending bills in history, appropriating over $840 billion to reinvigorate the American economy following the 2008 financial crisis.[31] Often referred to as “the stimulus package,” ARRA was the first legislative achievement of the Obama administration and the Democratic-controlled 111th Congress. In 2016, the nationwide infrastructural aims of HITECH would be enhanced by the 21st Century Cures Act (“21st Century Cures,” or “Cures”). Cures contained an even stronger interoperability mandate aimed at fostering total information liquidity in healthcare.[32]

Despite major hurdles and shortcomings – many of which are documented in a series of Government Accountability Office (GAO) reports – I show that HHS has largely been successful in its efforts to encourage the adoption of health IT systems among a wide array of health actors, essentially achieving its goal of a transformed and digitized healthcare system if not “nationwide interoperability.” In several waves of regulatory development, HHS has built an approximation of the nationwide interoperability infrastructure that it was charged with building by HITECH in 2009 and 21st Century Cures in 2016. HHS’s programmed vision has genuinely induced significant transformations in how services are administered and how health data are utilized in nearly every area of healthcare. These range from how patient data are collected and used by individual providers, to how public health data are generated and linked with clinical data sets, and how EHR data are used for secondary research purposes.

In this section, I explain some of the motivating metaphors that drove this programmed vision. I do so in order to provide a "10,000-foot view" or a macro perspective of this immensely complex collection of processes that have constituted the interoperability vision in federal policy and local practice – in my case, in Atlanta's clinical HIV/AIDS infrastructure. Methodologically, I follow the lead of Kathrin M. Cresswell and colleagues in suggesting that "[studying] IT in healthcare is…in many ways like trying to 'hit a moving target'; it requires different social theories than were present before its rise" both because the environment is so rapidly changing and because health IT policy and practice give rise to new social forms and forms of policy-making.[33] In first attending to the metaphors that motivate the policymaking strategies that I examine, I draw upon Tom Boellstorff's insight that while "[m]etaphors are not all-determining…their entailments matter, shaping and revealing pathways of thought and practice" in the construction of realities.[34] Exploring these metaphors provides context for detailed explanations of the main regulatory strategies and policy mechanisms that ONC has employed to achieve the programmed vision of total interoperability in healthcare.

Diagramming Nationwide Interoperability: ONC's "Health IT Ecosystem"

A close analysis of a graphical representation of what ONC characterizes as a "Health IT Ecosystem," illuminates the totalizing programmed vision of nationwide interoperability advanced by HHS.[35] Presented as part of a solicitation for public comments on a ten-year interoperability "vision paper," the graphic attempts to present an ideal vision of what ONC refers to when it says that its aim is to construct a "nationwide interoperable health IT infrastructure."

Figure 2.1. ONC's "Health IT Ecosystem" Diagram from "Connecting Health and Care for the Nation: A Ten-Year Vision to Achieve an Interoperable Health IT Infrastructure"

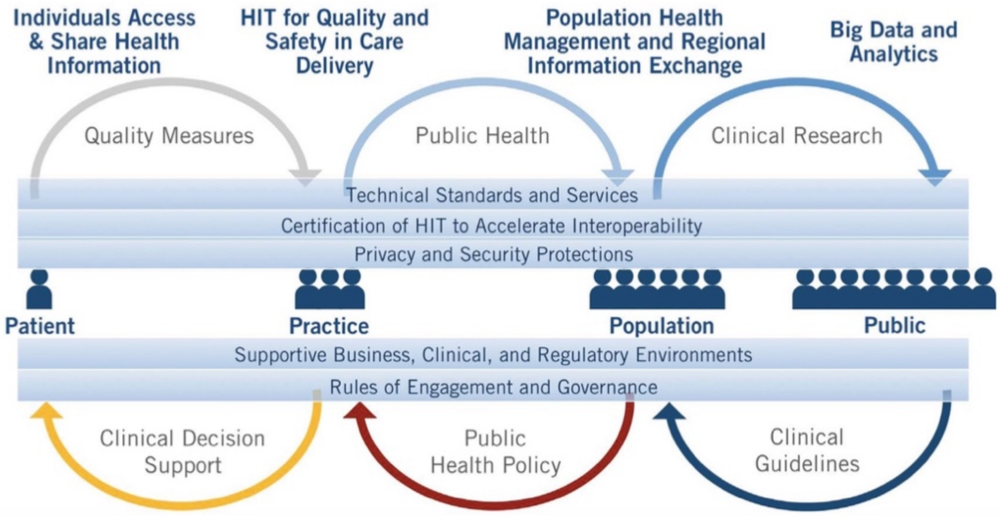


Figure 1. Health IT Ecosystem

Because this image was part of a call for public comments, the arrows, layers, and collections of silhouettes in different groupings encourage the viewer to interact with the diagram and to envision themselves as an actor situated within one or more of its sections, or even moving between them – traveling along one or more of the arrows. The diagram is therefore also an invitation. It was presented at the beginning of the 2014 document *Connecting Health and Care for the Nation: A Ten-Year Vision to Achieve an Interoperable Health IT Infrastructure*. This was itself the first blueprint for the *Nationwide Interoperability Roadmap*, released by ONC with feedback from stakeholders incorporated into it.

The graphic offers a schematic of ONC's idealized vision of an interoperable health IT system, presenting all the core technical, policy, and human building blocks of such a system and the stakeholders that would need to be involved in building and sustaining one like it.[36] Since it is part of a solicitation for input, ONC provides constituents of its vision of total interconnectivity with a literal diagrammatic framework to cognitively place themselves in while composing their feedback and conceptualizing their potential role in creating local and national interoperability. The diagram is a call both to project or imagine and to enact a future.[37] The graphic is designed to envision, to hail, and thus to enact or materialize the many constituencies of the health IT ecosystem that it posits. In doing so, the graphic plays a central role in building up and sustaining an imaginary of total interoperability that can be shared among disparate actors in this space and to materialize localized versions of this imaginary, both in the minds of stakeholders, and eventually in reality – although the "achievement" of this vision will always be (as I have argued and will further demonstrate), temporary, fleeting, and riven with necessary failure.[38]

The Health IT Ecosystem graphic serves as an ideal example of a diagrammatic method at work on ONC's part, having been produced so that stakeholders could spend time with it and employ it as a tool in developing fuller conceptualizations of how something as lofty as a "nationwide interoperable health IT infrastructure" might be constituted, and how they might take part in this work, either through participation in federal policymaking or as actors in their local health IT ecologies. In the same way, I describe this dissertation's method as diagrammatic.[39] These diagrams both envision and produce healthcare's programmable futures.

The diagram is a representation of the healthcare system from the perspective of a future interoperable health IT infrastructure as imagined by ONC. It attempts to reach out to the full range of constituents, policies, standards, flows, and other entities and processes that could collectively constitute a nationwide interoperable health IT infrastructure or any localized "health IT ecosystem" where systems and data are fully "liquid." As the viewer's eyes move from left to right, the scale of the system, groups of persons, or processes grows. In this way, it can be viewed as a whole, or as a series of vertically arranged sections, or in any number of other segments-in-motions – always, per the arrows (and as with "liquid" or "clouds") in motion.

The words above the diagram describe scaled processes, from the micro (individual patients sharing data) to the most maco ("big data"). The silhouettes in the middle represent different collectives of human actors, from the singular unit of the "patient" to the area of "practice" which encompasses both clinical and public health practitioners, to "populations" conceptualized as definable sets of people, to the grand notion of "the public" in the mode of what Michael Warner calls the "mass public" or what John Dewey calls "the great community," "saturated and regulated by mutual interests in shared meanings."[40]

The blue bars in the middle represent technical, legal, regulatory, and organizational "building blocks" – per ONC's framing – that function as translators between different actors in the imagined ecology. These actors – made up of assemblages of organizations, technologies, and people – hold the network together.[41] The bars can be read from top to bottom, from most technical ("standards") to least technical ("governance" practices). These binding agents – which take the form of regulatory strategies and health IT policy-making mechanisms – are the areas I focus on in the remainder of this section and the next.

The Toddler Matures into a Unicorn: A Perfect Metaphor for Health IT

In a 2016 presentation, Megan Douglas, then-Associate Project Director of Health IT Policy at Morehouse School of Medicine, gave a presentation offering her take on the difference between "health information exchange" and "interoperability." For Douglas, like many health IT policy professionals, the difference between these two things is simple enough to describe. An instance of "health information exchange" occurs when any one entity successfully transmits data to another via any mode (whether over a digital exchange network, phone call, or facsimile).

Interoperability, on the other hand, denotes for Douglas and other like her “seamless” or “liquid” movement of data between two or more systems at the moment it is needed “without special effort” on the part of the user.[42] This is the most common position that I encountered among health IT professionals when studying and discussing the difference between health information exchange (HIE) and interoperability. Further, HIE is often framed as a stage of development in an increasingly mature and robust healthcare system that will eventually become totally “interoperable.”

To illustrate where Douglas thought health IT was in 2016 (the era of “HIE”) versus where it was headed in the future (the era of “interoperability”), she employed two metaphors. Health IT in 2016 was a toddler in its “terrible twos” (uncooperative and difficult), but was on its way toward becoming a “unicorn”: a magic, mythical beast of great beauty and strength. “Unicorn” also happens to be a label applied to tech startup firms with valuations over $1 billion.[43] “Many have heard about it, but few have seen it,” pronounced Douglas’s “Interoperability Unicorn” slide.[44]

Figure 2.2. Slides: “Almost-Standard Gauge: Misadventures in Interoperability,” by Megan Douglas at the 3rd Annual Policy Prescriptions Symposium in 2016.


Health IT is in its...

The Interoperability Unicorn

“Many have heard about it, but few have seen it”

Douglas using the idea of a toddler maturing into a unicorn as a metaphor for the development of an interoperable health IT infrastructure is demonstrative of the doomed utopianism that characterizes the programmed vision that drives the development of Douglas's object of analysis: the concept and promise of interoperability and nationwide interoperability. Her presentation takes the viewer into the realm of nightmare and abject failure (toddlers often poop on themselves and rarely do what they are told) as well as unreachable utopic fantasy (unicorns are shimmering, dazzling, mythological creatures – not to mention fictitious).

On the one hand, the maturation of a toddler implies a conceptualization of development and growth that reflects heteronormative assumptions about the human life-course, and applies these to how health IT standards "mature" as they are used, especially when they are endorsed or made mandatory by major institutions such as ONC. On the other hand, human toddlers (no matter how queer they are or become during adolescence and adulthood) do not (ever) grow up to be living-and-breathing unicorns.

In most contexts, this would make Douglas's overall metaphor a bad one. However, in the U.S. health IT context, a human toddler maturing into a mythic unicorn is the perfect metaphor for the trajectory set by ONC, the federal government, and major private institutions that have endorsed the nationwide interoperability vision.

The growth of a human child without access to speech or intestinal continence into a mythical beast with otherworldly healing properties and powers to cleanse large bodies of water (per legend) is an apt analogy for the task of building a nationwide health IT infrastructure. Converting a healthcare system from one mediated almost entirely by paper records to one in which providers employ electronic records in a basic way, and then into a milieu where "all clinical data, including free text data, [are] liquid and accessible" "without special effort on the part of the user" and of high quality in just over a decade (per ONC's various timelines) is a task that practitioners themselves recognize is impossible.[45] Yet they work to achieve it, still, and often fervently insist that it will come to pass, even as they lament the project's constant and inevitable failure.

While Douglas's metaphor does not cohere in the normal way that metaphors "should," it works well as a metaphor for health IT precisely because the impossibility of ever reaching the utopian programmable future that nationwide interoperability promises is written into its pursuit.

What is a Health IT Standard and What is a U.S. Federal Health IT Standards Policy?: Similar Appearances, Critical Differences

A health IT standard and a health IT standard in U.S. federal health IT policy are two very different, but intimately related, creatures. Where health IT standards set mostly by private entities are technical specifications for the collection, storage, and exchange of health data, health IT standards policies function more like rules of the road. Policies determine which privately-maintained specifications health actors must use, or they identify preferred standards.

A "health IT standard," presented without further qualification or context, is merely a technical specification of any kind, associated with an underlying definition or term, that is maintained in a central repository or index by an organization that is recognized as authoritative for setting and maintaining standards for the collection, storage, and/or exchange of health data. The main sets of standards and standards-setting organizations used in U.S. health IT are the Logical Observation Identifiers Names and Codes (LOINC) maintained by the Regenstrief Institute, Systematized Nomenclature of Medicine – Clinical Terms (SNOMET CT) maintained by SNOMED International, and Health Level-7 (HL7). LOINC and SNOMED CT codes refer to capture and storage standards, whereas HL7 standards "provide a framework (and related standards) for the exchange, integration, sharing, and retrieval of electronic health information" using other standards, determining what format data must take during transmission between one entity and another (whether this exchange occurs directly between two entities or over a third-party health information exchange network).[46]

Each of these organizations maintains what are essentially extensive dictionaries and indices of numerical codes that are associated with specific diagnoses, medications, services, billing matters, and administrative processes. Health IT standards often refer to other standards. For example, HL-7 standards refer to SNOMED CT and LOINC standards, which in turn refer to diagnostic codes in the International Classification of Diseases (ICD, soon entering its 11th edition) or billing codes in the Current Procedural Terminology (CPT) maintained by the American Medical Association (AMA) and endorsed by the Centers for Medicare and Medicaid Services (CMS), the largest healthcare payer in the United States. Organizations that make health IT standards are generally accredited by the International Standards Organization (ISO), International Electrotechnical Commission (IEC), National Institute of Standards and Technology (NIST), and/or other entities that vest them with authority to perform standards-setting functions in the health marketplace.

Put another way, health IT standards are made by private institutions from whole cloth, or, more exactly, from known issues or needs that are articulated to them by healthcare entities or other stakeholders who participate in standards-setting processes led by private organizations. Federal agencies, particularly NIST, the National Library of Medicine (NLM), and ONC, are often involved. However, the work of making new health IT standards is different from the policymaking role that ONC plays in regard to determining which standards are required or preferred. Rather, ONC, as its name implies, "coordinates" between many entities that maintain health IT standards and other entities to establish what standards are required, recommended, useful, and what levels of adoption and maturity a standard can be said to have achieved.

A “health IT standard in U.S. federal health IT policy” is therefore not as much a standard as it is a regulation or technical guidance about standards. A health IT standard in U.S. federal health IT policy is the official recognition, in written policy, that one or more health IT standards that are maintained by one or more accredited entities, fulfils one or more informational needs in ensuring the standardization of a specific health data element during the capture, storage, and exchange of that data. HHS and other arms of the U.S. federal government are not as much in the business of making standards as they are in deeming certain standards worthy, and others less so. Worthiness and maturity are often very murky in this terrain, but are usually determined by the attestation of a standard’s functionality in practice by key stakeholders during policymaking processes led by ONC and cognate agencies such as the National Library of Medicine, which is “the coordinating body for clinical terminology standards within HHS.”[47]

Whereas health IT standards are simply codes associated with definitions that facilitate the collection, storage, and exchange of specific data elements in a health IT system or over an exchange network, federal health IT standards are policies that refer to standards. Federal health IT standards policies, rather than providing specifications themselves, offer direction or directives to entities about which standards work in practice, which standards entities ought to employ in practice, and, in some cases, which standards entities – such as health IT product developers seeking federal certification – are required to use.

Health IT standards function to facilitate the useful capture, storage, and exchange of information between a wide variety of actors. A developer of EHRs or other health IT products that facilitate the capture and exchange of information, a member of the informatics staff of a healthcare organization, a laboratory that is required to receive electronic notifications and physical samples from that healthcare organization and then to transmit results back to the provider and potentially to other entities such as public health departments, and a nurse or physician who collects a physical sample and marks certain boxes in an EHR during the course of ordering tests, all interact with or utilize the same health IT standard during the ordering of a particular routine test.

In the "technological drama" just described, it is the standard that facilitates the interoperation of these different human and nonhuman actors.[48] The policy recommending or requiring the use of a particular standards, on the other hand, supports continuity and functionality across contexts, thus working to ensure that disparate actors in specific technological milieus are employing the same standards or, put another way, speaking the same language, and thus able to meaningfully coordinate and act in concert with one another.

Without written policies that provide guidance and directives about standards-utilization, the exchange of health information on a wide scale could not occur. Without an entity vested with powers to direct actors in the health system to use specific standards, there would be no agreed-upon vocabulary to facilitate the transmission of data from one entity to another in a manner that would communicate information in a clinically useful way. ONC fills this role in U.S. healthcare, as the coordinating entity within HHS that makes health IT standards policies and builds consensus around which standards industry and other actors feel ought to be used. Now, I turn to the regulatory strategies and policymaking mechanisms that ONC uses to do this work.

III. ONC's Regulatory Strategies: ONC as Public Sphere and Decider

In this section, I detail the two main regulatory strategies that the Department of Health and Human Services (HHS) has utilized to build nationwide interoperability since 2009, working primarily through the Office of the Coordinator for Health Information Technology (ONC) and secondarily through the Centers for Medicare and Medicaid Services (CMS). The next section focuses on the department's policy-setting mechanisms.

No comprehensive account of the complex array of overlapping regulatory programs that govern and shape health IT utilization exists, and I do not present one here. Health IT's constituents, stakeholders, and institutional drivers are too numerous and disparate to attempt this. Instead, I present a "partial perspective" that accounts for the trajectory of health IT in the United States by focusing on its main drivers while also not reducing the construction of the national health IT infrastructure to mere effects of these primary developmental engines.[49] I accomplish this by focusing on the main regulatory strategies, policy mechanisms, and programs that HHS has operated since 2009 to enact its programmed vision of nationwide interoperability.

The emergence of a diversity of variously accessible forums hosted by ONC that rely on stakeholder input using rhetorical persuasion in the normal model of deliberative policymaking, as well as stakeholder participation through demonstration or experimentation in digital environments, is a significant development in the trajectory of contemporary health governance. It is an innovation in what Science and Technology Studies (STS) scholar Michel Callon and his colleagues call "technical democracy." Technical democracy involves the cultivation of "*hybrid forums*, in which the direction given to research and the modes of application of its results are discussed, uncertainties predominate, and everyone contributes information and knowledge that enrich the discussion."[50] ONC is perhaps best understood as an assemblage of such hybrid forums that fulfill its role of technical, regulatory, and economic coordination among health IT stakeholders – many of which are competitors in the market, but whose systems must interoperate in order for their products to work and for the nationwide interoperability vision to be meaningfully pursued.

The first regulatory strategy ONC utilizes is the staging of hybrid forums that facilitate the deliberate cultivation of consensus and dialogue among key stakeholders in health IT as well as the demonstration of technical know-how by key stakeholders on platforms the ONC maintains or supports. Consensus-building and informational exchange are opportunities for industry and other groups to voice their positions on issues that they deem important or which directly affect them. They also allow stakeholders to showcase approaches to specific problems in health IT that work or do not work in practice. By acting as a deliberative public sphere mostly populated by technical experts and by supporting opportunities for technical experimentation and demonstration that allow practitioners in the health IT community to validate their technical competencies and the validity of standards, ONC stages new models of hybrid technical governance.

ONC also works to ensure that all groups and individuals that have the interest and capacity to do so have meaningful opportunities to contribute to the development of policies by both marshaling persuasive arguments for their preferred standards and by demonstrating their technical know-how as a mode of persuasion. All these efforts are aimed at shoring up consensus and best practices in health IT, which are coextensive with one another in infrastructures that require shared norms about governance and technical interoperability.[51]

The second overall regulatory strategy is the issuance of binding regulatory decisions and non-binding regulatory guidance by ONC and cognate agencies, particularly the Centers for Medicare and Medicaid Services (CMS). Decision-making and the issuance of guidance take the form of rules issued by one or more agencies, binding criteria for health IT product development, and/or other technical recommendations. Decisions and guidance are generally published after one or more periods of dialogue, public comment, consensus-building, information-gathering, and technical demonstration. However, by exercising its decision-making and trajectory-setting power, ONC and partner agencies pick winners and losers in the health IT economy. Ultimately, ONC does not bind itself to the consensus that it cultivates, but treats it as guidance in making decisions and setting policy.

Regulatory Strategy 1, ONC and Hybrid Governance: Deliberation and Demonstration among Many Stakeholders

The first major regulatory strategy used by ONC to build the nationwide health IT infrastructure has been to facilitate ongoing dialogue and discursive exchange among health IT stakeholders. These efforts are mainly aimed at cultivating consensus among major actors in what is conceptualized as a competitive marketplace populated by rational actors with an interest in economically out-performing others in the context of cooperation regarding issues of data sharing and the interoperability of systems. ONC utilizes consensus to build supportive environments for the issuance and uptake of binding regulations and nonbinding technical guidance and recommendations.

Therefore, in addition to being the central entity coordinating the development of health IT policy and infrastructure in the United States, ONC also imagines itself as the key facilitator of a kind of health IT-specific public sphere for deliberative argument and discussion by stakeholders. ONC also builds and supports platforms, “sandbox,” and “proving ground”-style environments for healthcare organizations, health IT product developers, and other stakeholders to experiment with standards and submit the results of their attempts to use standards or products. This is a kind of hybrid governing strategy. It is hybrid in the Callon-ian sense, in that it involves holding open hybrid forums for many different kinds of stakeholders with varying expertise to participate in debate and deliberation. However, it is also a formal hybrid, allowing stakeholders to use multiple methods of persuasion that are both discursive/dialogic and technical/demonstrative in nature.

ONC functions as a relatively open multi-platform assemblage or environment set up for information sharing, debate, and experimentation among experts, practitioners, and stakeholders in a highly technical domain such as health IT. ONC elicits not only stakeholders' discursive participation, but also the use of their technical skills to demonstrate either arguments or the functionality of a technology or standards in experiment- or demonstration-based contexts. ONC is a prime example of an institution designed to enact Callon-style technical democracy. It facilitates broad-based participation and demonstrations of expertise in a persuasive mode via both "know-that" and "know-how" among builders and non-technical policy professionals.[52]

ONC imagines health IT's constituents as a hugely diverse and in-principle-limitless array of actors. Before issuing regulations or publishing guidance, ONC wants as many stakeholders as possible to be on board with the core elements of HHS's regulatory programs and the general trajectory of health IT, or at the very least to be informed. This is a kind of neoliberal governmentality where the state is envisioned as primarily responsive to the needs of private actors, as responsible for opening up new markets for industries, and where all participants are conceptualized as free and rational actors in a competitive market.[53]

The strategies used by ONC and HHS to facilitate discursive exchange and determine consensus exist on a continuum: from formal, high-stakes processes such as public comment periods that take place after Notices of Proposed Rulemaking are published in the Federal Register and eventually become binding regulations, or when drafts of documents such as the

Roadmap are published; to very informal, low-stakes communication such as conversations between individuals in the hallway at industry conferences or via email and phone correspondence.

Official advisory committees, task forces, and working groups are one of the primary mechanisms used by ONC to foster dialogue and cultivate consensus among stakeholders. These entities have names like the Health Information Technology Advisory Committee, the Health IT Policy Committee, the Health IT Standards Committee, and the Interoperability Standards Priority Task Force. They are made up of leading members of the healthcare industry, health IT product developers, standards-setting entities, philanthropy, academia, government, and other key areas of the health IT ecosystem. The primary advisory bodies are usually authorized or required by legislation such as HITECH and 21st Century Cures, with others being created on an *ad hoc* basis.[54] They meet regularly and give ongoing informal guidance to ONC, as well as formal written recommendations.[55] In turn, members communicate ONC's priorities and needs back to key actors in their sector.

In addition to being venues for the cultivation of consensus among key health IT actors, advisory committees are also designed to reflect the interests of different political parties and branches of government. This is primarily reflected in who has power to appoint members. For example, the Health Information Technology Advisory Committee must be "comprised of:

- No fewer than 2 members are advocates for patients or consumers of health information technology;
- 3 members are appointed by the HHS Secretary,
    - 1 of whom shall be appointed to represent the Department of Health and Human Services
    - 1 of whom shall be a public health official
- 2 members are appointed by the majority leader of the Senate;
- 2 members are appointed by the minority leader of the Senate;
- 2 members are appointed by the Speaker of the House of Representatives;
- 2 members are appointed by the minority leader of the House of Representatives"[56]

In addition to these statutory requirements, ONC works to ensure that its official advisory committees reflect a diversity of interests and perspectives within the industry, and touts its pluralistic makeup as a strength. For example, the archived website of the Health IT Standards Committee says that, during its existence, the

> [c]ommittee's membership reflected a broad range of stakeholders, including providers, ancillary healthcare workers, consumers, purchasers, health plans, technology vendors, researchers, relevant federal agencies, and individuals with technical expertise on health care quality, privacy and security, and on the electronic exchange and use of health information.[57]

Given the methods for making appointments to these advisory boards, and their potential impact on health IT policy as high-level advisor bodies to ONC, there are major barriers to membership and full participation in their work. While anyone can attend meetings (which are generally webcast), in order to serve on them a person must be an established expert and have the approval of a political official.[58]

While official ONC advisory committees are relatively exclusive, ONC offers many other opportunities for stakeholders to provide public comment and input on both proposed and existing regulations and standards that have much lower barriers to entry. Comment-seeking processes are usually conducted following the release of an early version of a non-binding guideline document or a rule that could eventually be proposed in the Federal Register, where federal regulations are proposed, commented on by stakeholders, and issued by agencies. Rather than the formal process of uploading comments to the Federal Register via its portal, informal public comment periods usually take place via email submission or webform directly to ONC staff; comment periods are made known through postings online and through emails sent to stakeholders and then circulated among practitioners. Some public comment periods are now effectively open in perpetuity, such as the interactive *Interoperability Standards Advisory* website.[59] Currently, the *Interoperability Standards Advisory* has an official annual comment period and an annually-published "reference edition." However, the *Interoperability Standards Advisory* also allows for year-round public comment through comment sections on its website; each standard referred to in the *Advisory* has its own such comment section.

ONC also convenes recurring and *ad hoc* conferences with keynote speakers, plenary sessions, networking opportunities, panel feedback sessions, and developer-focused "hackathon"-style gatherings. The office and other agencies within HHS also sponsor and participate in industry conferences such as the annual meeting of the Health Information Management and Systems Society (HIMSS), the largest health IT industry association, and events like Health Datapalooza. Health Datapalooza is a public-private partnership event put on by AcademyHealth, an entity supported by major federal agencies and industry groups. The description of the event both showcases ideologies of programmability that are foundational to U.S. health IT and presents the environment of consensus-building and technical problem-solving ONC aims to foster through its collaborative and hybrid regulatory strategies:

> Since its inception, the Health Datapalooza has become the gathering place for people and organizations creating knowledge from data and pioneering innovations that drive health policy and practice.[60]

In-person conferences like these and the ONC Annual Meeting (which I attended in 2017), ONC Interoperability Forum, and others are primarily designed for the dissemination of information about policy and the cultivation of consensus among communities of practitioners who will ultimately be charged with promoting, materializing, and reproducing the dominant programmed visions that drive contemporary U.S. health IT.

Outside of deliberative venues and comment periods, ONC and partnering organizations also maintain or support a range of digital "sandboxes," "contests," or "proving grounds" where actors in health IT can submit feedback or case studies that showcase some use of a standard, process, or tool, or which allow developers to work directly with an application in order to test its utility. In these environments, technical demonstration by stakeholders becomes a mode of prototyping, evidence-building, and persuasion that augments rhetorical persuasion and the presentation of evidence in normal dialogic modes. One such interface is the *Interoperability Proving Ground*, an interactive environment and database where entities are encouraged to submit successful interoperability projects that demonstrate the strengths and flaws of particular interoperability standards – and especially of those in the *Interoperability Standards Advisory*.[61] Another such platform is the Cypress testing environment, also called the Quality Reporting Document Architecture Data Reporting-Clinical Quality Management (QRDA-CQM) Sandbox, which provides developers the ability explore and work with the development and use of standards in quality management for their organization.[62]

ONC also regularly communicates that the agency is open to feedback, and encourages stakeholders to interact with staff on a regular basis. ONC, as an agency native to the era of open data and big data and which has strong claims to be at the vanguard of that *ethos* in contemporary governance, presents itself with an air of openness and approachability.[63]

Regulatory Strategy 2, ONC as Decider: Binding and Non-Binding Health IT Regulations

The second major regulatory strategy used by HHS to build the nationwide health IT infrastructure has been the issuance of binding and non-binding regulations, guidelines, and strategic plans or roadmaps with a trajectory-setting function. These different forms of policy-setting by ONC deeply shape the uptake, development, and utilization of EHRs, health IT standards, and health IT products.

Binding rule-making processes are administered through the Federal Register and are the primary tool that ONC and other agencies have utilized to foster EHR adoption and to cultivate an interoperable health IT ecosystem. Binding regulations issued in this way include the "Meaningful Use" program, paired with EHR and health IT certification criteria that were released from 2010-2015. These sets of rules were used to administer the EHR Incentive Payment program – described below – which supported uptake of EHRs, ensured their basic functionality in clinical practice, and established them as the main backbone of the envisioned nationwide health IT infrastructure.

Non-binding guidelines, best practices, and recommended standards for developers and users of health IT products like the *Interoperability Standards Advisory* primarily serve trajectory-setting functions, providing a degree of predictability in regard to long-term direction of specific standards and health IT generally in a way that binding regulations cannot provide. In the parlance of standards, non-binding health IT guidelines are generally "layered" on top of binding health IT standards policies; they are primarily informed by best practices developed by industry actors. Non-binding technical guidance is designed to foster a shared sense of trajectory, market predictability, and innovation among a diversity of stakeholders. Examples include the *Shared Nationwide Interoperability Roadmap*, a long-term interoperability guidance document that was released in 2015 following several rounds of public comment and industry feedback. The roadmap sets out the regulatory trajectory for building nationwide interoperability, but sets no policy itself. The most influential set of nonbinding technical guidelines developed to date are those in the *Interoperability Standards Advisory*. The *Interoperability Standards Advisory* centralizes ONC's preferred health IT interoperability standards and provides regular updates on the functionality, maturity, and implementation of specific standards. While product developers and other health actors are not required to use these standards, the presence of standards in the *Advisory* indicates ONC's endorsement and long-term investment in them.

Where binding regulations constitute the baseline for participation in federal health IT programs and the health IT marketplace in general, non-binding guidance documents use the foundation set by basic requirements to direct health IT industry actors and other stakeholders toward the utilization of ONC-preferred standards or developmental models that extend beyond basic requirements. Whereas binding regulations are directives and a form of sovereign power whereby the state asserts authority over private actors in order for the latter to participate at all, non-binding guidelines constitute a form of disciplinary power or soft control exercised by ONC.[64] This dual binding/nonbinding regulatory approach allows ONC to direct or guide the industry and other partners toward standards that it prefers while also providing developers and users of health IT products with a high degree of flexibility and confidence when developing technologies using standards that are not included in basic certification or utilization requirements.

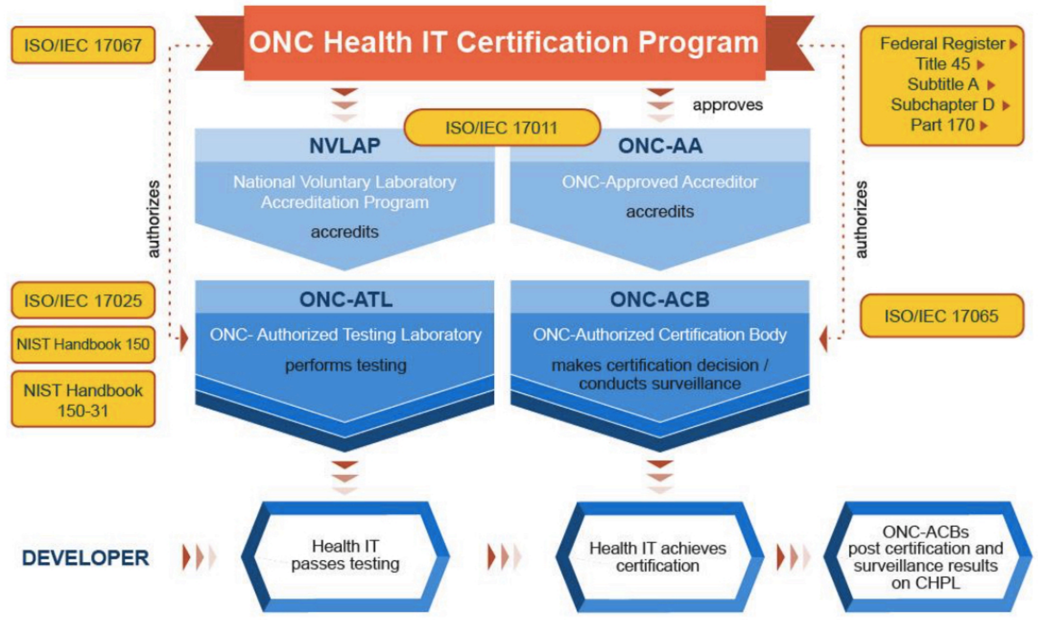
IV. Policy Mechanisms: EHR and Health IT Certification, EHR Incentive Payments, and Exchange Frameworks and Interoperability Standards

In this section, I detail the three main policy-setting mechanisms that the Department of Health and Human Services (HHS) has utilized to build nationwide interoperability since 2009. The three policy mechanisms that the Office of the National Coordinator for Health Information Technology (ONC), working very closely with the Centers for Medicare and Medicaid Services (CMS), has utilized to actualize its regulatory program are: (1) certification requirements for electronic health records (EHRs) and health IT products, (2) financial incentives to providers who attest to their "meaningful use" of EHRs, and (3) the creation of health information exchange infrastructures, frameworks, and interoperability standards. Each of the mechanisms and regulatory strategies is critical to the others' functionality and, as I explain below, together constitute the foundations of U.S. health IT policy and the development of the nationwide interoperable infrastructure.[65]

Policy Mechanism 1, Certification Programs for Health IT Products

ONC's Health IT Certification Program is the foundational policy basis for HHS's nationwide interoperability strategy. The program was authorized by the Health Information Technology and Clinical Health Act of 2009 (HITECH) and first launched in 2010 as the EHR Certification Program. The program was initially built to grant federal certification to EHR products, giving technologies that met the certification criteria the designation of "Certified Electronic Health Record Technology" (CEHRT, pronounced "sirt"). Only providers who utilized federally-certified EHRs were eligible to attest to their "Meaningful Use" of the technologies and therefore to participate in the EHR Incentive Payment Program, discussed below. Certification is essential for a health IT product and its manufacturer to become major players in the marketplace. The Health IT Certification Program is therefore ONC's main method of gatekeeping and quality assurance for health IT products. The diagram in Figure 2.3 below, produced by ONC, provides a visualization of the Health IT Certification Program.[66]

Figure 2.3. Diagram of the ONC Health IT Certification Program



Yellow bubbles refer to either statutory authority for the Health IT Certification Program, or to one or more guiding standards or process recommendations that are issued by entities such as the National Institute of Standards and Technology (NIST), the International Standards Organization (ISO), and International Electrotechnical Commission (IEC). ONC uses these master standards to establish its own accreditation, testing, certification, and monitoring practices to operate the certification program. As shown in the blue chevrons, rather than certifying EHRs and other health IT products itself, ONC accredits private entities to do certification, assessment, and monitoring work on health IT products. This style of privatized regulation is another hallmark of neoliberal governance.[67]

Policy Mechanism 2, the "Meaningful Use" of CEHRT: The EHR Incentive Payment Program[68]

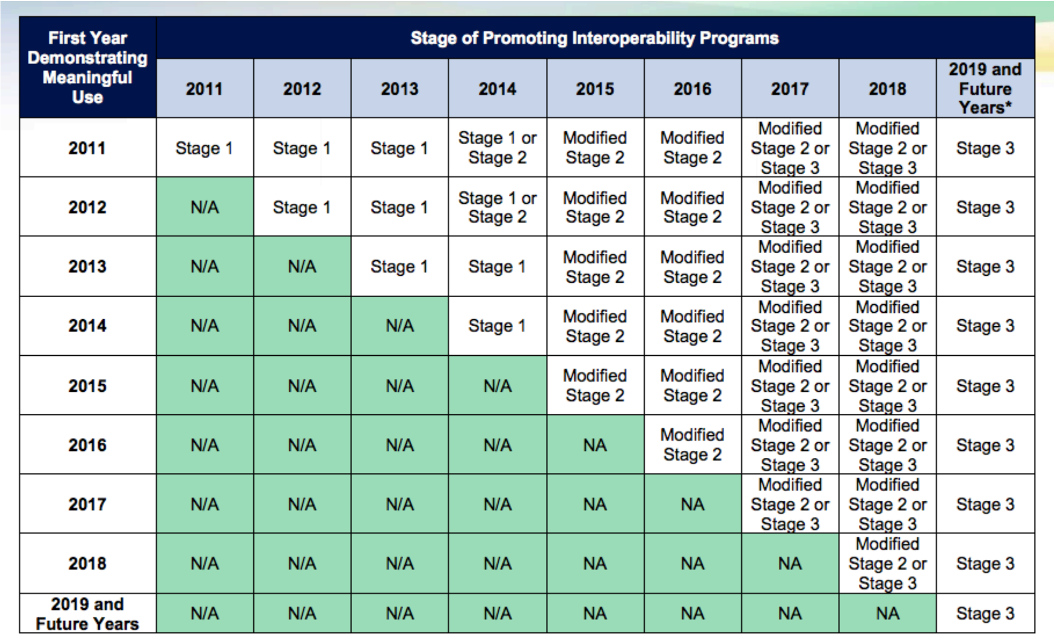
Rules defining EHR certification criteria were released along with paired "Meaningful Use" (MU) rules in three stages from 2010-2015. MU criteria directed healthcare providers about how to utilize – "meaningfully use" – CEHRT in their practices and then about how to self-attest to their meaningful use in order to participate in the EHR Incentive Payment Program. The Incentive Payment Program is operated by CMS, with coordination by ONC.

If EHRs were to be the backbone of the nationwide health IT infrastructure, incentive payments to providers that rewarded them for their utilization of CEHRT have been the primary mechanism for ensuring that healthcare organizations speedily adopt health IT. Eligible providers attesting to their meaningful use of CEHRT can receive incentive payments of up to $63,750 over six years. That is not a massive sum. However, when one considers that a hospital or provider group might employ or contract with many eligible providers, the total adds up to a substantially larger amount. Further, the program is not designed to pay for the full digitization of a healthcare organization. Rather, it is intended to provide enough funds to jumpstart the complicated, expensive, and long-term (indeed, endless) process of digitization.

Paired sets of EHR certification and MU rules were issued in three stages: in 2010 (Stage 1 MU and 2010 CEHRT criteria), 2012 (Stage 2 MU and 2012 CEHRT criteria), and 2015 (Stage 3 MU and 2015 CEHRT criteria). Each process involved public comment periods in the Federal Register and ongoing consultations between ONC, other branches of HHS, and industry actors through official advisory committees and other forums. MU rules set criteria for provider utilization of certified health records and were overseen by CMS, while EHR certification criteria were issued by ONC and defined the basic technical requirements for EHRs to become certified. Draft rules were issued and public comment periods were administered separately. However, draft notices of proposed rule-making and final rules were released on the same day by both ONC and CMS for all three stages. This required many organizations to submit two sets of related comments: one to CMS addressing MU criteria and another at ONC addressing EHR certification criteria.

In 2018, following the interoperability mandate of the 21st Century Cures Act, the "Meaningful Use" program was renamed "Promoting Interoperability" and the EHR Incentive Payment Program began to be phased out in favor of "merit-based" and "quality payment" programs operated by CMS. These programs – not considered in this dissertation – penalize providers for non-utilization of EHRs and other health IT systems or rewarded providers for certain kinds of advanced utilization, rather than providing financial incentives as a reward for basic utilization. The figure below, produced by CMS in 2018 – shortly after Meaningful Use was renamed Promoting Interoperability – shows a timeline of the MU program rollout and early phase-out from 2011 to 2019.[69]

Figure 2.4. Table Produced by CMS Showing Meaningful Use (later "Promoting Interoperability") Program Development and Early Phase Out from 2011-2019



First Year Demonstrating Meaningful Use	Stage of Promoting Interoperability Programs								
	2011	2012	2013	2014	2015	2016	2017	2018	2019 and Future Years*
2011	Stage 1	Stage 1	Stage 1	Stage 1 or Stage 2	Modified Stage 2	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2012	N/A	Stage 1	Stage 1	Stage 1 or Stage 2	Modified Stage 2	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2013	N/A	N/A	Stage 1	Stage 1	Modified Stage 2	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2014	N/A	N/A	N/A	Stage 1	Modified Stage 2	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2015	N/A	N/A	N/A	N/A	Modified Stage 2	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2016	N/A	N/A	N/A	N/A	NA	Modified Stage 2	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2017	N/A	N/A	N/A	N/A	NA	NA	Modified Stage 2 or Stage 3	Modified Stage 2 or Stage 3	Stage 3
2018	N/A	N/A	N/A	N/A	NA	NA	NA	Modified Stage 2 or Stage 3	Stage 3
2019 and Future Years	N/A	N/A	N/A	N/A	NA	NA	NA	NA	Stage 3

Describing the policy mechanics that will facilitate the full transition from incentive payments for the meaningful use of CEHRT to other forms of payment adjustment for heath IT (non-)utilization is outside the scope of this dissertation. However, the renaming of the MU program to “Promoting Interoperability” in the context of an overall regulatory trajectory toward nationwide interoperability lays bare the long-term purpose and practical effect of the MU program, which was ultimately to convert programs designed to foster the “meaningful use” of EHRs by individual providers into programs that will “promote interoperability” or the active exchange of information between different healthcare organizations.

This outcome was in fact foretold by the 2015 *Interoperability Roadmap* and the text of the 2009 HITECH Act itself. EHR product certification and the meaningful use of certified EHRs by individual providers was never merely an effort to convince physicians and healthcare organizations to digitize. These regulatory pushes were always-already core elements in the much more far-reaching programmed vision of fostering nationwide health information liquidity and interoperability.

Policy Mechanism 3, Health Information Exchange Frameworks and Interoperability Standards

The third mechanism that HHS has used to build a nationwide health IT infrastructure since 2009 is the cultivation of information environments that are friendly to the exchange of health information between different actors in the healthcare system. This is particularly true for the exchange of data between healthcare entities that are using CEHRT products made by different vendors, but who seek or are required to exchange health data with one another. The ability to exchange, send, and receive data using CEHRT developed by different firms is crucial to the success of HHS’s interoperability strategy. To this point, 21st Century Cures makes “information blocking” a serious offense.[70]

HHS has worked to create a health data ecology friendly to exchange through several distinct programs and streams of regulatory activity. The first is funding and supporting the development of health information exchange (HIE) infrastructures by working directly with state and territorial governments. The second is by funding and accrediting Regional Health IT Extension Centers – public-private partnerships based in states, territories, or regions of states that assist small providers in EHR implementation and the construction of HIEs.[71] The third has been through the development of interoperability standards through the *Interoperability Standards Advisory*, which has been released annually since 2015, and offers suggested standards that are built or "layered" on top of standards in EHR certification criteria. These exchange frameworks and standards in the *Interoperability Standards Advisory* – along with the EHR infrastructure – have laid the groundwork for the next phase of infrastructural development in health IT, which will create binding interoperability criteria for the first time.[72]

Complexity in Disentangling Health IT Policies and the Health IT Ecosystem

The many overlapping programs just described are extremely complex and difficult to disentangle from one another. They are therefore often misunderstood or confused with one another – even by health IT professionals. For example, because Meaningful Use attestation requirements and EHR certification criteria rulemaking processes proceeded in tandem with one another in three distinct phases, they are often confused with one another or are conceptualized and discussed as a single program, usually referred to under the discursive umbrella of "Meaningful Use."[73] However, as I have described, MU attestation requirements and EHR certification criteria are distinct. ONC operates the health IT Certification Program and CMS operates the MU program and the distribution of incentive payments. The complexity of this assemblage of programs and the ways in which they interface poses many challenges for non-specialists who seek to influence health IT policy.

LGBTQ health advocates' framing of "Meaningful Use" after the inclusion of sexual orientation and gender identity (SO/GI) data elements in 2015 Base EHR certification criteria is illustrative of this problem. After SO/GI data elements were required in EHR certification criteria issued by ONC in 2015, LGBTQ health advocates wrote an article titled “Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health.”[74] However, SO/GI data were not actually included in Stage 3 MU attestation requirements, only in the 2015 Base EHR certification criteria. This means that the Stage 3 MU did not require providers or healthcare organizations to demonstrate that they were collecting or utilizing SO/GI in order to receive incentive payments from CMS. Rather, SO/GI elements were merely required for inclusion in the “demographics” section of EHRs in order for specific EHR products to achieve federal certification and therefore to remain eligible for participation in the EHR incentive payment program and players in the marketplace.

Whether a data element is included in both MU and CEHRT criteria, or only in CEHRT criteria, is important to trace the trajectory of a specific standard in U.S. health IT policy. Inclusion in both MU and CEHRT means that a data element must be present in the technology and that providers must self-attest to their utilization of these fields. Inclusion in certification criteria only means that the fields must simply be available for providers to use at their discretion.

While ONC’s certification program was initially intended only for EHRs – the backbone of the national health IT infrastructure – the certification process ONC established for certifying EHRs gradually expanded to encompass other privately-developed health IT products, such as health information exchanges, and processes that these products facilitate (such as the secure exchange of health information). This pattern of gradual expansion, whereby certification standards gradually “evolve” and expand into other territories as technologies are adopted and standards become “mature,” is a hallmark of standards-development generally and has been a critical tool in the development of the nationwide health IT infrastructure. It is an example of a kind of intentional infrastructural expansion or “infrastructuring.”[75] The health IT certification program – formerly only a program designed to certify EHRs – continues to grow in this way, and now includes assessments of HIEs, technology adoption levels, determinations about the functionality of standards in specific products, and the monitoring of ongoing provider technology utilization. What was, in 2010, a basic checklist for EHRs is now becoming an expansive program and set of testing environments used to certify an array of health IT products.

V. An Exemplary Case: MetroATLCare Invests in the Promise of Interoperability Despite Persistent and Constitutive Technological Failure

The previous two sections focused on the idealized process of health IT policymaking and implementation. This section turns the focus to the everyday reality of interoperability, focusing on the quotidian technological and organizational failures that have unfolded during a relatively robust interoperability project pursued by MetroATLCare, a large HIV/AIDS Service Organization (ASO) in metropolitan Atlanta’s Ryan White infrastructure. As a reminder to readers, the Ryan White HIV/AIDS program is administered by the Health Resources and Services Administration (HRSA) and is the payer of last resort for HIV/AIDS care in the United States primarily serving the uninsured and under-insured. In metro Atlanta, the local Ryan White program is administered by Fulton County.

The following exchanges between me, several HIV professionals in Atlanta who work for MetroATLCare and Fulton County, and especially with Michael Zales – the data manager at MetroATLCare – showcase the frustrations of individuals positioned squarely in the middle of multiple entangled hierarchies of health information architecture, federal health safety net programs, health IT regulations, and Atlanta’s under-resourced and highly political HIV care infrastructure. These fieldwork data also show how people working with the same infrastructure can not only possess different understandings of what a technology or piece of software is, but exist in such different relations to the infrastructure that they enact distinct, hyper-local realities that are particular to their specific position in the sociotechnical assemblage in which they are situated.

MetroATLCare Goes All-In on Interoperability

Many years you have lingered around my cabin door
Oh, hard times come again no more…
Hush-a-bye hard times go ye away
I don't intend to be treated this way
-Dolly Parton, "Hush-A-Bye Hard Times,"
9 to 5 and Odd Jobs (1980)

MetroATLCare Data Manager Michael Zales – who is an AIDS activist and Dolly Parton fan in addition to being a longtime employee of this organization – is a proverbial "true believer" in the promise of interoperability and data quality for enhancing the wellbeing of people living with HIV/AIDS. He is so committed to interoperability at MetroATLCare that he spearheaded a Health Resources and Services Administration (HRSA)-funded Special Project of National Significance (SPNS or "spins") grant for his organization.[76]

This project aimed to establish an automated feed between MetroATLCare's EHR and Fulton County's build of CAREWare using Health Level 7 International (HL7) exchange standards. As a reminder, CAREWare is federally-maintained software used by all Ryan White grantees in the Atlanta metropolitan area (and about half of Ryan White grantees nationally) to deliver periodic and annual data reports. Per MetroATLCare's Executive Director, Gary Hayman, who has overseen the expansion of what was once a small ASO into a local behemoth over the course of his twenty-plus year tenure, the project has been successful.

> **Gary Hayman, Executive Director:** We proved it worked…And it worked up until [Fulton County] upgraded their servers, and then everything stopped. *The data is still going through* - it is still coming out of the EMR [electronic medical record] system, still going through, messages are still going through. They're just not going through the socket into the server [at Fulton County]…
>
> Nobody really understood exactly how this would work. We just knew we wanted to make it work. We knew what our ideas were, what the components were, what the socket thing was…and nobody really had a clue. We just knew if we could make this work, if we can actually go into [MetroATLCare's EHR] and pull these elements, figure out a way to massage it and get it into this one, this would be the best day ever…So, it got funded and we brought in the folks to start working on it, and [looked] at what our options were…You had Fulton County involved, you had CAREWare involved, you had [the EHR vendor] involved, *in a non-profit*.
>
> So, it was getting four entities to all agree: we're gonna step on the red dot first and then go green. It was a very tricky thing to make it happen, it was a huge learning curve for Michael, who managed all of it for us. And at the same time, he's trying to do that, the data's still gotta be collected and turned in. That didn't stop while we were doing this project. That had to continue the whole time.

In an experience that is typical of both Fulton County's HIV infrastructure and of health IT projects generally – and especially of automation-motivated interoperability projects pursued by under-resourced organizations like MetroATLCare, as Hayman's statement "*in a non-profit*" suggests – after an initial steep learning curve, the feed was established and worked. However, the HL7 interface between the two systems – referred to as "sockets" by Gary – was not properly maintained on the county's end. In Gary's mind, this means that the project was a success because the organization had "proved it worked" and "messages are still going through." However, the story from the technicians' standpoint was rather different. Messages may have been going through over the HL7 feed, but they were not being received. This made the project a total failure from the perspective of Fulton County. A consideration of this shows how the MetroATLCare SPNS project caused multiple, competing realities to emerge within the broader Ryan White infrastructure.

Fulton County CAREWare manager Greg Nowitzki told me matter-of-factly that "it'll never work again" and that "you know, I wish it would have worked, but we don't necessarily at Fulton County have the expertise necessary to deal with it, unfortunately." Nor, as Gary's statements suggests he believes, were MetroATLCare's data "still coming out of the EMR system" – at least not in a fashion that they could be received. Data being transmitted in the absence of an entity with the technical and organizational capacity to receive them are not, per se, "going through" to anywhere. Given this, whether the data were actually being transmitted is more of a philosophical question than a practical matter: without a receiver, their transmission is of no practical consequence, let alone a success.

Data were going through to Fulton from MetroATLCare – but in a different way. At the time I interviewed Gary and Michael in June of 2017, data between MetroATLCare and Fulton County were still being translated manually from the EHR into CAREWare at regular intervals through a laborious manual "Provider Data Input" (PDI) process that was built by Michael and executed by a team of MetroATLCare staff at regular intervals as required by Fulton County and HRSA. This process went on as Michael continued to try and build a functional feed between his organization's EHR and *either* an internal serve that would facilitate a less labor-intensive PDI process *or* directly to Fulton County – anything that would produce some semblance of automated reporting. Despite the investment of federal and local resources by all actors in this network, Michael still had to, per Greg at Fulton County, "login to the VPN [Virtual Private Network] once a month and fire it up and send" a PDI report.

Neither Greg (Michael's counterpart in systems administration at Fulton County) nor Gary (Michael's boss at MetroATLCare) understood that the current report-generating process was not simply a matter of "[firing the EHR] up and [sending]" a report from MetroATLCare to

Fulton County, or that “messages are still going through” from the EHR in a way that would easily allow Michael to push the data through. They did not know that the process remained essentially analog and manual. No single actor in this network could precisely say what the others were doing, or what the SPNS project had accomplished – only what it could *theoretically* accomplish (or, in Gary’s case, a misunderstanding about what the feed was doing when it was “sending messages through”). Despite these (sometimes wildly) divergent relations to and impressions of the project, everyone involved remained firmly invested in the value of the SPNS project and the pursuit of digitally automated reporting and the interoperation of systems.

Managing these divergent understandings are some of the many challenges that Michael Zales has faced as a data manager. As invested as he and the other actors in this network are in cultivating some degree of automated interoperability between MetroATLCare and Fulton County’s build of CAREWare, Michael is often overcome by the obstacles he faces in pursuing that outcome. This is true both for his organization and for the broader HIV care infrastructure in Atlanta, where he is a recognized leader in assessment, quality assurance, and informatics who is often called upon by other agencies, the county itself, and even high-level CAREWare personnel for his expertise. His frustrations relate not only to failures regarding the construction of automated reporting infrastructures, but to the basic quality of the data he is entrusted to report.

Near the end of a long day of interviews at MetroATLCare’s facility in Atlanta’s historically gay Midtown neighborhood (a building that has since been sold by the organization to make way for a high-rise as part of late-stage gentrification), Michael and I were reflecting on this process and the general relationship between data in the clinic’s EHR and CAREWare.[77] It was one of many similar conversations that we had that day and over the course of my two years in Atlanta regarding both the value and quality of the data that organizations collect as well as the impossibility of its easy utilization due to forces outside of Michael's control.

> **SM**: I was just having this conversation with [a clinician and division director at MetroATLCare], and…she basically thinks clinical data in EHRs, and CAREWare data in general, are "garbage in, garbage out."
>
> **Michael**: Yes, totally! Explain to me, I mean, I have *for the life of me* tried to figure out what value do you have if you…have a category like "medical case management" [tone becomes ponderous]…
>
> Yes, medical case management: *there should be a treatment plan*! Is the person virally suppressed, or are they retained in care? Like, to me, those are the measures that would gauge the impact of the program. But [HRSA and Fulton County] put everything down to "was it a phone call or was it face-to-face? And we just wanna know how many of those happened." What? *Why*, you know, **why**?
>
> And then they're asking us to put in these responses for [a] screening tool into CAREWare that add up a calculation that create a score to gauge if somebody should be, you know, referred for case management, referred for substance abuse, legal issues, or mental health. And they're asking us to put that into CAREWare. It's just a lot of numbers and the day it happened, with no data reporting on it, no reports being run on it, *not even sharing it with other agencies*.
>
> I – I don't understand. I'm very frustrated with data reporting.
>
> And, you know…I want to make sure it's accurate. I see the potential to utilize something to learn about a population or learn about the work we're doing, but I don't see *anyone* monitoring or ensuring its quality or its consistency…and *you need consistency*.
>
> Like, when I – we – did our viral load suppression, community viral load report, to figure out where were the hardest hit communities, they gave us a printout of all of the lab values that were put in CAREWare, and there were like viral loads of like "0.047." I'm like, "Who? What?" Or *zero*!
>
> *There's no such thing as a zero viral load!* there's either a "less than" or "undetectable." And I get that – but…there was no structure to say, "this is how you should put this information in there."
>
> So, I really feel like it is "garbage in, garbage out." And it doesn't have to be. It really doesn't have to be.

Michael's viewpoint and experience is typical of other data managers and health IT professionals whom I have worked with during fieldwork. In one breath, clinical EHR data and automated interoperability are spoken about as if they are the future of healthcare and a potential boon for poor people living with HIV, individuals served by safety net agencies, providers, patients, researchers, *ad infinitum*. In the next breath, quality data collection and the meaningful exchange of information also seem – and actually *are* – unattainable due to a multiplicity of organizational and technical hurdles that prevent their achievement. Michael is describing the experience and feeling of living squarely in the middle of a totalizing programmed vision, in all its schizoid gyrations and the multiple competing realities it produces for different actors in the network.

Michael's hopeful and exasperated affect, as well as the content of his speech, express the feelings of a frustrated person caught up in a sociotechnical snarl of human and non-human forces that involve high highs and low lows.[78] He is a motivated actor trapped in a network that encourages, incentivizes, and then prevents him from enacting the goals of interoperability and improved health data quality that all the actors say they want. Some (such as Hayman) even believe that the goal has been achieved, living in a different (managerial and visionary) reality than Zales's (technical and organizational) reality. In being so trapped, Michael gets glimmers of the promised interoperable future he strives for even as the structure of the network also ensures that this future will always be falling apart before his eyes. After all, the feed between CAREWare and his organization's EHR did work for a short time, before it broke and was never again fixed. Michael even held out hope that it would work again despite the county CAREWare manager's matter-of-fact statement (from his own bureaucratic reality) that it never would.

In a telling fashion that illustrates how pervasive this problem of persistent technological failure is – reaching into every corner of contemporary health practice and thus constituting a foundational element of the programmed vision of total interoperability in healthcare – Michael's frustrations are not limited to his attempts to get his organization to automatically report data to

CAREWare consistently (which would, in his eyes, constitute the "achievement" of "interoperability"). Rather, his complaint extends to the process of working with all clinical data, MetroATLCare's EHR, and the health workers who operate it every day: personnel Michael must both be responsive to and train to enter data correctly. Near the end of our conversation, Michael expounded upon the many challenges of even getting clinical and non-clinical staff to enter basic demographic information correctly – another persistent problem actors told me about during fieldwork:

> Internally, as far as us using our EHR system…we are very limited. I feel like we have a lot of round pegs and we have a square hole in our EMR, to try to get the information in there. We are having to function within the confines of what this shared domain will allow us to do, *just to record information*, so we can – first of all – see that it happened and what's going on with the patient. Two, be able to pull it out and report it back to our funders. And it's very frustrating to try to put some quality control over how that information is put in…
>
> There's so many users and there's so many to try to keep track with and we have so many interns and people that don't have the same buy-in, to understand why it's important to put an accurate date of birth in the box, instead of today's date. *That's not the day they were born!* I run reports and it'll show me that someone's two months old. I'm like, what? Did they sign the consents? [chuckle] You know?
>
> So just those types of little things – that attention to detail, that, to me, just are implied: here's a box; type the person's name. *Try to type it correctly if you can*.
>
> And that's why I really hope that – at least in my mind that – I think that automation and interoperability, if we connect systems and they talk [that would be good]. But again, if it's garbage talking, what are we learning?

Indeed. If this is the typical health IT experience – of holding out hope in the context of persistent technological failure as the programmed vision of total interoperability charges ahead – what *are* we learning about the promise and perils of interoperability a decade into its (very expensive and consequential) pursuit in the United States?

Looking backwards in time from the vantage of 2019, in a health IT ecosystem that genuinely has been transformed by EHRs, health IT systems, and interoperability standards –

changes that are likely to reverberate in profound and multi-valent ways that will not be fully understood for many years – what are we learning about the gambles made to get here? What are the real and potential consequences of programmed visions of the future in healthcare, as they are realized, as they fail, and as they give way to new and unexpected outcomes?

VI. Conclusion: What Are We Learning?

As I say early in this chapter, there is no single comprehensive overview of current U.S. health IT policy. To this point, owing to the many complexities of administering health IT programs and the rapidity of change in this space, I am of the view that producing one is not possible. Here, I have engaged in the rather more specific project of tracing the emergence of the nationwide interoperable health IT infrastructure through a series of regulatory expositions and vignettes from my fieldwork. However, several competing analyses of federal programs designed to foster health IT utilization, and which discuss nationwide interoperability exist in the health IT policy and informatics literatures.[79] This chapter adds to that body of work, both in its analysis of the trajectory of U.S. health IT and the efficacy of U.S. health IT programs. The chapter has also made contributions to – and interventions in – interdisciplinary studies of health information systems, digital studies and data studies, infrastructure studies, social theory, and social studies of biomedicine. In this conclusion, I explore some of the other lessons that can be extracted from the pathways carved through the national interoperability project in this chapter.

While the national health IT infrastructure has been developed with secure storage and exchange as a centrally-articulated goal, the implications for patient privacy, data security, and informed consent in the new health information environment are enormous and scandalously under-examined. Along with other scholars, network security professionals, and popular writers, I contend that the new paradigm in health information management has developed far too quickly to ensure anything like “privacy” or “doctor-patient confidentiality” as these have historically been understood by laypersons, in law, or healthcare. The pace of infrastructural development has accelerated with far greater rapidity than regulators can keep up, leading to a situation in which few widespread best practices exist to ensure meaningful privacy or ethical uses of health data in the new health IT ecology.

As part of this critique, I argue that programs to develop the new health IT paradigm have moved forward without adequate mechanisms to educate, seek the meaningful consent of, or provide modes of refusal or non-participation for patients and providers. In this way, the chapter is a contribution to the critique of Terms of Service (ToS), End-user License Agreements (EULAs), “de-identification” of records, and various crises of consent regarding the use of individuals’ data that have emerged from critical digital studies, recent studies of developments of uses of health data, and digital data generally.[80]

It is difficult to overstate the reach of potential consequences stemming from new applications of health IT, and it would be incorrect to state that researchers (in academia or industry) are aware of the full range of new uses of electronic medical data that are currently at work in the economy. Consider one high-profile example. In 2018, the Cambridge Analytica scandal surrounding malicious uses of Facebook Data to influence the United States presidential election – an affair that also involved a Cambridge University professor – created an industry-wide crisis regarding uses of social media data.[81] This scandal led to U.S. Congressional and U.K. Parliamentary hearings and played a major role in ushering in a new paradigm in the management of both individuals’ data by social media firms and the regulation of digital content.[82] Fallout from this event also led Facebook both to acknowledge and to suspend a project that aimed to match patient EHR data with Facebook users’ data in a partnership with

Stanford Medical School and the American College of Cardiology.[83] The revolution in health IT is already caught up in the newest, most consequential, and still-emergent controversies over uses and re-uses of health data outside the bounds of normal practice.

However, beyond new uses of EHR data by social media firms, the digital health information economy faces a wide range of questions about (and challenges to) existing best practices. The community of stakeholders in health IT will almost certainly have to come to terms with many of these as the volume of interoperable health data continues to grow, the speed at which these data move accelerates, and the number of interoperable health IT infrastructures data pass through expands (and with its expansion, as I explore below, increased opportunities for breach).[84] A selection of just a few issues in this area include: the ethical re-use of "de-identified" EHR data, how to de-identify EHR data so that it cannot be re-identified when matched against other datasets, the relationship between medical informed consent and digital health technologies' Terms of Service, the commercialization of health data held by laboratories and other entities in ways that were not formerly possible, how to ethically build "learning" health systems" with decision-support affordances, the regulatory and technical collapse of public health data and clinical data caused by the expansion of new interoperable infrastructures that link these different datasets, and others.

Further, the development of new infrastructures has led to substantive tensions in HHS policies, putting assertions that patients should have the right "to control" their electronic health data at odds with current practices, such as the secondary reuse of electronic health data held by public health departments or of clinical electronic health record data for research purposes.[85]

The chapter's contributions to social theory are presented during the discussion of the regulatory and policy-setting mechanics ONC utilizes to shape and set health IT policy. ONC stages modes of hybrid governance for both debate and demonstration across a wide array of actors. In addition to holding space for discursive exchanges about health IT between stakeholders, ONC maintains and/or supports digital "proving grounds," and open application program interfaces (APIs) where actors in health IT can conduct tests of products, submit feedback, or present the results of case studies that showcase some use of a specific standard, process, or tool. ONC is therefore not only a facilitator of "technical spheres of argument" – a longstanding notion in theories of deliberative democracy, the coproduction of knowledge and society, and the role of expertise in policy-making – but also of technics as argument or demonstrated know-how as argument. This is, in part, an effect of a new kind of governmental mindset that has bled outward from Silicon Valley and the tech world into federal health policymaking, wherein demonstration and prototyping are central modes of persuasion. The requirement for ONC to build more infrastructures that function in this way, as well as more open APIs that are accessible "without special effort" to users is a central feature of the 21st Cures Act's mandate for nationwide interoperability and the prevention of "information-blocking" in a competitive economic environment. As venues and methods for demonstrating the veracity of health IT products and standards expands, this model of hybrid governance is likely to continue become more robust and encroach into other areas of policy.

For critical scholars of biomedicine and health, the chapter insists that any consideration of contemporary health practice or policy in the United States must include some attention to the role of digital systems in the administration of care or other activities. Health IT, healthcare, and health are now essentially coextensive phenomena. Healthcare is mediated by digital systems at nearly every point in the continuum of care, thus making contemporary health itself a digitally-mediated phenomenon and therefore unthinkable without some attention to this mediation, and especially how this mediation occurs differently for people who are differently positioned vis-à-vis hierarchies of race, class, gender, sexuality, sexuality, age, and access to insurance and/or social services.[86] However, to date, the Centers for Medicare and Medicaid Services (CMS) has not required the collection of demographic data that would assure the collection of enough useful information to identify and eliminate health disparities within populations.

In this vein, the chapter raises the question of who (other than health IT product developers) primarily benefits from the pursuit of nationwide interoperability? A segment of the health IT equity community located in organizations such as Morehouse School of Medicine's Health IT Project in the National Center for Primary Care in Atlanta, and the National Health IT Collaborative for the Underserved have developed convincing arguments that better data collection and exchange protocols for groups that experience health disparities – such as racial and ethnic minorities, the homeless, the uninsured and under-insured, people living with HIV, and LGBTQ people – stand to benefit disproportionately from EHRs and new health IT systems. The primary argument of this cohort is that the increased exchange of information between health IT systems and the stratification of patient health outcomes by demographic variables in EHRs will contribute to the improved quality of care delivered when people receive care, report for care at new sites, and thus help to eliminate disparities that exist between different groups within systems.[87] However, as long as the infrastructures to deliver care remain inadequate, it is difficult to imagine that more efficacious data collection or utilization will do much more than make small improvements to the desperate situation of U.S. healthcare for those without private insurance, or who are working class, or who are chronically ill, or who are otherwise marginalized.

Breach as Interoperability's Flipside

One of the most frequently discussed issues in health IT is the issue of breach and cybersecurity. Network security professionals increasingly frame the problem as not being a question of *if* beach will happen to an organization, but when it will happen, why, who will do it, under what circumstances it will occur, and how to respond when it does. The main approach is no longer to *prevent* data breaches from *ever occurring*, but instead to put as many safeguards as possible in place so that breaches do not occur, and to build plans about how to respond *when* they do.[88] It therefore behooves health IT's stakeholders to prepare for a variety of possible health data futurities: a project that several STS scholars have been pursuing for some time.[89]

For digital studies and data studies, the chapter contributes to the trenchant critique of technological determinism that grounds much contemporary technological discourse and applications of big data.[90] The chapter brings many of these insights to the already-robust literature on social studies of healthcare, health technology, and health data.[91] Most critiques of data utopianism, digital universalism, and mass surveillance are generally focused on government surveillance facilitated by telecommunications firms and Internet Service Providers (ISPs), surveillance as practiced by large digital platforms such as Google and Facebook, or Internet governance practices. However, this chapter adds to a growing literature showing that these same logics now extend deeply into the apparatuses used to administer healthcare and are central to the trajectory of health policy and practice.[92] By drawing attention to issues of cybersecurity and breach in health IT, it also intervenes in academic and activist conversations that question, push back against, or resist contemporary practices of data utilization in healthcare and other contexts.[93]

The chapter's main contributions to infrastructure studies are to highlight the problem of network security in contemporary health information architecture and to develop new discourses in health IT cybersecurity. I draw on Alexander R. Galloway and Eugene Thacker's theory of "the exploit" to explain that, no matter how secure a health database or exchange framework might be (or purport to be), it will always necessarily be subject to being breached, whether by an actor within the network or by the actions of an external actor.[94] Like the familiar metaphor of a chain only being as strong as its weakest link, a digital network is only ever as secure as its weakest node, and to employ a dialectical framing, the flip-side of total interoperability and information liquidity is total network security failure.

While the notion of "total network failure" is as determinist as that of total interoperability, the problem of data breach (and of massive breach) is a very real issue in the new interconnected health IT ecology that only becomes intensified as the scope of health IT expands. Preventing the compromise of network security is the central aim of the health IT cybersecurity industry – a large and rapidly-growing sector of the economy.[95] Further, although the risks of infrastructural development in health IT are discussed far less frequently than the promise of this work for the future of healthcare, HHS recognizes breaches in network security as a serious problem.

Per a requirement in the HITECH Act, the HHS Office of Civil Rights maintains a portal where all HIPAA-covered entities are required to voluntarily report breaches of Protected Health Information (PHI) affecting 500 or more individuals. The portal publicly lists reported breaches. Entries in the hundreds of thousands or millions – and occasionally the tens of millions – are not uncommon. In 2014, for example, the Montana Department of Public Health and Human Services reported a breach resulting from an external hack that affected 1.06 million people, which is approximately the same number of people that live in the state. The hack, attributed to "an undetected and unpatched application code vulnerability," compromised critical aspects of the department's records for a nine-month period, including individuals "demographic, clinical, and financial information." The state notified the media, developed stronger protocols, and offered identity theft protection products to affected individuals; however, the damage was done and the compromised data are quite possibly in the possession of one or more actors outside of the network.[96] This is a very common story in health information security.

Health data are also a sought-after commodity, ill-gotten or otherwise. Further, ransomware attacks, where data are held hostage by hackers and health workers are locked out of systems until a sum of money is paid to release the data, are also a major issue faced by healthcare organizations.[97] Greater informational liquidity and access comes with an increase in the number of actors, nodes, and entry points into infrastructures, and therefore more opportunities for network security to be compromised. The central network security problem posed by information security professionals is increasingly not "whether" a network will be breached, but when, and how to mitigate damage once it occurs.

If total interoperability, exchange, and programmability is the imaginary space that HHS and ONC encourage health actors to work within and to cognitively place themselves, the lack of an accompanying discourse on the risks of this approach to patients and practitioners that goes beyond merely developing and encouraging best practices in network security is a failure of the imagination that ought to be remedied or at least explicated. The chapter – and this dissertation – contributes to the work of thinking beyond the current paradigm of improved network security, in part by turning attention to the labor involved in ensuring security and the policymaking processes from which understandings of network security and breach emerge.

References for Chapter 2

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[1] Don Rucker, “Automation in Healthcare Is Transforming Medicine,” *HIMSS Blog*, October 1, 2018, https://www.himss.org/news/healthcare-automation-transforming-medicine; See also, Don Rucker, “Achieving The Interoperability Promise Of 21st Century Cures,” *Health Affairs Blog*, June 19, 2018.

[2] I refer readers to the Appendix on methods and sources, which includes a description of some of the many documents produced by ONC and other agencies related to the development of the nationwide health IT infrastructure that are too numerous for individual citation here.

For a selection of documents I refer to frequently in the body of the text, see, ONC, “Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0” (The Office of the National Coordinator for Health Information Technology (ONC), 2015), http://bit.ly/2AHUnzH; ONC, “Connecting Health and Care for the Nation: A Ten-Year Vision to Achieve an Interoperable Health IT Infrastructure” (The Office of the National Coordinator for Health Information Technology (ONC), 2014) http://bit.ly/2TG7kRs; Office of the National Coordinator for Health Information Technology (ONC), “2018 Interoperability Standards Advisory Reference Edition,” 2018, http://bit.ly/2siVnWp; ONC, “Interoperability Roadmap Statements of Support” (The Office of the National Coordinator for Health Information Technology (ONC), October 8, 2015), http://bit.ly/2smqDDQ; Office of the National Coordinator for Health Information Technology (ONC), “Federal Health IT Strategic Plan, 2015-2020” (Washington, D.C.: Office of the Secretary, United States Department of Health and Human Services, 2015), http://bit.ly/2M4xKdo.

[3] “21st Century Cures Act,” Pub. L. No. 114–255, 42 USC 201 120 STST 1033 312 (2016); “The Health Information Technology for Economic and Clinical Health Act (HITECH),” H.R. 1-112 § 13001 (2009).

[4] Describing the precise mechanisms by which ONC builds up and sustains this consensus among stakeholders in health IT is the main object of this chapter. On “building up” as a practice of reality-making in actor-network theory, see, John Law in *After Method: Mess in Social Science Research* (London; New York: Routledge, 2004), 94 and 160,.

On stakeholder theory in political deliberation, organization management, and policy, see, R. Edward Freeman, *Strategic Management: A Stakeholder Approach*, Reissue (Cambridge New York Melbourne Madrid Cape Town Singapore: Cambridge University Press, 2010 [1984]). I apply a convergent approach to stakeholder theory, conceptualizing stakeholders who engage in health IT policy as operating with a shared set of professional norms, while also calling attention to the constructedness, fungibility, relational nature, and ultimate contingency of those norms. See, Thomas M. Jones and Andrew C. Wicks, “Convergent Stakeholder Theory,” *Academy of Management Review* 24, no. 2 (April 1999): 206–21. A convergent approach to stakeholder theory has been applied thusly in health policy analysis, see, Sara Rubinelli and Per Maximilian von Groote, “Stakeholder Dialogue as Deliberation for Decision Making in Health Policy and Systems: The Approach from Argumentation Theory,” *American Journal of Physical Medicine & Rehabilitation* 96 (February 2017): S17–22.

I augment this approach with insights from STS, infrastructure studies, and ANT, see especially: Kathrin M Cresswell, Allison Worth, and Aziz Sheikh, “Actor-Network Theory and

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Its Role in Understanding the Implementation of Information Technology Developments in Healthcare," *BMC Medical Informatics and Decision Making* 10, no. 1 (December 2010); Marc Berg, "Accumulating and Coordinating: Occasions for Information Technologies in Medical Work," *Computer Supported Cooperative Work (CSCW)* 8, no. 4 (December 1999): 373–401; R Stuart Geiger and David Ribes, "Trace Ethnography: Following Coordination through Documentary Practices," in *2011 44th Hawaii International Conference on System Sciences* (2011 44th Hawaii International Conference on System Sciences (HICSS 2011), Kauai, HI: IEEE, 2011), 1–10; Volkmar Pipek and Volker Wulf, "Infrastructuring: Toward an Integrated Perspective on the Design and Use of Information Technology" 10, no. 5 (May 2009): 447–73.

[5] Cornelius Puschmann and Jean Burgess, "Metaphors of Big Data," *International Journal of Communication* 8 (2014): 1699; Tung-Hui Hu, *A Prehistory of the Cloud* (Cambridge, Massachusetts: The MIT Press, 2015), *passim*.

[6] Sabina Leonelli's defines "data"

> as a relational category applied to…outputs that are taken, at specific moments of inquiry, to provide evidence for knowledge claims of interest to the [actors] involved. Data thus consist of a specific way of expressing and presenting information, which is produced and/or incorporated in…practices so as to be available as a source of evidence, and whose…significance depends on the situation in which it is used. In this view, data do not have truth-value in and of themselves, nor can they be seen as straightforward representations of a given phenomenon. Rather, data are essentially fungible objects, which are defined by the *portability* and their *prospective usefulness as evidence*.

"What Counts as Scientific Data? A Relational Framework," *Philosophy of Science* 82, no. 5 (December 2015): 811.

[7] See, Software & Systems Engineering Standards Committee, "Interoperability," *IEEE 610-1990 - IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries* (IEEE, 1990).

There have been many attempts to parse "interoperability" from "health information exchange" in the health IT policy discourse, including by interlocutors in Atlanta, as I describe in the section of this chapter titled "The Toddler Matures into a Unicorn." See, for example: Douglas Fridsma, "Interoperability vs Health Information Exchange: Setting the Record Straight," *Health IT Buzz* (blog), October 14, 2013.

However, the concept is used by some (such as CAREWare developers) to describe processes that others (such as health IT policymakers or advanced health IT product developers) would characterize as falling far short of their preferred definition. Interoperability is not only relative because it is a sign with arbitrary meaning. It is extremely relational because it acquires so many different meanings and is used in so many different ways in practice. For me to posit some fundamental consistency of definition of "interoperability" would fall into one or more of three traps: (1) be a disingenuous analytical maneuver on my part that would flatten the complexity of interoperability as an object of analysis, (2) preference the definition of some actors' over those of others, or (3) determine arbitrarily who has authority to decide what interoperability "really is" and "is not."

Rather, I treat interoperability as multiple, in the sense that Annemarie Mol characterizes specific disease-states as multiple for different communities of practice, and reality itself as multiple and always in flux. See, Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002), 4-6, 32-6, and *passim*; Annemarie Mol, "Ontological Politics. A Word and Some Questions," *The Sociological Review* 47, no. 1_suppl (May 1999): 74–89.

[8] Health Information Management and Systems Society of North America (HIMSS), "HIMSS Definition of Interoperability" (HIMSS, April 5, 2013), https://www.himss.org/sites/himssorg/files/FileDownloads/HIMSS%20Interoperability%20Definition%20FINAL.pdf; As of this writing in early 2019, the HIMSS definition was being revised by HIMSS membership. For information on the 2019 Revision process, see, HIMSS, "What Is Interoperability?: Defining Interoperability in the Health Ecosystem," March 23, 2019, https://www.himss.org/library/interoperability-standards/what-is-interoperability.

[9] Wendy Hui Kyong Chun. *Programmed Visions: Software and Memory*. Cambridge, MA: MIT Press, 2011, 9 and *passim*.

[10] See, for example, ONC, "Ten-Year Vision" and "Roadmap"

[11] Ibid.

[12] This is part of the *statutory* definition of interoperability in 21st Century Cures. It is highly influential, but not authoritative. Rather, it is one demonstration of the concept's multiplicity.

[13] Yanni A. Loukissas, *All Data Are Local: Thinking Critically in a Data-Driven Society* (Cambridge, MA: The MIT Press, 2019), 1-9.

[14] On foundational discourses in technology studies that pertain to processes of "bringing forth" and partial "appearance" (or "semblance") in the use of technology, I refer readers to the esoteric dialogue between Martin Heidegger in "The Question Concerning Technology" and Hannah Arendt in *The Life of the Mind*, which was published some years later. See, Hannah Arendt, *The Life of the Mind*, A Harvest Book (San Diego, CA: Harcourt, Inc., 1981), 38-40; Martin Heidegger, *The Question Concerning Technology and Other Essays*, trans. William Lovitt (New York: Harper & Row, 1977), *passim*.

[15] On the materialization and rematerialization of objects of knowledge through the entanglement of actors' labor, concepts, and things, see, Michelle Murphy, *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Durham: Duke University Press, 2006), 14.

On the notion of constant double-movement or double-articulation in processes of becoming – toward actualization in reality and also toward being subsumed into the raw stuff of which realities are made, see, Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi (Minneapolis: University of Minnesota Press, 1987), 37-43. All becoming occurs – all things exist – as Deleuze and Guattari say

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elsewhere in regard to the self, “at the threshold” of these two multiplicities of virtuality and actuality, see, 275.

[16] Chun, *Programmed Visions*, 9.

[17] ONC, “Roadmap,” iv-v.

[18] Martin French, “Gaps in the Gaze: Informatic Practice and the Work of Public Health Surveillance,” *Surveillance and Society* 12, no. 2 (2014): 227.

[19] On some of the serious and pervasive quality issues regarding clinical EHR data, see, Taxiarchis Botsis et al., “Secondary Use of EHR: Data Quality Issues and Informatics Opportunities,” *AMIA Joint Summits on Translational Science Proceedings. AMIA Joint Summits on Translational Science* 2010 (March 1, 2010): 1–5.

[20] Chun, *Programmed Visions*, 9

[21] Ibid.

[22] For an excellent history of computing and its ideologies from the perspective of closed systems, see, Paul N. Edwards, *The Closed World: Computers and the Politics of Discourse in Cold War America* (Cambridge, Mass.: MIT Press, 1997). For an alternative perspective on the history of computing that traces the history of open information and standards, see, Andrew L. Russell, *Open Standards and the Digital Age: History, Ideology, and Networks* (New York, NY: Cambridge University Press, 2014).

[23] Richard F. Gillum, “From Papyrus to the Electronic Tablet: A Brief History of the Clinical Medical Record with Lessons for the Digital Age.” *The American Journal of Medicine* 126, no. 10 (October 2013): 853–57; Micky Tripathi, “EHR Evolution: Policy and Legislation Forces Changing the EHR.” *Journal of The American Health Information Management Association* 83, no. 10 (October 2012): 24–29.

[24] Micky Tripathi, “EHR Evolution,” quoting Clement McDonald et al. “The Regenstrief Medical Record System: a quarter century experience.” International Journal of Medical Informatics 54, no. 3 (1999) 226.

[25] Ibid.

[26] Ibid.

[27] See, Lisa Nakamura, “Indigenous Circuits: Navajo Women and the Racialization of Early Electronic Manufacture,” *American Quarterly* 66, no. 4 (2014): 919–41; Wendy Hui Kyong Chun, “On Software, or the Persistence of Visual Knowledge,” *Grey Room* 18 (Winter 2004): 26–51; Marie Hicks, *Programmed Inequality: How Britain Discarded Women Technologists and Lost Its Edge in Computing*, History of Computing (Cambridge, MA London, UK: MIT Press, 2018). See also, Christian Sandvig, “Connection at Ewiiaapaayp Mountain: Indigenous Internet

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Infrastructure," in *Race After the Internet*, ed. Lisa Nakamura and Peter Chow-White (New York: Routledge, 2012).

[28] See, Bruno Latour, *Pandora's Hope: Essays on the Reality of Science Studies* (Cambridge, Mass: Harvard University Press, 1999); Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences*, (New York NY: Vintage Books, 1994): 250; Matthew Jones, "Data Mining: The Critique of Artificial Reason, 1963-2005" (January 11, 2016), https://lsa.umich.edu/digitalstudies/news-events/all-events.detail.html/27030-2308476.html.

[29] Julia Adler-Milstein and Ashish K. Jha, "HITECH Act Drove Large Gains in Hospital Electronic Health Record Adoption," *Health Affairs* 36, no. 8 (August 2017): 1416–22, https://doi.org/10.1377/hlthaff.2016.1651.

[30] HITECH, Subtitle A, Section 3001, b; For a history of ONC, see, ONC, "Interoperability Roadmap," vi-vii.

[31] Congressional Budget Office, "Estimated Impact of the American Recovery and Reinvestment Act on Employment and Economic Output in 2014" (Washington, DC: United States Congress, February 20, 2015), https://www.cbo.gov/publication/49958. Readers are directed to the website of the Government Accountability Office for further reading in the form of a series of reports on issues attending rollout of the EHR Incentive Payment Program and related programs.

[32] Rucker, "Achieving the Interoperability Promise"; Cresswell, Worth, and Sheikh, "Actor-Network Theory and Its Role," 1.

[33] Cresswell, Worth, and Sheikh, "Actor-Network Theory and Its Role," 1.

My approach is also informed by main currents in social theory that center agonism and debate as productive forces in liberal democratic governance. See, Chantal Mouffe, "Deliberative Democracy or Agonistic Pluralism," *Social Research* 66, no. 3 (Fall 1999): 745–58; G. Thomas Goodnight, "The Personal, Technical, and Public Spheres of Argument: A Speculative Inquiry into the Art of Public Deliberation," *Argumentation and Advocacy* 48, no. 4 (March 2012): 198–210; See also, Andrew Knops, "Debate: Agonism as Deliberation - On Mouffe's Theory of Democracy," *Journal of Political Philosophy* 15, no. 1 (March 2007): 115–26.

[34] Tom Boellstorff, "For Whom the Ontology Turns: Theorizing the Digital Real," *Current Anthropology* 57, no. 4 (August 2016): 387–407, https://doi.org/10.1086/687362, 390.

[35] In addition to the diagrammatic method that I describe in the introduction, the close reading of this diagram is motivated by a quote from Friedrich Nietzsche's "Mixed Opinions and Maxims," where he writes that one "criticizes a person, a book, most sharply when one pictures their ideal." See, "Appendix: Seventy-Five Aphorisms from Five Volumes," in *On the Genealogy of Morals and Ecce Homo*, ed. Walter Arnold Kaufmann. (New York: Vintage Books, 2011), 176.

[36] Law, *After Method*, 160; Berg, "Accumulating and Coordinating," 373–401.

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[37] The diagram is a dramatization, in policy, of what Casper Bruun Jensen describes as health records and health information systems functioning as infinitely complex “future-generating devices” for practitioners, following Hans-Jorg Rheinberger. See, Casper Bruun Jensen, “An Experiment in Performative History: Electronic Patient Records as a Future-Generating Device,” *Social Studies of Science* 35, no. 2 (April 2005): 241–67; Hans-Jorg Rheinberger, “Experimental Systems: Historiality, Narration, and Deconstruction,” *Science in Context* 7 (1994): 65–81.

[38] The co-deployment of multiple critical terms with variegated genealogies in this paragraph builds upon the theoretical apparatus that underlies and motivates this dissertation.

My use of “hail” is rooted primarily in Louis Althusser’s formulation of “interpellation” as the moment one recognizes oneself as a product of ideology in *On the Reproduction of Capitalism: Ideology and Ideological State Apparatuses* (London; New York: Verso, 2014), 190-196. However, unlike Althusser, who framed power as a negative operation performed upon the subject by agents of “ISAs,” rather than both a negative and positive operation that produced new sorts of subjects, my usage of “hail” is also more simply meant to denote an act of recognition by an actor in a particular mode of address or object (such as a diagram). Ernesto Laclau and Chantal Mouffe name the act of intentionally calling out to others in the mode that ONC does in its vision papers and calls for public comment an “articulation.” See, *Hegemony and Socialist Strategy: Towards a Radical Democratic Politics*, 2nd ed (London; New York: Verso, 2001).

When one recognizes themselves in a specific mode of address they are hailed – and acts of hailing impart ideologies, create subjects, bring out new constituencies, create new publics, form new polities, enact new stakeholders, and assist in materializing new realities. This is as true in health IT policy as in any other field of activity. This approach is also informed by Michael Warner’s work, particularly in the opening pages of *Publics and Counterpublics*, where he writes that “Publics…have become an almost natural feature of the social landscape, like pavement...Your attention is everywhere solicited by artifacts that say, before they say anything else, *Hello, public!*” (New York, NY: Zone Books, 2002), 7. This is the sort of hailing that ONC’s diagram is doing, to an in-principle-limitless range of actors, whom the office (and I) call “stakeholders.”

My use of “materialize” drawn chiefly from Michelle Murphy, who writes in *Sick Building Syndrome and the Problem of Uncertainty*, on the materialization of physical objects and objects of knowledge, that

> It is not so easy to materialize a new object…At stake in writing a history of the contested reality of chemical exposures is the historicity of what counts as real, of what did and did not matter. To do this, I have conveyed matter, not in terms of a prior thingness but rather in terms of the processes of history, concrete social and technical arrangements and the effects of power – hence my use of the verb *materialize*. (15)

ONC’s diagram works to materialize new knowledge-objects in the way that Murphy describes: tracing the “concrete social and technical arrangements of power” so that actors can imagine new ones in a transformed health IT ecosystem.

My definition of “reality” comes from an assemblage of actor-network theorists such as Murphy, Annemarie Mol, Bruno Latour, and John Law. However, I am chiefly informed by John Law’s approach in essays such as *After Method*, “Notes on the Theory of the Actor-Network:

Ordering, Strategy, and Heterogeneity," and "Seeing Like a Survey." Reality is simply what actors, working together in networks, bring about and sustain: it is what they enact and materialize. See also, Boellstorff, "For Whom the Ontology Turns."

As Law notes in *After Method*, these realities are vaguely constituted, are constantly changing and in flux. When technologies are involved, they need recalibration or what Andrew Pickering calls "'tuning' in the sense of tuning a radio set or car engine...No one knows in advance the shape of future machines and what they will do, but we can track the process of establishing that shape," by following the actions of both human and non-human actors in the network. See, John Law, "Notes on the Theory of the Actor-Network: Ordering, Strategy, and Heterogeneity," *Systems Practice* 5, no. 4 (April 10, 1992): 379–93; John Law, "Seeing Like a Survey," *Cultural Sociology* 3, no. 2 (July 1, 2009): 239–56; Andrew Pickering, *The Mangle of Practice: Time, Agency, and Science* (Chicago, IL: University of Chicago Press, 1995),14-15.

ONC's ecosystem envisions chaotic realities like these, that require constant tweaking, tuning, and tinkering: both in policy and local environments where technologies are used. Describing messy realities requires messy – if also exacting – theorization: theory that, along with the realities toward which it is aimed, *also produces new realities*.

[39] Deleuze and Guattari, *A Thousand Plateaus*, 145-6.

[40] John Dewey, "Search for the Great Community," in *The Public and Its Problems* (Athens: Swallow Press, 1991), 143–84; Michael Warner, "The Mass Public and the Mass Subject," in *Publics and Counterpublics* (New York, NY: Zone Books, 2002).

[41] Karen DeSalvo, "DeSalvo: Health IT Is 'More Than Just EHRs,'" *Biomedical Instrumentation & Technology* 49, no. 1 (January 2015): 55–59.

[42] This is both a finding from fieldwork engagements – including conversations with Douglas – but is also widely reproduced in discourses about "exchange" versus "interoperability" in health IT discourse. See, Douglas Fridsma, "Interoperability vs Health Information Exchange."

[43] Aileen Lee, "Welcome To The Unicorn Club: Learning From Billion-Dollar Startups," *TechCrunch*, November 2, 2013, https://techcrunch.com/2013/11/02/welcome-to-the-unicorn-club/; Howie Xu, "In Venture Capital, It's Still the Age of the Unicorn: In Five Years, Unicorn Startups Have Gone from a Rare Breed to the New Normal," *TechCrunch*, November 11, 2018, https://techcrunch.com/2018/11/11/age-of-the-unicorn/.

[44] Megan Daugherty Douglas, "Almost-Standard Gauge: Misadventures in Interoperability" (June 11, 2016).

[45] Rucker, "Automation in Healthcare is Transforming Medicine."

[46] Health Level-7 International (HL7), "Introduction to HL7 Standards" (HL7, n.d.), http://www.hl7.org/implement/standards/.

[47] National Library of Medicine (NLM), "NLM Health Data Standards Executive Summary for 2016," 2016, http://wayback.archive-it.org/org-

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350/20170420135011/https://www.nlm.nih.gov/healthit/executive-summaries/2016.html. See also, National Library of Medicine (NLM), "A Platform for Biomedical Discovery and Data-Powered Health: Strategic Plan 2017–2027" (Bethesda, MA: National Institutes of Health, December 2017), https://www.nlm.nih.gov/pubs/plan/lrp17/NLM_StrategicReport2017_2027.pdf.

[48] I lift this term from Bryan Pfaffenberger, "Technological Dramas," *Science, Technology, & Human Values* 17, no. 3 (July 1992): 282–312, https://doi.org/10.1177/016224399201700302.

[49] On "partial perspectives," see, Donna Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." In *Simians, Cyborgs, and Women: The Reinvention of Nature*, 183–202. New York: Routledge, 1991.

[50] Michel Callon et al., *Acting in an Uncertain World: An Essay on Technical Democracy*, 1. paperback ed, (Cambridge: MIT Press, 2011), 9.

[51] Ibid.

[52] Callon et al., *Acting*; see also, Josh Boyd, "Public and Technical Interdependence: Regulatory Controversy, Out-Law Discourse, and the Messy Case of Olestra," *Argumentation and Advocacy* 39, no. 2 (September 2002): 91–109, https://doi.org/10.1080/00028533.2002.11821579; Goodnight, "The Personal, Technical, and Public Spheres of Argument"

[53] David Harvey, "The Neoliberal State," in *A Brief History of Neoliberalism*, Reprinted (Oxford: Oxford Univ. Press, 2011), 64–86.

[54] HITECH, Section 3002 established the Health IT Policy Committee. This entity would later be converted into the Health Information Technology Advisory Committee by 21st Century Cures, Section 3002.

[55] Health Information Technology Advisory Committee, "Recommendations to the National Coordinator for Health IT" (The Office of the National Coordinator for Health Information Technology (ONC), 2019), https://www.healthit.gov/topic/federal-advisory-committees/recommendations-national-coordinator-health-it.

[56] Health Information Technology Advisory Committee, "Health IT Policy Committee" (The Office of the National Coordinator for Health Information Technology (ONC), 2019), https://www.healthit.gov/hitac/committees/health-it-policy-committee.

[57] Health Information Technology Advisory Committee, "Health IT Standards Committee" (The Office of the National Coordinator for Health Information Technology (ONC), 2019), https://www.healthit.gov/hitac/committees/health-it-standards-committee.

[58] Health Information Technology Advisory Committee, "Health Information Technology Advisory Committee (HITAC)" (The Office of the National Coordinator for Health Information

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Technology (ONC), 2019), https://www.healthit.gov/hitac/committees/health-information-technology-advisory-committee-hitac.

[59] In addition to a normal public comment period, individual entries in the *Interoperability Standards Advisory* have open comment sections that remain open; see, for example, the "sexual orientation" entry: https://www.healthit.gov/isa/representing-patient-identified-sexual-orientation. This was also communicated at the 2017 ONC Annual Meeting. See, "Advancing Interoperability Through Recognized Standards: ONC's Interoperability Standards Advisory (Conference Panel)." Washington, DC, 2017.

[60] AcademyHealth, "2019 Health Datapalooza: A Decade of Turning Information into Innovation." (Washington, DC, 27-28 2019), https://www.academyhealth.org/events/2019-03/2019-health-datapalooza.

[61] Office of the National Coordinator for Health Information Technology (ONC), "2018 Interoperability Standards Advisory Reference Edition," 2018, https://www.healthit.gov/isa/sites/default/files/2018%20ISA%20Reference%20Edition.pdf.

[62] Office of the National Coordinator for Health Information Technology (ONC), "Cypress - QRDA-CQM Sandbox," https://sitenv.org/sandbox-qrm-cqm.

[63] Russell, *Open Data*; Rob Kitchin, *The Data Revolution: Big Data, Open Data, Data Infrastructures and Their Consequences* (Thousand Oaks, CA: SAGE Publications Ltd, 2014).

[64] See, Wendy Hui Kyong Chun, *Control and Freedom: Power and Paranoia in the Age of Fiber Optics* (Cambridge, Mass.: MIT Press, 2006); Alexander R. Galloway, *Protocol: How Control Exists After Decentralization* (Cambridge, MA: MIT Press, 2004).

[65] For this section, I owe a particularly large debt of gratitude to my colleague and interlocutor Megan D. Douglas. See also, Douglas, Megan Daugherty, Daniel E. Dawes, Kisha B. Holden, and Dominic Mack. "Missed Policy Opportunities to Advance Health Equity by Recording Demographic Data in Electronic Health Records." *American Journal of Public Health* 105, no. S3 (July 2015): S380–88. https://doi.org/10.2105/AJPH.2014.302384.

[66] ONC. "Health IT Certification Program Overview." The Office of the National Coordinator for Health Information Technology (ONC), January 30, 2016. https://www.healthit.gov/sites/default/files/PUBLICHealthITCertificationProgramOverview_v1.1.pdf.

[67] Harvey, *A Brief History*, 64-87.

[68] Centers for Medicare and Medicaid Services, "Stages of Promoting Interoperability Programs" (Washington, DC, 2018), https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stages_ofMeaningfulUseTable.pdf.

[69] Ibid.

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[70] Several weeks before this dissertation was submitted, a draft Notice of Proposed Rulemaking on this topic was published by ONC at the HIMSS Annual Meeting.

[71] Matt Kendall, "Regional Extension Centers Working to Assist Providers to Achieve Meaningful Use of Electronic Health Record Systems" (2010), https://www.hhs.gov/opa/sites/default/files/regional-extension-centers.pdf; ONC, "Regional Extension Centers (RECs)" (The Office of the National Coordinator for Health Information Technology (ONC), 2010), https://www.healthit.gov/topic/regional-extension-centers-recs.

[72] HHS Press Office, "HHS Proposes New Rules to Improve the Interoperability of Electronic Health Information," February 11, 2019, https://www.hhs.gov/about/news/2019/02/11/hhs-proposes-new-rules-improve-interoperability-electronic-health-information.html.

[73] The murkiness of the distinction between Meaningful Use and EHR certification requirements is only one dimension of the lack of shared understandings of these programs among stakeholders. In the case of LGBTQ health advocates, during interviews and conversations during fieldwork, it was not always clear that they understood several details about the exact location of sexual orientation and gender identity (SO/GI) standards in health IT certification requirements. Specifically, SO/GI data elements were required in the "demographics" section of the 2015 "Base EHR Definition," but not in the Common Clinical Data Set (CCDS). The location of SO/GI standards in the "demographics" section of the Base EHR Definition versus the CCDS would become important during regulations and frameworks issued later, such as the United States Core Data for Interoperability (USCDI) data set, which is not considered in this dissertation. Source: correspondence and interviews with LGBTQ health policy advocates during 2017 and 2018. Also see, Sean R. Cahill et al., "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health," *LGBT Health* 3, no. 2 (April 2016): 100–102, https://doi.org/10.1089/lgbt.2015.0136.

[74] Ibid.

[75] Pipek and Wulf, "Infrastructuring," 447–73.

[76] HRSA HIV/AIDS Bureau, "Using Technology to Improve Health Outcomes," August 2014; HRSA HIV/AIDS Bureau, "Program Fact Sheet: Part F: Special Projects of National Significance (SPNS) Program," December 2016, http://bit.ly/2VKSPO9; Pamela Belton et al., "Special Projects of National Significance (SPNS) Program (Ryan White HIV Program Part F): A Presentation for the Division of State HIV/AIDS Programs" (August 30, 2017), http://bit.ly/2FpU9k4, 8.

[77] On "late-stage" gentrification, see, Japonica Brown-Saracino, *A Neighborhood That Never Changes: Gentrification, Social Preservation, and the Search for Authenticity* (Chicago; London: The University of Chicago Press, 2009), 203-9.

[78] On the affective experience of coding as a combination of euphoric highs, crushing lows, and superhuman feats that involve coders entirely "[submitting] their will and being to technology,"

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see, E. Gabriella Coleman, *Coding Freedom: The Ethics and Aesthetics of Hacking* (Princeton: Princeton University Press, 2013), 13.

[79] See, Julia Adler-Milstein et al., "Electronic Health Record Adoption in US Hospitals: The Emergence of a Digital 'Advanced Use' Divide," *Journal of the American Medical Informatics Association* 24, no. 6 (November 1, 2017): 1142–48, https://doi.org/10.1093/jamia/ocx080; Julia Adler-Milstein and Ashish K. Jha, "HITECH Act Drove Large Gains"; Kathrin Cresswell, Allison Worth, and Aziz Sheikh, "Implementing and Adopting Electronic Health Record Systems: How Actor-network Theory Can Support Evaluation," *Clinical Governance: An International Journal* 16, no. 4 (October 18, 2011): 320–36, https://doi.org/10.1108/14777271111175369; Megan Daugherty Douglas et al., "Missed Policy Opportunities"; Melissa M. Goldstein and Hyatt Thorpe Jane, "The First Anniversary of the Health Information Technology for Economic and Clinical Health (HITECH) Act: The Regulatory Outlook for Implementation," *Perspectives in Health Information Management* 7 (September 1, 2010); John Thune et al., "REBOOT: Re-Examining the Strategies Needed to Successfully Adopt Health IT" (United States Senate, April 16, 2013), https://www.amia.org/sites/default/files/files_2/EHR-White-Paper.pdf.

[80] Critiques and ethical analyses of new surveillance practices – along with uses and re-uses of person-level data – abound in contemporary digital studies, data studies, big data studies, and scholarship on medical information systems.

On the ethics of big data, see, Wenhong Chen and Anabel Quan-Haase, "Big Data Ethics and Politics: Toward New Understandings," *Social Science Computer Review*, November 14, 2018; James Popham, Jennifer Lavoie, and Nicole Coomber, "Constructing a Public Narrative of Regulations for Big Data and Analytics: Results from a Community-Driven Discussion," *Social Science Computer Review*, August 28, 2018.

Literature that addresses ethical issues in new uses of health data, with particular attention to the re-use of EHR data, alternative approaches to patient data governance, and novel models of negotiating and ensuring patient control over their data includes: Nancy E. Kass and Ruth R. Faden, "Ethics and Learning Health Care: The Essential Roles of Engagement, Transparency, and Accountability," *Learning Health Systems* 2, no. 4 (October 2018); Lisa M. Lee, "Ethics and Subsequent Use of Electronic Health Record Data," *Journal of Biomedical Informatics* 71 (July 2017): 143–46; Adam Tanner, *Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records* (Boston: Beacon Press, 2016); Adam Tanner, "Patient Consent and the Commercialization of Lab Data," *Clinical Chemistry* 63, no. 2 (February 2017): 475–76; Corey M. Angst, "Protect My Privacy or Support the Common-Good? Ethical Questions About Electronic Health Information Exchanges," *Journal of Business Ethics* 90, no. S2 (November 2009): 169–78; Mhairi Aitken et al., "Public Responses to the Sharing and Linkage of Health Data for Research Purposes: A Systematic Review and Thematic Synthesis of Qualitative Studies," *BMC Medical Ethics* 17, no. 1 (December 2016); Trisha Greenhalgh et al., "Tensions and Paradoxes in Electronic Patient Record Research: A Systematic Literature Review Using the Meta-Narrative Method: Electronic Patient Record Research," *Milbank Quarterly* 87, no. 4 (December 2009): 729–88; A. Geissbuhler et al., "Trustworthy Reuse of Health Data: A Transnational Perspective," *International Journal of Medical Informatics* 82, no. 1 (January 2013): 1–9; Samantha Adams, Nadezhda Purtova, and Ronald Leenes, eds., *Under Observation: The Interplay Between EHealth and Surveillance*, 2017; Steven C. Tiell et al., "Informed

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Consent and Data in Motion: Preventing Unintended Consequences through Stronger Data Ethics" (Accenture Labs, 2016).

See also, John Cheney-Lippold, *We Are Data: Algorithms and the Making of Our Digital Selves* (New York: New York University Press, 2017); Alexander R. Galloway, *The Interface Effect* (Cambridge, UK; Malden, MA: Polity, 2012); Wendy Hui Kyong Chun, *Updating to Remain the Same: Habitual New Media* (Cambridge, MA: The MIT Press, 2016).

[81] Matthew Rosenberg, "Professor Apologizes for Helping Cambridge Analytica Harvest Facebook Data," *The New York Times*, April 22, 2018, https://www.nytimes.com/2018/04/22/business/media/cambridge-analytica-aleksandr-kogan.html.

[82] For an STS-oriented analysis of the wide-ranging ethical problems raised by uses of person-level psychometric data in "big data" sets held by social media firms that the Cambridge Analytica scandal raises, see, Luke Stark, "Algorithmic Psychometrics and the Scalable Subject," *Social Studies of Science* 48, no. 2 (April 2018): 204–31.

[83] See, Jacob Kastenakes, "Facebook Spoke with Hospitals about Matching Health Data to Anonymized Profiles," *The Verge*, April 5, 2018, http://bit.ly/2VKvcFp.

[84] In *Big Data, Little Data, No Data: Scholarship in the Networked World*, Christine Borgman emphasizes the utility of using languages of spatiality and velocity to conceptualize the expansion of data infrastructures and the movement of data across networks: (Cambridge, Massachusetts: The MIT Press, 2015).

[85] ONC, "Federal Health IT Strategic Plan," 25.

[86] Julia Adler-Milstein et al., "Electronic Health Record Adoption in US Hospitals."

[87] See, Megan Daugherty Douglas et al., "Missed Policy Opportunities to Advance Health Equity"

[88] See, Verizon, "2018 Data Breach Investigations Report" (New York, NY: Verizon, 2018). https://enterprise.verizon.com/resources/reports/dbir/, 5; Deloitte and National Association of State Chief Information Officers, "States at Risk: Bold Plays for Change: A Joint Report from Deloitte and the National Association of State Chief Information Officers" (Washington, DC, October 2018); Jennifer Burnett, "Not If, But When," *CSG E-Newsletter*, August 2017, http://bit.ly/2VJkbo; Protenus in collaboration with DataBreaches.net, "Q3 2018 Protenus Breach Barometer Report: Insider-Wrongdoing Accounts for Increasing Number of Breached Patient Records over the Course of 2018" (Baltimore, MD, October 2018), http://bit.ly/2RJsDEG; Diana Manos, "Hacking and Mega-Breaches: 2018 the Worst Year Yet?," *Healthcare IT News (HIMSS Media)*, November 16, 2018, https://shar.es/aaTluY.

[89] See, for example: Joan Rodon Mòdol, "Citizens' Cooperation in the Reuse of Their Personal Data: The Case of Data Cooperatives in Healthcare," in *Collaboration in the Digital Age*, ed. Kai Riemer, Stefan Schellhammer, and Michaela Meinert (Cham: Springer International Publishing,

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[90] Chun, *Control and Freedom*; danah boyd and Kate Crawford, "Six Provocations for Big Data," *SSRN Electronic Journal*, 2011, https://doi.org/10.2139/ssrn.1926431; Matt Jones, "Data Mining."

[91] Aitken et al., "Public Responses to the Sharing and Linkage of Health Data"; Geissbuhler et al., "Trustworthy Reuse of Health Data"; Lee, "Ethics and Subsequent Use of Electronic Health Record Data"; Purtova, "Health Data for Common Good"

[92] Wullianallur Raghupathi and Viju Raghupathi, "Big Data Analytics in Healthcare: Promise and Potential," *Health Information Science and Systems* 2, no. 1 (December 2014), https://doi.org/10.1186/2047-2501-2-3; Tanner, *Our Bodies, Our Data*; Tanner, "Patient Consent and the Commercialization of Lab Data."

[93] Joan Rodon Mòdol, "Citizens' Cooperation"; Finn Brunton and Helen Nissenbaum, "Vernacular Resistance to Data Collection and Analysis"; Jonah Bossewitch and Aram Sinnreich, "The End of Forgetting: Strategic Agency beyond the Panopticon," *New Media & Society* 15, no. 2 (March 2013): 224–42, https://doi.org/10.1177/1461444812451565; John Cheney-Lippold, *We Are Data*; Zach Blas, "Queer Technologies," n.d., http://www.zachblas.info/projects/queer-technologies/; Claudia Aradau and Tobias Blanke, "The (Big) Data-Security Assemblage: Knowledge and Critique," *Big Data & Society* 2, no. 2 (December 27, 2015), https://doi.org/10.1177/2053951715609066; Stefania Milan, "Political Agency, Digital Traces, and Bottom-Up Data Practices," *International Journal of Communication* 12 (2018): 507–27.

[94] Per Galloway and Thacker:

> Protocological struggles do not center around changing existent technologies, but instead involve discovering holes in existent technologies and projecting potential change through these holes. Hackers call these holes "exploits."
>
> Thinking in these terms is the difference between thinking socially and thinking informatically, or the difference between thinking in terms of probability and thinking in terms of possibility. Informatic spaces do not bow to political pressure or influence, as social spaces do. But informatic spaces do have bugs and holes, a byproduct of high levels of technical complexity, which make them as vulnerable to penetration and change as would a social actor at the hands of more traditional political agitation.

The Exploit: A Theory of Networks (Minneapolis: University of Minnesota Press, 2007), 81-2.

[95] See, Steve Morgan, "2018 Cybersecurity Market Report: Cybersecurity Ventures Predicts Global Cybersecurity Spending Will Exceed $1 Trillion from 2017 to 2021" (Menlo Park, CA,

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May 31, 2017), https://cybersecurityventures.com/cybersecurity-market-report/; Gaurav Pendse, "Cybersecurity: Industry Report and Investment Case" (New York, NY: NASDAQ, June 25, 2018), https://business.nasdaq.com/marketinsite/2018/GIS/Cybersecurity-Industry-Report-Investment-Case.html.

[96] Per the investigation outcome, accessed through the HHS HIPAA breach portal:

> Montana Department of Public Health and Human Services, the covered entity (CE), experienced a server hacking incident due to an undetected and unpatched application code vulnerability, which allowed misuse of its information system resources for about 9 months. The incident affected over 1 million individuals' demographic, clinical, and/or financial information. Upon discovery, the CE immediately took the affected server offline, reported the incident to state and federal law enforcement, and conducted an investigation with assistance from an independent forensics firm. The CE provided breach notification to HHS, affected individuals, and the media. It also set up a call center and offered credit monitoring and identity theft services for all eligible individuals. OCR confirmed that the CE implemented a number of corrective actions as a result of this incident, including technical enhancements and safeguards to protect its information systems and network resources. OCR provided substantial technical assistance, and the CE implemented alternate safeguards, policies, and procedures to more effectively identify and remediate potential vulnerabilities in its server-hosted applications."

[97] Elizabeth Snell, "How Ransomware Affects Hospital Data Security," *Health IT Security*, 2016, https://healthitsecurity.com/features/how-ransomware-affects-hospital-data-security; Kim Zetter, "Why Hospitals Are the Perfect Targets for Ransomware," *WIRED Magazine*, March 30, 2016, https://www.wired.com/2016/03/ransomware-why-hospitals-are-the-perfect-targets/.

Chapter 3. Standardizing Sexuality and Gender in the Nationwide Health IT Infrastructure: The "Do Ask, Do Tell" Campaign, "SO/GI," and Data Ontology Management

I. Introduction

For decades, using slogans such as “if they don’t count us, we don’t count,” and “#CantEraseUs,” LGBTQ advocacy organizations and queer demographers in the United States have argued that data collection about sexual and gender minorities on surveys, in health records, and in other data gathering instruments is vital to the individual and collective good of LGBTQ people and to the success of the LGBTQ political movement.[1] These arguments are extensions of visibility politics that first took root in the 1970s gay liberation movement and continue to shape LGBTQ politics through to the present. Queer visibility politics are rooted in the idea that “coming out” as LGBTQ to one’s family, friends, medical providers, employers, and others is a critical strategy for reducing discrimination, creating queer social worlds, building a political base for more queer-affirming policies, and that disclosure of one’s status as queer or trans is generally a vital tactic in the struggle for sexual and gender minority wellbeing.[2]

During the presidential administration of Barack Obama (January 2009-January 2017), the LGBTQ health movement saw major federal gains in this area, with the administration prioritizing LGBTQ data collection as part of sweeping reform processes aimed at incorporating the interests of LGBTQ health actors into the federal health policy apparatus. Sociologist Steven Epstein has documented limited practices of LGBTQ “inclusion” in previous decades. However, Obama administration initiatives led to new levels of LGBTQ “incorporation” into the federal policy apparatus in healthcare and other areas that far exceeded inroads made by the LGBTQ health movement under any previous administration.[3]

The proactive integration of LGBTQ health advocates' priorities into federal policy and the nation's health infrastructures was both central to – and driven by – the concomitant emergence of a new consensus in LGBTQ health in the 2010s. This consensus – driven by both private sector actors and federal government entities – yielded increased financial and research support for the cause of LGBTQ health and the recognition of LGBTQ people as a "health disparities group" or "key population." Major institutions that contributed to the new consensus included federal agencies such as the Centers for Medicare and Medicaid Services (CMS) and other branches of the Department of Health and Human Services (HHS), key civil society organizations beginning to take up LGBTQ issues or to take positions on matters of LGBTQ human rights, and major healthcare institutions such as learned societies and healthcare accreditation organizations incorporating LGBTQ criteria into their governing or certification documents.[4]

The biopolitical incorporation of sexual and gender minority health advocates' interests into the federal policy apparatus is also best understood as a central part of a sea change in federal policies toward LGBTQ people. These included more highly-visible developments that were widely covered in the media such as the repeal of the U.S. military's "Don't Ask, Don't Tell" policy in 2010, the judicial repeal of the 1996 Defense of Marriage Act in *United States v. Windsor* in 2013, and the legalization of same-sex marriage by the Supreme Court in the *Obergefell v. Hodges* decision in 2015. As these widely-publicized events unfolded, so did the investment of substantial federal resources into the development of new LGBTQ health research agendas, the validation of sexual orientation and gender identity (SO/GI) measures on surveys, and the addition of LGBTQ populations into data collection priorities across a variety of federal data collection apparatuses.

History may prove gains made by the LGBTQ movement during the Obama years to be fleeting. Further, more queer and trans-affirming federal policies do not always equate to improved material conditions in the everyday lives of LGBTQ people (especially for multiply-marginalized queers).[5] However, the influence of the Obama administration's reforms on the place of sexual and gender minority populations in federal policy – and, as an extension of this, into biomedical and public health practice – during the 2010s cannot be denied. During this period, LGBTQ people went from the relative margins of federal health policy to somewhere nearer to the center. And as I show herein, the development of queer and trans-affirming federal policies during this period are particularly pronounced in health policy, healthcare, and in efforts to standardize and promote the collection of LGBTQ data in health contexts.

However, starting in 2017, tides began to turn in the other direction for LGBTQ health advocates. In addition to potential federal policy changes affecting the rights of trans and gender non-conforming people under interpretations of "sex" in U.S. federal civil rights provisions and the launch of a "Conscience and Religious Freedom Division" at the department, the administration of Donald Trump has successfully proposed to retroactively remove sexual orientation and gender identity data from several federal surveys where the questions had been added, including from the 2020 Census. As these proposals have been put forward or moved ahead, LGBTQ advocates, HIV/AIDS organizations, statisticians, and health experts have also stood in relatively united solidarity to resist them – sometimes even engaging in highly public campaigns to marshal support for the cause of protecting existing policies and data collection practices by federal agencies and federally-administered surveys. In addition to the removal of

LGBTQ survey questions, other efforts to advance LGBTQ health in federal policy have stopped or stalled. These include the existence of LGBTQ coordinating entities at HHS and agencies within the department, and White House staff dedicated to sexual and gender minority issues. The future of many recent advances in federal LGBTQ policy are very unclear.

However, this chapter focuses on the campaign to incorporate sexual orientation and gender identity (or, again, what advocates call "SO/GI") data standards into the nationwide interoperable health IT infrastructure during the Obama era. I focus especially on the 2012-2015 "Do Ask, Do Tell" campaign led by Fenway Health – an LGBTQ health clinic and policy organization founded in 1971 at the dawn of the gay liberation movement – and the Center for American Progress (CAP), a liberal think tank. I tell the story of how these organizations leveraged the new consensus in LGBTQ health, efforts to incorporate LGBTQ-oriented priorities into the national health architecture, and the federal push to digitize the healthcare system as part of the federal economic stimulus package to incorporate SO/GI standards into the national health IT infrastructure.

In recounting this story, I explore the various frictions – data frictions and conceptual frictions – that have shaped the emergence and material existence of sexual orientation and gender identity in federal policy and among an interdisciplinary range of biomedical actors in clinical and public health settings in Atlanta and New England.[6] I articulate SO/GI health IT standards as adopted by the Office of the National Coordinator for Health Information Technology (ONC) as "exceptional standards," owing to the specific form of technical guidance governing their incorporation into health IT systems and electronic health record certification criteria issues in 2015. These regulations required certain SO/GI classifications to be displayed differently on-screen than they appeared in the underlying documentation architecture, which used terms that LGBTQ advocates claimed to be outdated or even offensive. I describe how the implementation of the standards in clinical environments and health IT infrastructures are staging new data management strategies and clinical ontologies related to sexuality and gender. I also discuss SO/GI standards' uncertain future in an era where SO/GI measures and LGBTQ health advances in federal policy are under active threat from within the federal apparatus and from outside actors aligned with the right-wing.

II. The New Consensus in LGBTQ Health, the 2011 Institute of Medicine LGBT Health Report, and SO/GI Data as Wellspring

The new consensus in LGBTQ health developed in the United States following the release of a landmark 2011 Institute of Medicine (IOM) report called *The Health of LGBT People: Building a Foundation for Better Understanding*, along with several other critical developments in federal policy and governance related to sexual and gender minority wellbeing. These reforms extend beyond federal policy advances and include major civil society institutions, healthcare professional and facilities accreditation bodies, an increase in research and publication led by NIH, and concerted efforts to incorporate the interests of LGBTQ health advocates into the private and public healthcare systems. However, the IOM report was the most critical element in solidifying the new consensus. It set the trajectory moving ahead for LGBTQ health policy and research, defined the baseline of known issues regarding the health needs of LGBTQ subpopulations, and centralized the "gold standard" definitions for key terms and known issues in LGBTQ health.[7]

Major developments in the new consensus in LGBTQ health can be grouped into four areas of policy development. The first is the introduction of LGBTQ health objectives into guiding federal documents such as *Healthy People 2020* (which sets public health goals for the country), into strategic plans issued by entities such as the Department of Health and Human Services (HHS) Data Councils Executive Committee, and into the basic requirements of healthcare facility accreditation bodies like The Joint Commission and continuing education requirements for some medical provider and health professional associations. The second area of policy development encompassed the official recognition by HHS, and major healthcare groups such as American Medical Association and the American Public Health Association that LGBTQ populations are a "disparity group" alongside racial and ethnic minorities, people with disabilities, indigenous people, women, the poor, and other groups.[8] The third area of policy development was the creation of dedicated coordinating entities for LGBTQ health at the all-HHS or agency-specific level in the form of groups like the LGBT Issues Coordinating Committee (which reported directly to the HHS secretary and issued annual reports during the Obama years) and the National Institutes of Health Sexual and Gender Minority Research Office, or at the cross-agency level, such as the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity or White House employees dedicated to LGBTQ issues. The fourth was official policy advocating for or requiring standardized and improved sexual and gender minority research agendas, increased funding dedicated to LGBTQ health research and services, and support for the implementation of LGBTQ data collection in a multiplicity of contexts: from the highest governing entities at HHS, the National Center for Health Statistics at CDC, NIH governing bodies, and the Office of the National Coordinator of Health Information Technology (ONC) to the most localized contexts such as provider-patient interactions in federally-funded community health centers. These entities, called Federally Qualified Health Centers (FQHCs), constitute much of the country's clinical public health safety net, and have been required to collect and report SO/GI data on all clients as of 2016; this was a critical aspect of LGBTQ incorporation led by HHS.[9]

Together, these four areas of policymaking – each in and of themselves sprawling and wide-reaching in scope and effect – provided the material, legal, and discursive basis for meaningful transformations in LGBTQ health that were driven by federal activity and which took place from 2009-2017. They are the foundation of the new consensus in LGBTQ health as it has come into material existence, and are the key drivers of LGBTQ incorporation at HHS.

While the groundwork for many of these efforts had been laid by LGBTQ advocates working with the Obama administration since before the 2011 IOM report was released,[10] the report centralized many recommendations pertaining to the development of federal sexual and gender minority health policies, solidified and presented the consensus of an interdisciplinary collection of experts in sexual and gender minority health on critical issues in LGBTQ health, provided gold standard definitions of critical terms and problem areas in LGBTQ health, and set the trajectory for nearly all sexual and gender minority health reforms that followed its release. This is because IOM plays an official advisory role to HHS. Taken together with President Obama and HHS Secretary Kathleen Sebelius's commitment to making LGBTQ health a priority for the administration during Obama's first term as an element of broader healthcare reform efforts – particularly those following passage of the Patient Protection and Affordable Care Act of 2010 and of HITECH in 2009 – the IOM report was a kind of super-catalyst for policy change and the incorporation of LGBTQ actors' interest into multiple federal apparatuses. It is a kind of reference document for the new consensus in LGBTQ health, and also played a major role in creating this new consensus and bringing it about in policy and reality.

Data as Primary in The New Consensus

Four of the seven recommendations in the IOM report pertained to the development, validation, implementation, standardization, and alignment of sexual and gender minority health research agendas and SO/GI data elements. These included (1) the development of an NIH research agenda on topics related to LGBTQ health, (2) the incorporation of SO/GI questions into the battery of demographic questions asked on federal surveys, (3) the collection of SO/GI data in electronic health records, and, crucially, (4) the "development and standardization of sexual orientation and gender identity measures" that would "assist in synthesizing scientific knowledge about the health of sexual and gender minorities" across increasingly-interoperable health IT systems used by clinical, research, and public health infrastructures in what ONC characterizes as local, regional, and nationwide "health IT ecosystems."[11]

Beyond enhancing the wellbeing of LGBTQ people, incorporating standardized SO/GI data collection and building SO/GI data into clinical and informatics workflows were framed as a kind of wellspring from which a potentially limitless number of other positive outcomes would flow for patients, providers, healthcare organizations, and the entire healthcare system. These ranged from improved organizational culture in clinics, better LGBTQ "cultural competency" or sensitivity in the provision of services, better quality management practices in healthcare organization management, and stronger health IT network architectures.

Frictions: "SO" and "GI" as Structured Data Elements in Survey Research and Medical Records Versus "Sexual Orientation" and "Gender Identity" as Concepts

Data collection and the development of cognitively tested and validated SO/GI measures were central focuses of federal LGBTQ health policy reforms that followed from the new consensus. However, this is but one aspect of a whole range of research developments in sexual and gender minority health that go beyond the development of metrics for SO/GI – research focused on better understanding the specific disparities faced by sexual and gender minority populations, and a multiplicity of topics falling under the umbrella of sexual and gender minority health. To wit, NIH engaged in a multi-year strategy involving a Request for Information and the development of a strategic plan to execute both the IOM report's recommendations and the information it gathered from stakeholders during the construction of the strategic plan.[12] The research that has followed from the agenda set by NIH and other major institutional actors is presently changing understandings of sexual orientation and gender identity as concepts in biomedicine and other contexts. That is an expansive territory, and tracing the work involved in the conceptual evolution of sexual orientation and gender identity and the full range of issues in sexual and gender minority health is not my task here.[13] Instead, I am interested in mapping how the dominant biomedical definitions of sexual orientation and gender identity have been operationalized in instruments used to capture data about them in structured formats in health IT systems that are useful to researchers, informaticists, and others who work with datasets that include data about sexual orientation and gender identity.

Therefore, the baseline definitions I use for sexual orientation and gender identity come from the 2011 IOM report (which remains essentially unchanged from the vantage of 2019). In this framing, "sexual orientation" is a composite and relational characteristic defined by one's (1) personally-held "sexual identity" or "self-identification" (e.g. gay, lesbian, bisexual, straight, or queer), (2) their "sexual behaviors" (usually measured as penile, oral, vaginal, or anal sex with a partner of one or another gender), and (3) their "sexual attractions" to persons of one or another gender.[14] The gold standard metric for sexual orientation is an amalgam of all three elements collected using multiple questions using a single instrument. However, IOM notes that any of the three elements, or any two or more gathered in combination with one another, constitute the collection of data about sexual orientation, writing that "most researchers studying sexual orientation have defined it operationally in terms of one or more of these three components."[15] Data collection about any three of these elements is data collection about sexual orientation, but collection of all three elements is ideal and thus the gold standard.

"Sexual orientation" does not capture a great deal of other aspects of "sexuality," which is a far more capacious concept than sexual orientation in any of its current or historical dimensions. Sexuality, in addition to being an aspect of an individual's self, is also a system that structures and orders society.[16] Sexual orientation also has a more complicated history than I am able to explore here.[17] Therefore, for the purposes of this chapter, the IOM gold standard definition of sexual orientation is the one that I adopt.

"Gender Identity," per IOM "refers to a person's basic sense of being a man or boy, a woman or girl, or another gender (e.g., transgender, bigender, or gender queer—a rejection of the traditional binary classification of gender)." It is distinct from the concept "sex" or "sex assigned at birth," and "gender expression."[18]

From this point forward in this chapter, when I am referring to sexual orientation (or one of its three elements – identities, attractions, and behaviors) and gender identity as concepts, I use the full term. However, when I say "SO/GI," "SO," or "GI," I am referring to structured data elements that ask the respondent or patient *a single question* about their "sexual orientation" or "gender identity" to populate a field in a survey or medical record. Usually, the fields are presented as in Figure 3.1, below, which I extract from a 2016 Fenway Health publication intended to educate healthcare providers on how to collect "SO/GI data" in electronic health records (EHRs), and which reflect both best practices for "SO/GI" data collection in medical records and health IT standards adopted by the Office of the National Coordinator for Health IT (ONC) in 2015 at Fenway's recommendation, as I explain herein.

Figure 3.1. SO/GI Questions from the 2016 Fenway Educational Pamphlet "Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records"[19]

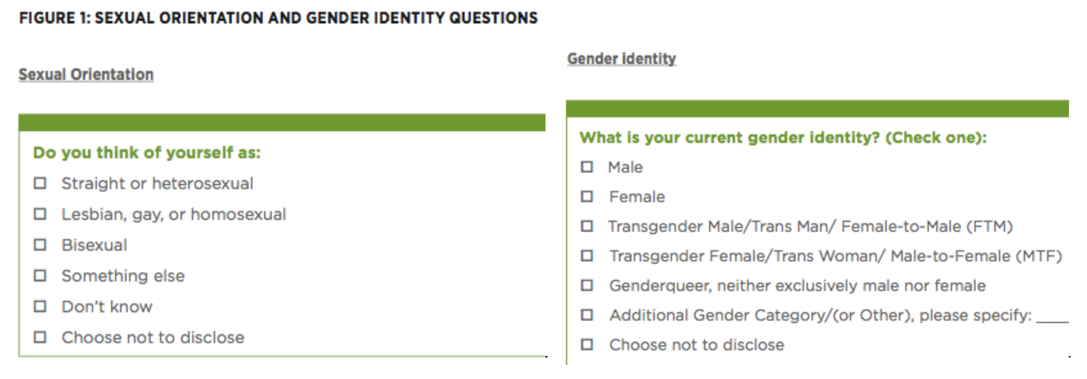


FIGURE 1: SEXUAL ORIENTATION AND GENDER IDENTITY QUESTIONS

Sexual Orientation

Do you think of yourself as:

- ☐ Straight or heterosexual
- ☐ Lesbian, gay, or homosexual
- ☐ Bisexual
- ☐ Something else
- ☐ Don't know
- ☐ Choose not to disclose

Gender identity

What is your current gender identity? (Check one):

- ☐ Male
- ☐ Female
- ☐ Transgender Male/Trans Man/ Female-to-Male (FTM)
- ☐ Transgender Female/Trans Woman/ Male-to-Female (MTF)
- ☐ Genderqueer, neither exclusively male nor female
- ☐ Additional Gender Category/(or Other), please specify: ____
- ☐ Choose not to disclose

Critically – and to reiterate what I have already said, so as to impress upon the reader the importance of understanding this specific point for the analysis that herein – the questions in Figure 3.1 are not the only ways to measure sexual orientation and gender identity. However, they are the questions that LGBTQ health proponents chose to advocate for in the health IT and clinical data collection contexts in the 2010s. This will become crucial to understand during my attempts to describe when an instance of "sexual orientation" data collection can be said to have occurred. As I show, differently-positioned actors have divergent views or perceptions about this; these reflect ontological differences in their understanding of sexual orientation and their day-to-day uses of different kinds of data about sexuality.

Cognitively tested and validated metrics exist to measure all three elements of a person's sexual orientation: their sexual identity or self-identification (as gay, lesbian, bisexual, straight, et cetera), their behaviors (the sorts of people with whom they have had sex or the kinds of sex they have had – usually in the past 12 months), and their attractions (the kinds of people to whom they feel sexually or amorously drawn). However, as I will show, "SO" data are usually gathered using a one-element question that is about identity, as in Figure 3.1. These were not only the health IT standards lobbied for by LGBTQ health advocates, but are also the only data that many influential actors and practitioners in LGBTQ health believe constitutes "legitimate" sexual orientation data collection. These actors situated in the LGBTQ health movement (such as Fenway Health) often actively disqualify data about sexual behaviors and attractions as being about "sexual orientation." For these entities, only data about sexual identity categories usually get to count as "sexual orientation data." This is not the case in HIV practice, where many actors treat HIV risk hierarchy data, or data about recent sexual behaviors, as sexual orientation data.

The uni-categorical standardization of SO in health IT, along with the widespread dissemination of educational materials by Fenway Health (largely funded by HHS) promoting the position that "sexual orientation data collection" can only be said to have occurred when identity data have been collected – versus a position that would also count data about sexual behaviors and/or attractions as data about "sexual orientation" – both has the effect of creating new sexual orientation ontologies and of raising deep, profound, pressing, and clinically important questions about what it means to collect data about "sexual orientation" in healthcare. What gets to count as data collection about "orientation" (versus some other aspect of sexuality) is a major determining factor in how "sexual orientation" is materially constituted as a clinical object in specific organizations, bounded times and places, or areas of practice in biomedicine and health. Sexual orientation appears and manifests as a much different sort of clinical object in practice if behavioral data get to count as data about "orientation," when compared to situations in which only identity-based data get to fit the bill.

As I show herein, through examples from fieldwork, the ontological issues raised by this state-of-affairs is on particularly acute display in contexts where data about sexual behaviors is collected, but where data about sexual identities is not. In these situations – where behavioral data are gathered, but not identity data are not – whether data about “sexual orientation” are being collected is a highly contested matter that is context-bound, fraught, difficult-to-map, and ultimately dependent on how the individual or organization being asked conceptualizes “sexual orientation.”

In what follows, an exploration of health IT policymaking reveals how a certain conceptualization of sexual orientation preferred by LGBTQ health groups – single-element “SO” rooted in identity categories as reflected in Figure 3.1 – became dominant in health IT standards and clinical electronic health records in the United States in the 2010s as a central development in the new consensus in LGBTQ health. This is followed by several ethnographic explorations and a single detailed case study of one multi-site FQHC in New England, and how that organization incorporated SO/GI data into their work. These studies collectively show how different kinds of data about sexual behaviors, identities, attractions, and HIV status (especially “HIV risk hierarchy” data) exist in tension and friction with one another in biomedical and public health practice. The frictions produce variegated methods of data utilization, and thus biomedical sexualities and sexual realities that are particular to specific times, places, organizations, and areas of practice that conceptualize sexual orientation in different ways.

III. The “Do Ask, Do Tell” Campaign to Make SO/GI National Health IT Standards

Health IT Policy Review and an Introduction to National Standards

The previous chapter offers a thorough analysis of the immensely complex Meaningful Use (MU) Program, Electronic Health Record (EHR) and health IT Certification Program, EHR Incentive Payment Program, and the federally-driven development of a “nationwide interoperable health IT infrastructure” from 2009 onward.[20] To briefly review, the Office of the

National Coordinator of Health Information Technology (ONC) sets criteria that determine how an EHR product can become "Certified Electronic Health Record Technology" (CEHRT, pronounced "sirt"). Meaningful Use standards require providers to attest to their utilization – their "meaningful use" – of certified electronic health records in their practices in order to receive incentive payments from the Centers for Medicare and Medicaid Services (CMS). Meaningful Use standards and EHR certification criteria are – together – the two core branches of health IT policy and infrastructural development in the United States.

EHR certification criteria and Meaningful Use criteria were developed in three rounds, each involving the issuance of proposed regulations and public comment periods: in 2010 (Stage 1 MU and CEHRT criteria), 2012 (Stage 2 MU and CEHRT criteria), and 2015 (Stage 3 MU and CEHRT criteria). In 2015, along with Stage 3 Meaningful Use and EHR certification criteria, ONC also issued the first *Interoperability Standards Advisory*, a nonbinding document of recommended standards that are "layered" on top of binding EHR certification criteria. *Interoperability Standards Advisory* guidelines are intended to facilitate the easy transmission of data elements between organizations and over exchange networks in the increasingly-interoperable health IT ecosystem. Following public comment periods, an updated ISA has been released annually since 2015.

The Failed 2010-2012 Campaign for Federal SO/GI Health IT Standards

Fenway Health led a limited effort to include SO/GI in health IT policy during the Stage 2 Meaningful Use and EHR certification process in 2012. This included a public comment to ONC from Fenway recommending the incorporation of SO/GI into both EHR certification criteria and Meaningful Use provider attestation requirements.[21] Neither ONC nor CMS adopted

Fenway's recommendations. Fenway's full campaign with the Center for American Progress (CAP) and other coalition partners began during the buildup to the Stage 3 process in 2015.

The Successful 2012-2015 Campaign to Persuade ONC to Make SO/GI into National Health IT Standards

"Kellan Baker of the Center for American Progress cautioned against entering a new regime of 'Don't Ask, Don't Tell' in health care."

> -From "Closing Remarks" in *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary*, published by the Institute of Medicine in 2013

After the unsuccessful campaign to get SO/GI included in Stage 2 EHR certification criteria and provider attestation criteria in 2012, Fenway, with its new partner the Center for American Progress (CAP), began to take a more coordinated approach to building an evidence base and a robust strategy for incorporating SO/GI health IT standards during the Stage 3 MU and 2015 EHR certification criteria process.[22] The result would be the inclusion of SO/GI in binding EHR certification criteria, but not in Stage 3 Meaningful Use criteria. This meant that providers would not need to attest to the fact that they were collecting SO/GI data in their certified EHRs to receive incentive payments. However, SO/GI would need to be included in EHR products in order for them to receive certified electronic health record technology (CEHRT) designation and thus be eligible for physicians to utilize for the purposes of participation in the EHR Incentive Payment Program. During this campaign, SO/GI would also be incorporated in the *Interoperability Standards Advisory*.

Fenway and CAP played a leading role in convening a 2012 Institute of Medicine (IOM) workshop on collecting and utilizing SO/GI data in EHRs, the proceedings of which were published in 2013 as a workshop summary titled *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records*. This event, and the published workshop summary, was in some ways a sequel or follow-up to the major 2011 IOM LGBT health report. Dr. Harvey

Makadon, then-Director of the Fenway Institute's National LGBT Health Education Center, was one of the lead facilitators of this day-long consensus-building and skills-and-experience-sharing workshop. The workshop featured 19 presentations, including ones from Fenway, survey researchers, Kaiser Permanente, The Mayo Clinic, Vanderbilt University Medical Center, several agencies within HHS, LGBTQ advocacy groups such as Lambda Legal, academic researchers, and experts from other stakeholder-institutions.[23]

During this time, Fenway also formed a close working partnership with CAP, and secured a $450,000 annual National Cooperative Agreement grant from the Health Resources and Services Administration (HRSA) to develop and disseminate SO/GI data collection, implementation, and utilization guidelines and provider educational materials through its National LGBT Health Education Center.[24] Working with CAP, Fenway conducted a multi-site study to test and validate SO/GI questions at its own clinic and three other Federally Qualified Health Centers (FQHCs) in different parts of the country with a mixture of racially diverse patient populations in both urban and rural areas. FQHCs are the backbone of the clinical safety net and social services infrastructure for the uninsured and under-insured in the United States.

In September of 2014, the Fenway and CAP team published data from the study in *PLOS One*, the open-access journal of the Public Library of Science, as an article titled "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." This article was central to what would become the branded "Do Ask, Do Tell" campaign – a kind of macabre homage to the anti-gay military "Don't Ask, Don't Tell" policy which had been repealed by the Democratic-controlled Congress and President Obama in 2010. The "Do Ask, Do Tell" SO/GI campaign included provider and healthcare organization educational materials emblazoned with the slogan, presentations with that title, and a standalone toolkit/website – DoAskDoTell.org – to encourage healthcare organizations and clinicians to self-train and self-educate on SO/GI data collection. DoAskDoTell.org was launched in April 2015 with funding from The Robert Wood Johnson Foundation.[25]

ONC and CMS published the initial Notices of Proposed Rulemaking for Stage 3 Meaningful Use (MU) and 2015 Electronic Health Record certification criteria in the Federal Register on March 20th, 2015: the portal that federal agencies use to administer rule-making processes, collect feedback from stakeholders, and to issue binding regulations. Initial rules are proposed, followed by a public comment period, followed by the issuance of the final rule.

In the initial proposed 2015 rules, SO/GI were not included in the MU requirements: providers would not be required to attest to their collection of SO/GI to receive incentive payments for the utilization of Certified Electronic Health Record Technology. SO/GI *were included* in EHR certification criteria in the initial proposed rule. However, SO/GI fields were only present in "an optional social, psychological, and behavioral data module, and not as part of the Demographics criterion (as included in the Base EHR definition), or as part of the Common Clinical Data Set."[26] This meant that, per ONC's requirements, EHR vendors would have the *option* of including SO/GI in this (rather minor) section of certified EHRs, but would not be *required* to include SO/GI. This posed a major problem for the standards, and for Fenway and CAP, who wanted SO/GI to be both required elements for EHR products to become certified and for providers to be required to collect SO/GI data in order to demonstrate their meaningful use of health records and receive incentive payments. The initial proposed rule did neither of these things.

During the 60-day comment period on the initial proposed rule from March to May 2015, Fenway and CAP assembled and mobilized a grand coalition of 103 other institutions in favor of SO/GI. This coalition included organizations in the safety net health center community, the HIV/AIDS community, the LGBTQ health community, grassroots community based organizations, university medical centers, and other stakeholders. Fenway and CAP built this action-oriented expert-stakeholder public by writing and circulating two public comments onto which organizations could affix their endorsement: one targeting ONC that addressed EHR certification criteria and a second targeting CMS that addressed Stage 3 MU criteria.[27]

In both comments, the grand coalition lobbied for inclusion of "sex assigned at birth," "sexual orientation" and "gender identity" questions in both the MU provider self-attestation criteria and the EHR certification criteria. However, they only succeeded in persuading ONC to adopt the SO and GI questions, and only in the EHR certification criteria, not in Meaningful Use requirements that would require providers to collect SO/GI in order to receive payments. In the public comment pertaining to EHR certification criteria, the coalition wrote that SO/GI should be included in *both* the "Demographics criterion that all EHRs must be able to track" and the "Common Clinical Data Set" (CCDS, the most important dataset in the criteria) in order to "facilitate its exchange among providers during transitions of care and referrals, as well as its availability to patients and authorized representatives via view/download/transmit."[28] But ONC did not choose to make SO/GI part of the CCDS.

Ultimately, ONC met the Fenway coalition in the middle. SO/GI would be included as mandatory elements in the "demographics" section of the Base EHR Definition, but not in the Common Clinical Data Set (CCDS). Further, the existing "administrative sex" field would remain. This field does not include any fields for people who have sex designations other than "m" or "f" at birth; it only includes "male," "female," and "unknown." Per ONC and CMS:

> In the final rule, ONC is requiring that Health IT modules enable a user to record, change, and access SO/GI to be certified to the 2015 Edition "demographics" certification criterion. By doing so, SO/GI is now included in the 2015 Edition Base EHR definition, which is a part of the definition of CEHRT. We note that certification does not require that a provider collect this information; it requires only that their CEHRT enable the provider to do so. CMS and ONC believe including SO/GI in the "demographics" criterion represents a crucial step forward to improving care for LGBT communities.[29]

This distinction regarding the location of the standards in the "demographics" section of the base EHR definition only versus in both the base EHR definition and the CCDS, while seemingly minor, would become hugely consequential in future years. SO/GI's non-inclusion in the CCDS would play a major role in their exclusion from new health IT interoperability standards initially proposed in 2018. These standards, called the Draft Trusted Exchange Framework and Common Agreement (TEFCA) and U.S. Core Data for Interoperability (USCDI), are outside the scope of this dissertation, but are addressed briefly in this chapter's conclusion on "SO/GI's Uncertain Future in Health IT."

Fenway Declares Victory

After the rules were released in 2015 requiring that SO/GI be included in EHR certification criteria but not in Meaningful Use attestation criteria that would require providers to collect SO/GI data to receive incentive payments, Fenway and CAP announced unequivocal victory. The organizations did so both in a press release and in the academic journal *LGBT Health*. However, Fenway did so on terms that were, on balance, not *exactly* reflective of the rules that had been issued. In the opening of the *LGBT Health* article, titled "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health," Fenway and CAP authors said:

> In an historic move that will advance health for LGBT people, the U.S. Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) announced on October 6, 2015 that they will require that all electronic health record (EHR) systems ***certified under the Meaningful Use incentive program*** have the capacity to collect sexual orientation and gender identity (SO/GI) information from patients. The CMS final rule indicates that "CMS and ONC believe including SO/GI in the 'demographics' criteria represents a crucial step forward to improving care for LGBT communities." (p.408) Certainly, ***including SO/GI in the Meaningful Use incentive program*** is one of the most important things the US government has done to promote better understanding of LGBT health disparities and interventions to reduce them.[30]
>
> (emphasis mine)

This statement is not false. However, it is also not, strictly speaking, correct, if one hews to the exact structure of the EHR Incentive Payment program.

To receive payments through the EHR Incentive Payment Program, providers must attest to their meaningful use of certified electronic health record technology. However SO/GI were not included in the data elements required for provider attestation, which is what "meaningful use" refers to: providers' utilization ("use") of certified EHRs in a substantive ("meaningful") fashion. Therefore, the claim that ONC and CMS had "[included] SO/GI in the Meaningful Use incentive program" by making health IT vendors include SO/GI fields in the demographics section of the base EHR definition was (if read generously) an oversimplification of the facts or (if read less generously) pushing the boundaries of the truth.

Further, the full story behind the standards that Fenway had successfully convinced ONC to incorporate into the EHR certification criteria was rather more complicated than this narrative of straightforward "SO/GI victory" let on. Fenway, CAP, and the grand coalition acknowledged serious problems with the standards that they had lobbied for in their public comments.

Arguing in Favor of “Problematic” and “Outdated” SO/GI Standards

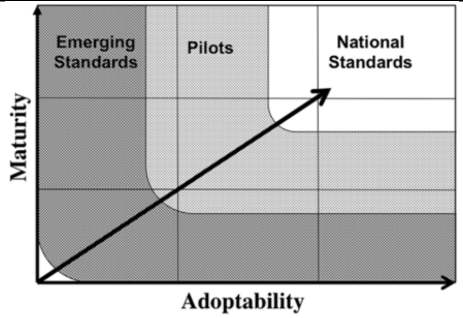
The fundamental problem that Fenway and CAP faced during the 2012-2015 “Do Ask, Do Tell” campaign, from a standards-setting perspective, was a lack of existing health IT standards that reflected up-to-date language for SO/GI data elements. There were no available health IT standards that matched the biomedical gold standard definitions of sexual orientation and gender identity as defined by the Institute of Medicine LGBT health report or the social categories used in everyday life by the vast majority of LGBTQ people and other sexual and gender minorities to describe themselves.

The best codes available were in the Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) – a major set of health IT standards maintained by a private organization, SNOMED International. These codes used the terms “homosexual” and “transsexual” instead of the preferred categories “gay or lesbian” and “transgender.” The lack of available up-to-date SO/GI standards required Fenway to assemble a set of extremely technical arguments – a kind of regulatory “fancy footwork” – about why it was in HHS’s interests, providers’ interests, and patients’ interests for ONC to adopt existing SNOMED CT SO/GI specifications: codes whose underlying definitions contained language that Fenway and the mainstream LGBTQ health community recognized as less-than-ideal and even in some cases offensive or even harmful to LGBTQ patients.

Further, outside the problems the standards posed from an LGBTQ health perspective, the Fenway and CAP-led coalition had to persuade ONC to deviate from normal best practices in health IT standards policymaking and instead to adopt their guidance, which was to adopt rather untested, unpiloted SO/GI standards: those described in the coalition’s public comments. The questions were associated with validated data collection best practices; however, the standards themselves (and the particular requirements that the coalition was recommending) were untested.

The normal standards-setting process would be to first revise available standards or to create new standards by working with SNOMED CT and other actors in the health IT standards community, and then to pilot those standards, before asking ONC to set "national standards" in policies such as EHR certification criteria. The graphic below represents this process from an ONC publication on national standards-setting that is often referred to by practitioners simply as "the Dixie Baker paper," after its first author. In going straight to EHR certification criteria, SO/GI standards bypassed aspects of the usual process.[31]

Figure 3.2. Normal National Standards Development Diagram Produced by ONC and Included in "the Dixie Baker Paper"[32]



In the absence of existing standards that met the SO/GI gold standard, the solution proposed by Fenway in its public comments – and endorsed by all 103 signatories in the grand coalition – and essentially adopted by ONC, was to keep the underlying/off-screen SNOMED CT codes for "homosexual" and "transsexual" in place in the information architecture, while also requiring health IT vendors to employ a different on-screen display of these fields to end-users of certified EHRs: as "gay or lesbian" and "transgender."[33] This is well within the powers of ONC, which is the final authority on health IT standards in the United States. However, it is not normal best practice and required special and exceptional justification.

To accomplish the exceptional form of standardization the coalition was requesting from ONC, Fenway and CAP argued that "gay and lesbian" was synonymous with "homosexual" and that “transsexual” was synonymous with “transgender.” ONC would adopt these recommendations. However, this argument – that the terms contained in the underlying SO/GI specifications that Fenway successfully argued for were synonymous with the terms displayed on-screen – would not be endorsed by the organization or other signatories in almost any other conceivable venue or context.

The argument that “homosexual” is synonymous with “gay and lesbian” is less problematic than the case of trans terminology. “Homosexual” is a clinical term that many (but not all) gays and lesbians have resisted using since gay liberation. However, the argument that “transsexual” is conceptually synonymous with “transgender” is simply not true. “Transgender” has a complicated history that intersects with many other categories – among them “sexual inversion” (often also framed as a discursive precursor to homosexuality), “transvestism,” “transgenderism,” “transgendered,” and “transsexuality.”[34] A full exploration of the genealogy of the term is not possible here, and indeed, the field of trans studies is presently grappling with and rearticulating its history in ways that extend beyond my own current abilities and this project’s archive.[35] However, transsexuality is presently – in the current biomedical gold standard as defined by the Institute of Medicine and LGBTQ health education materials I studied for this dissertation – a subcategory within the “super-category” of transgender. Definitions of transsexual generally require (A) patient self-identification as transsexual, and (B) medical transition involving surgical work or the taking of hormones. Transsexual and transgender are not conceptual synonyms; they are conceptual cousins, or neighbors in the same conceptual neighborhood.[36]

The problems with the standards are reflected in the coalition’s public comments issued during the rule-making process as well as in Fenway’s provider-focused educational modules. In their comments to ONC and CMS, Fenway and CAP recognized that the underlying standards were "suboptimal," "problematic," "fundamentally off-putting," and that "many LGBT people themselves dislike these terms, considering them outdated and stigmatizing."[37] However, no other standards existed in SNOMED CT or another health IT nomenclature that exactly matched the terms Fenway and its partners wanted to display on screen. Fenway and its partners were therefore placed in the position of simultaneously arguing for the adoption of SO/GI standards that went against their own best practices, the terms used by most sexual and gender minorities to describe themselves, the gold standard in LGBTQ health, *and* for ONC to go outside of its own best practices to require EHR firms to use different language on-screen than was contained in the underlying architecture.

This extended quotation from Fenway and CAP's public comment for the 2015 *Interoperability Standards Advisory* captures their position and recommendations:

> We further recommend that all ONC rulemaking on electronic health records…require certified EHR systems to show all front-end users, such as healthcare, providers, staff, and patients, a single standard set of questions and answers with appropriate language around concepts related to SO/GI, regardless of the wording of the codes that the answers map onto in the underlying EHR Architecture…
>
> - Sexual orientation:
>   - Homosexual .... SNOMED CT® 38628009
>   - Heterosexual .... SNOMED CT® 20430005
>   - Bisexual .... SNOMED CT® 42035005
>   - Other .... HL7 V3 nullFlavor OTH
>   - Asked but unknown .. HL7 V3 nullFlavor ASKU
>   - Unknown .... HL7 V3 nullFlavor UNK
>
> - Gender identity:
>   - Identifies as male gender. SNOMED CT®446151000124109*
>   - Identifies as female gender. SNOMED CT® 446141000124107*
>   - Female-to-male transsexual. SNOMED CT® 407377005
>   - Male-to-female transsexual. SNOMED CT® 407376001
>   - Identifies as non-conforming gender. SNOMED CT® 446131000124102*
>   - Other .... HL7 V3 nullFlavor OTH

> - Asked but unknown .. HL7 V3 nullFlavor ASKU
>
> While the codes for sexual orientation and gender identity have some functionality, they are suboptimal. Terms such as 'homosexual' and 'transsexual' are sometimes used to describe minority sexual orientation and gender identity, but many LGBT people themselves dislike these terms, considering them outdated and stigmatizing. Collecting SO/GI data in EHRs offers the opportunity for LGBT patients and their providers to form a positive therapeutic relationship based on trust, but this opportunity will not be realized if the language used to ask these questions is fundamentally off-putting.
>
> We therefore recommend that ONC work with [the National Library of Medicine] to create the following SNOMED CT codes and allow them to be used as synonyms for the existing SNOMED codes that are problematic:
>
> - Instead of "homosexual": "gay" and "lesbian"
> - Instead of "female-to-male transsexual": "transgender man"
> - Instead of "male-to-female transsexual": transgender woman[38]

Fenway also encouraged ONC and the NLM to develop new SNOMED CT codes for SO/GI in the long-term. This would replace the outdated ones that the coalition encouraged ONC to adopt. To date, these new codes have not been developed, nor have the existing codes been revised, nor is there evidence that processes are underway to revise or develop new SNOMED CT codes.

However, if, per Fenway and CAP's recommendation, new or alternate SNOMED CT codes were developed, there would be no effect on existing SO/GI standards from the perspective of federal health IT policy barring another round of national standards-setting in which the new codes – untested, unpiloted, and (in the language of health IT) immature – would be adopted by ONC. The revision of current SNOMED CT codes would pose problems of its own, from provision-of-care, health IT systems-development, and standards-setting perspectives. Namely, the current requirements regarding SO/GI incorporation would need to be removed from certified health IT, and the national infrastructure, and replaced with new ones; this would likely bring SO/GI back to early-phase adoption and maturity ratings, thus making "SO/GI" standards weaker from a health IT perspective, and affecting the meaning of existing SO/Gi data in the health IT ecosystem. However, any consideration of what exact ramifications would stem from the revision of the existing specifications would be – at this point – entirely speculative. Suffice it to say: any revision to existing SO/GI standards would pose problems for the standards' maturity and adoption levels, for the viability of SO/GI standards in the national health IT architecture, and for SO/GI data as it currently exists in the healthcare system following implementation of the 2015 standards.

Saddled with Suboptimal National SO/GI Standards

To summarize: SO/GI advocates were placed in the position of simultaneously arguing for the adoption of standards that went against their own best practices, that went against terms used by most sexual and gender minorities to describe themselves, the gold standard in LGBTQ health as defined by the 2011 Institute of Medicine Report and their own training materials. ONC also side-stepped best practices in health IT to set national standards requiring EHR firms to use different language on-screen than was in the underlying architecture for their products. Making the argument that it was appropriate for these categories (gay or lesbian/transgender) to be used "as synonyms for the existing SNOMED codes" (homosexual/transsexual) was only possible for Fenway and its coalition partners because the context of the argument was health IT standards-setting. In the absence of standards that reflected gold standard SO/GI fields – and without the necessary time to go to SNOMED CT to generate and pilot new standards before 2015 EHR certification rule-making – Fenway and CAP had little choice but to engage in regulatory and technical compromise.

By arguing in favor of outdated standards in the underlying architecture, and then for those standards to be displayed using different classifications on-screen that would reflect current best practices and terminology, Fenway and CAP were primary drivers of a situation where the healthcare system is likely to be saddled with suboptimal SO/GI standards for many years. To reiterate: even if alternative standards were developed, it would not affect current ONC policies regarding the standards that are required in binding health IT certification criteria and non-binding guidance such as the *Interoperability Standards Advisory*. In order to implement new, updated health IT standards policies that reflect current biomedical terminology, the old ONC-required standards would have to be replaced with new ones. Even if the effect of this would be to bring national SO/GI health IT standards into closer alignment with the biomedical gold standards, this could also essentially take SO/GI back to square one from the perspectives of standards maturity, adoption, and implementation. The current standards would need to be replaced with the new ones, and this is a complex technical undertaking requiring assessment, testing, and rollout processes that would likely take years and funding to execute uniformly.

What are the main consequences of this for the healthcare system, providers, product developers and patients? The most glaring one is that all transgender women and transgender men will remain "transsexuals" in the underlying specifications contained in their medical records. However, to all front-end users (assuming that all vendors follow ONC's very specific guidance), the term "transgender" will be displayed. Is this a matter of consequence? That lies mostly in the eye of the beholder. So far, in the life of the standards, the issue has not been widely raised – a likely effect of their extreme obscurity as a policy artifact, despite their ubiquity as a feature of electronic health records.

Current national SO/GI standards and their manner of incorporation into EHRs and other health IT products are now central to the emergence of sexuality and gender in biomedical practice across scales. Because they are present in all certified EHR technologies, they now shape everyday dramas of administering care to patients in localized settings and at larger scales.

These standards are playing a role in how doctors and patients interact as well as broader transformations in biomedical informatics in clinical organizations or public health entities that are using SO/GI data to engage in regional, national, or statewide planning and program execution.

Conceptually Flattening SO: From Three Elements in Biomedicine to One in Health IT

The approach that Fenway and its coalition partners took in promoting a one-element, identity-based on-screen definition of SO has had the practical effect of flattening the conceptual complexity of SO in health IT policy, at least when compared to "sexual orientation" as a concept in biomedicine. The current gold standard definition of sexual orientation is a composite and relational characteristic defined by one's (1) personally-held "sexual identity," (2) their "sexual behaviors," and (3) their "sexual attractions."[39] "Orientation" is an amalgam of all three. However, SO as promoted by Fenway in health IT policy and incorporated into EHR certification criteria and the *Interoperability Standards Advisory* is the conceptual equivalent of "sexual identity" – sometimes called "sexual orientation identity" by Fenway. It is not the three-part gold standard definition, but a single element of sexual orientation.

The decision for Fenway and CAP to pursue an identity-focused SO question was intentional. They could have tested a multi-part question in their "Do Ask, Do Tell" study published in *PLOS One* in the lead-up to the 2015 public comment period. They in fact did so for gender, testing a two-step "sex at birth" and "gender identity" question.[40] Fenway and CAP also clearly understand the three-part sexual orientation gold standard. Indeed, Fenway clinicians and researchers played a major role in inventing and building up consensus around this standard through their membership on the committee that wrote the 2011 Institute of Medicine LGBT Health report and earlier research.[41]

During my research on Fenway, both before and after I conducted two days of fieldwork at the organization's main offices in Boston, I made it a primary goal to determine – to the extent that it was possible – why Fenway and CAP opted to go with a one-step SO question for federal EHR certification criteria, rather than a three-part question that would reflect the gold standard. I wanted to understand why the organization seemed to invest in identity above-and-before the other two metrics (attractions and behaviors).

The basis for Fenway's decision to proceed in the manner just described emerged clearly from some of the statements made to me in justifying their decision, their organizational conceptualization of "sexual orientation," and their formal arguments in letters to ONC. Further, Fenway's investment in sexual identity over sexual behaviors and/or attractions is at least partly rooted in the organization's emergence from the gay liberation and LGBTQ movements' investment in visibility politics. This is reflected in the organization's public comments during health IT standards-setting. For example, in the organization's comment on the ONC's proposed *Nationwide Interoperability Roadmap* in 2014, the visibility agenda is prominent:

> Because most clinical records systems do not support the collection of structured SO/GI data, however, LGBT people *are often invisible in care settings*. This *invisibility* masks disparities and impedes the provision of important health care services for LGBT individuals, such as appropriate preventive screenings, assessments of risk for sexually transmitted infections such as HIV, and effective interventions for behavioral health concerns that may be related to experiences of anti-LGBT stigma and discrimination. Like all patients, LGBT people have many concerns related to their relationships, desire to have families, and issues of aging that occur in different stages of the life cycle. An opportunity to share information about their sexual orientation and gender identity in a welcoming environment will facilitate important conversations with clinicians who are in a position to be extremely helpful.[42]
>
> (emphasis mine)

This emphasis on invisibility and LGBTQ visibility is consistent with the organization's statements in publications such as the IOM workshop summary report, the DoAskDoTell.org website/toolkit, and provider trainings hosted by the Fenway Institute's National LGBT Health Education and Training Center. The organization is more invested in a classic notion of gay identity rooted in LGBTQ politics than in a more fluid or capacious understanding of sexuality rooted in attention to attractions, behaviors, or other metrics – at least when it comes to structured data collection.

Fenway's Style: A Preference for Identity Data and Equivocation Between "Sexual Identity" and "Sexual Orientation"

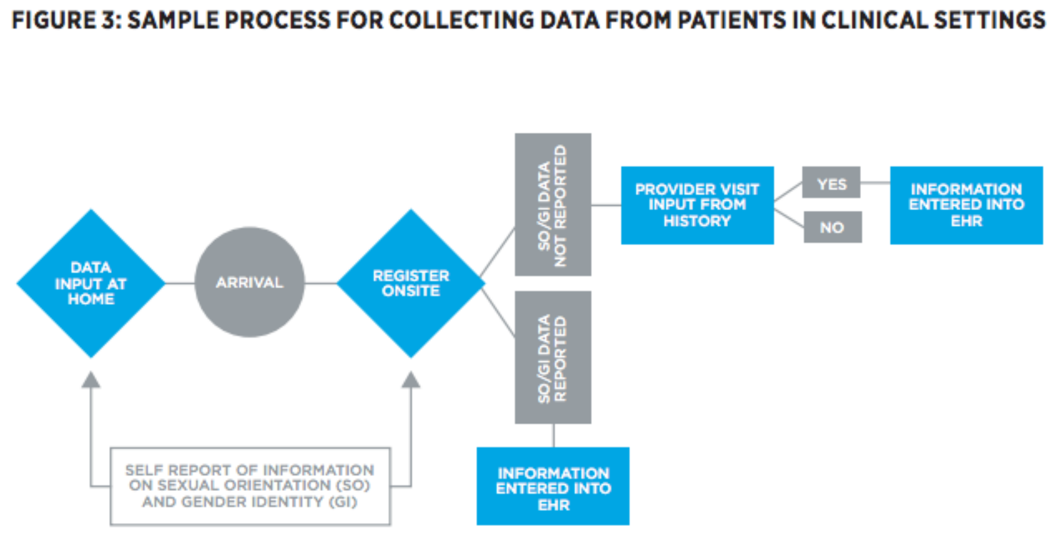
Trying to understand why Fenway opted for a single-element SO question by analyzing Fenway's published provider education materials and attending their webinar education sessions and "SO/GI Office Hours" was not helpful. While examining relevant documents in preparation for interviews, I noted that Fenway maintains two different sets of technical guidance about gathering data about patients' sexuality.

The first set is geared toward individual medical practitioners and clinicians who may be engaged in collecting comprehensive sexual histories. The main publication is "Taking Routine Histories of Sexual Health: A System-Wide Approach for Health Centers," published jointly by Fenway and the National Association of Community Health Centers (NACHC).[43] This document includes a detailed sexual risk assessment that closely resembles a CDC template used in HIV testing events, and other information about how providers ought to ask patients questions about sexual behaviors, attractions, and identities. The bulk of the questions are focused on sexual behaviors. In this toolkit, the word "orientation" is saved for the final question, lumped in with identity, as almost a side-concern or final aside to ask the patient: "Do you have any concerns or questions about your sexual orientation, sexual identity, or sexual desires?"[44] In sum, in

Fenway’s materials educating providers on how to take sexual histories, identity-based “orientation” is something of an afterthought.

However, a second set of Fenway educational documents are framed as instructing clinical organizations on how to collect “SO/GI” data and record it in EHRs. These materials are far more numerous, well-promoted (such as the DoAskDoTell.org site), and are the focus of several HHS-funded projects at Fenway related to SO/GI rollout – particularly at low-cost Federally Qualified Health Centers and community health centers, which, since 2016 have been required to collect SO/GI.[45] Regarding sexuality, these materials do not discuss collecting data about behaviors or attractions, except to say that “providers may ask [SO/GI questions] as part of the social or sexual history.”[46] Rather, these materials offer instructions on how to populate the “SO” fields included in the 2015 Base EHR certification criteria: a one-element, identity-based question.

Figure 3.3. Fenway’s Model for SO/GI Collection Diagram Used in Training Materials



There is not even basic information about the three-part gold standard definition of sexual orientation in many of these documents, although Fenway does elaborate on the concept’s three components in its webinar-based trainings on SO/GI and in the “SO/GI Office Hours” that the organization held semi-regularly in 2016, most of which I attended. However, the focus of these trainings remains primarily on populating the SO/GI field, and the SO field is a one-element, identity-based question.

I brought this issue up during two days of interviews at Fenway Health’s austere, 14-story Ansin building in Boston, a stone’s throw away from Fenway Park, where the Boston Red Sox Baseball team plays. I tried to ask why Fenway went with a single-field SO question in many different ways, and how personnel at Fenway themselves conceptualized “sexual orientation” and what data elements (identities, behaviors, or attractions) that they thought needed to be collected in order to constitute “sexual orientation” data collection.

I asked Sean Cahill, Director of Health Policy Research of the Fenway Institute, about why his team chose to go in the direction of a single, identity-based SO question in health IT rather than a three-part question that reflected the gold standard in biomedicine and survey research. I showed Sean the two different sets of Fenway educational materials on my laptop screen, and asked him why they did not use the term “sexual identity” for “sexual orientation” in their materials on SO/GI data collection, such as the DoAskDoTell.org website.

> **Sean Cahill**: I think you've gotta understand, this is aimed at a mainstream, healthcare provider audience. And if you say “sexual identity,” that could confuse people... “Orientation” has been around for decades now: “sexual orientation.” And I believe that identity is one of three components of that, but I think if we just said “collect sexual identity and gender identity data,” I think that would confuse people.
>
> People get very confused…About sex and gender. They conflate them, they think they're synonyms...So, I feel like our main focus has been getting healthcare providers to ask the patients, “Are you gay?” I.e. “Are you homosexual?” “Are you lesbian?” Now some lesbians identify as gay, so “”I.e., “Homosexual - gay male, lesbian?” “Are you bisexual? Do you identify that way, or do you identify as heterosexual?” And I think it's also a great thing for providers to do a sexual history of their patient if their patient is sexually active. But in terms of collecting data in the EHR, our main focus has been on sexual orientation identity questions.

Sean's use, at the very end of his response, of the term "sexual orientation identity" is a linguistic phenomenon that has recently been added to the SO/GI lexicon, as a synonym for "sexual identity." I first encountered "sexual orientation identity" in Fenway and CAP's 2015 article in *LGBT Health*, published after the MU Stage 3 and 2015 EHR Certification final rule was issued.

I also asked two members of Cahill's team – Pat and Jordan – about these issues. Their responses show the equivalence that Fenway draws between "sexual orientation" and "sexual identity" as concepts, and shows that Fenway does not generally consider collecting data about "sexual behaviors" alone as data collection about "sexual orientation."

> **SM**: If [health centers] are collecting detailed data about sexual behaviors but not identities, are they collecting sexual orientation data?
>
> **Pat, Fenway Research Team Member**: I would say "no," and I would kind of piggyback on what Jordan has been saying, that the oversimplification of these questions is in order to accommodate a whole range of understandings of these things, but yeah…I would say ultimately "no"…You can project whatever category you want onto that person [based on behaviors], but that's not necessarily their sexual identity. Sexual behavior doesn't always line up with sexual identity.
>
> **SM:** Jordan, same question to you. In your view, if an organization is collecting detailed data about sexual behaviors, are they collecting data about sexual orientation?
>
> **Jordan**: Yeah, I don't think so – or it is definitely a very, very oversimplification of it – so you're not capturing all of it, and I think that stems from the whole idea that the only clinically-relevant part of sexual orientation is the sexual activity part of it or is the sexual behavior part of it. But there are a lot of disparities – health disparities – that can come about because the identity is stigmatized and the sexual behavior can cause other health outcomes…So it is important to ask about the identity itself separate from the sexual behaviors, I believe, to get the full picture.
>
> And I guess the way that we've been reporting it in our project, we've been asking health facilities across the country if they're collecting SO/GI data and we've been saying for them if they report that they only collect sexual behavior data, we mark that as a "no."

While it is clear that everyone at Fenway Health has a firm conceptual grasp on sexual orientation as a three-part concept in biomedicine, it is also clear that, for the purposes of collecting “SO” data in EHRs or data about “sexual orientation,” the matter is rather straightforward. Identity data must be collected by an organization if that organization is to qualify as collecting “orientation” data, from the perspective of many Fenway personnel. Only identity-based SO data count as data about “orientation” in this view. Other data – such as data about behaviors and attractions – are clinically relevant data about sexuality, but they do not usually rise to the level of determining “orientation.”

Notably, the one Fenway clinician that I had the chance to interview – Dr. Jennifer Potter, a faculty member at Harvard Medical School, co-chair of the Fenway Institute, and Director of the LGBT Population Health Program at Fenway – did not take such as clear position. Instead, Dr. Potter insisted on the multi-dimensional nature of sexual orientation and on the importance of collecting all three elements. She also acknowledged that Fenway did place an overwhelming emphasis on identity variables over others in its sexual orientation metrics. She expressed a personal interest in the collection of more data about sexual attractions.

> **SM**: So, in your understanding, if a clinic is collecting detailed data about sexual behaviors but not sexual identities, are they collecting data about sexual orientation?
>
> **Dr. Potter**: Not completely, no. No. I mean you need to have all of them…you need the identity, you need the attraction piece, you need the behavioral piece, all three.
>
> **SM**: So, you need all three pieces. So, in your understanding, if an organization was asking the EHR question, the SO/GI questions…and they're not doing, for example, a sexual history, would you say that they're collecting sexual orientation data?
>
> **Dr. Potter**: Well, it depends on which collection instrument you're really looking at. I think you're right. Most of the ones that I've seen and the ones that we use here are basing it on identity. And then, because the patients are coming here for their care, we do a good job at collecting the sexual behavior history, we do have that too. Ideally, it would be nice to have it all in the same place, so an instrument that was capable of getting that by self-report from an individual, at some periodicity, would be incredibly helpful.

I repeated what she said as I typed notes, and then asked if such a template existed at Fenway:

> **SM:** "It would be nice to have it all in the same place" – meaning the identity, attraction, behavior questions all in one template. Does that mean that here at Fenway you currently have the sexual orientation question that asks about identity and then a separate template for behaviors, like in a progress note?[47]
>
> **Potter**: It's not even really a template, most of the time. It may exist in certain subgroups. Like I don't know about…what it has for the HIV population. It may have more of a templated sexual behavior thing, but for general, the women's groups in particular, there isn't a template that I'm aware of. People take their free form history. There is an EHR sheet that you can record it on…So, you can pull up a sheet and it has various check boxes and things like that, so you may be able to electronically pull from that now. But not everyone uses that consistently, some people are still free-texting it.
>
> **SM:** Got it. To ask the question in another way, basically, in Fenway's educational materials I see "sexual orientation" often function as sort of shorthand for "sexual identity."
>
> **Potter**: Yeah.
>
> **SM:** Why is that?

Potter pondered this question for several seconds before responding.

> **Potter**: Ah - It's a good question. I mean, I guess part of the reason is that people think that they're collecting the sexual behavior history adequately in the clinical realm, which is probably more or less true. I think what is not being collected, *really at all*, is the attraction piece – and it has been found to be important in distinguishing small sub-populations from one another. So, you can have a group that's attracted to, but not behaving and doesn't have an identity, that looks a certain way clinically, that is different from a person who has a clear identity piece that is going along with also being attracted. And that's really fascinating – and I think we do need to ultimately drill down to that level. It's probably the most awkward to ask the attraction question, you know? It's just a little bit more awkward. I think we're not used to doing that and it needs a little bit more work to bring it along.
>
> **SM**: Is there a place to ask about attractions in Fenway's EHR?
>
> **Potter**: No. Not that I know of…I don't practice here particularly, so that's why I'm not so up on these answers. I know at my practice at [Beth Israel Deaconess Medical Center], we don't do any templated stuff. We all hand-write (or actually type) our notes (or dictate them) and *nobody asks about attraction* – or at least nobody records anything about attraction.

Potter sees the lack of standardized three-part SO/GI templates in EHRs as a major deficiency and acknowledges Fenway's primary emphasis on identity-based SO categories. She thinks the greatest dearth in clinical data collection around sexuality pertain to questions of attraction (which is in alignment with my fieldwork findings in the clinical context) and laments the widespread lack of EHR templates that would capture all three of sexual orientation's dimensions.

The Investment in LGBTQ Visibility in Clinical Contexts: Beyond Fenway

The tendency of LGBTQ health advocates to emphasize identity over other variables in data collection about sexual orientation was a not a quirk specific to Fenway – it cuts across the movement. I asked multiple LGBTQ health advocates in Atlanta variations on the question "if an organization is collecting behavioral data, but not data about identity, are they collecting data about orientation?" I received a definitive answer of "no" nearly every time.

> **SM**: If an agency is collecting data about HIV risk factors, and detailed data about sexual behaviors, those data are not explicit sexual orientation data in your view?
>
> **Jeff Graham, Executive Director of Georgia Equality**: Yeah, not necessarily. I think it's implied but it depends on what the detailed sexual history would look like. But unless someone is very explicitly asking about the perceived sexual orientation, self-identified sexual orientation of the person that they're speaking with, their sex partners, even questions around gender or gender identity around sex partners - you could get answers about anal or oral sex, and what does that mean?
>
> **SM**: What is the difference between those other kinds of data and sexual orientation data? I'm trying to get the difference between categories like gay, lesbian, bisexual *as identity categories* versus behaviors.
>
> **Jeff**: See, I would say that they don't necessarily correlate. I think you still have to ask someone what is their own sexual orientation.
>
> **SM**: Right. Using terms that are about identity, you mean?
>
> **Jeff**: Mm-hmm. Yeah.

Consider also the response of Linda Ellis, Executive Director of two organizations, The Phillip Rush Center: Supporting Atlanta's LGBT Community (the city's modest LGBTQ center) and

The Health Initiative: Georgia's Voice for LGBTQ Health. Linda, among other duties, conducts LGBTQ health training sessions aimed at providers and healthcare organizations across the state of Georgia.

> **SM**: So, Linda, here's my question: if an organization is collecting detailed behavioral data about sexuality, but they are not asking if people identify as LGBT, are they collecting sexual orientation data?
>
> **Linda**: No.
>
> **SM**: No? Ok.
>
> **Linda**: No. They are collecting data based on behavior, not identity, and they are two different questions.
>
> **SM**: Ok, but are they collecting data about sexual orientation?
>
> **Linda**: No.
>
> **SM**: Ok, cool.

Emily Brown, leader of the Atlanta Coalition for LGBTQ Youth and then-employee at Georgia Equality, expressed similar views:

> **SM**: Emily, if an organization is collecting data about sexual behaviors, are they collecting sexual orientation data?
>
> **Emily Brown**: No. No, they're not. Do you want me to elaborate?
>
> **SM**: Sure.
>
> **Emily Brown**: They're collecting data on behavior, which is completely different from sexual orientation data. Sexual orientation data would be collected by asking something along the lines of "what's your sexual orientation?" – completely distinct.
>
> **SM**: Uh-huh. Which would elicit…
>
> **Emily Brown**: …elicit responses like: "straight," "gay," "heterosexual," "homosexual," "bisexual," "pansexual," "asexual,'" "I don't understand the question," "N/A," "ran out of the room screaming."
>
> **SM**: Ok, got it.

Or consider Jamil Aaronsky, an employee of The Health Initiative who also gives presentations about transgender healthcare and LGBTQ health trainings to providers in Georgia:

> **SM**: If someone is taking a detailed sexual history, but aren't having conversations about identities, and recording that data, in your understanding, would that provider be collecting sexual orientation data?
>
> **Jamil Aaronsky, LGBTQ Health Educator**: I would hope so, but again, it's not required. It really depends upon the place of business, how they operate, and what their general MO [*modus operandi*] is. But it's possible to say that they're not, just as much as they are.
>
> **SM**: Is it safe to say that your understanding of sexual orientation data is about gay, bi, lesbian identities?
>
> **Jamil**: Mm-hmm.
>
> **SM**: Okay, gotcha...I go to HIV providers, and…ask them if they…collect sexual orientation data. A lot of folks are saying "yes," and point to [the risk assessment or HIV risk hierarchy]. But they're not asking any questions about identities. But…when people in LGBT politics are talking about “sexual orientation,” they're really talking about identity…That was where you fell in…right?
>
> **Jamil**: Right!

In conclusion, my fieldwork data and health policy analysis data show that – overwhelmingly, but not in every instance – LGBTQ health advocates, educators, and practitioners treat “sexual identity” data as data about “sexual orientation.” However, data about sexual behaviors do not qualify as “orientation” data in the LGBTQ health world, despite behaviors being one of three elements in the IOM definition of orientation. This is the ontological basis for many understandings of sexuality, gender, and uses of relevant data, and corresponding sexual realities at LGBTQ organizations where this style is employed.

However, as my response to Jamil indicates, I found the story to be rather different in the realm of HIV practice. In HIV organizations, a variety of different kinds of data are enacted as data about “orientation.”

“The Reverse is Also True”: Data about Sexual Behaviors and HIV Risk Hierarchy Data Functioning as Sexual Orientation Data

“The second half of [*Cargo in the Blood*] is titled *The Reverse Is Also True*, suggesting that another, opposite view of an idea, subject or narrative is sometimes as revealing as its supposed authentic version. Just as considering both sides of an argument can open up new readings, the images reproduced in this section have been inverted in various ways and their colors and saturations have been subjected to numerous experiments with filter treatments so as to produce new images.”

-Artist Russell Mills, reflecting on *Cargo in the Blood*, an
artistic collaboration with Trent Reznor[48]

While most people in the LGBTQ health world unambiguously feel that identity is a necessary element if an organization can legitimately claim to be collecting “sexual orientation” data, this is not true in the HIV world, even at some HIV/AIDS Service Organizations (ASOs) that tout their LGBTQ focus. Many HIV organizations refer to the collection of behavioral data *or* “HIV Risk Hierarchy” data intended to capture how individuals became HIV-positive as data about “sexual orientation.” This is true across scales in the HIV/AIDS apparatus.

For example, the *National HIV/AIDS Strategy of the United States* (NHAS) and *NHAS: Updated to 2020* use HIV risk hierarchy data to infer information about “sexual orientation.” Versions of the strategy and its progress reports refer to “gay and bisexual men” and “heterosexual women.” However, these data are reported out using the fields “male-to-male sexual contact” and “heterosexual contact with a person known to have, or to be at high risk for, HIV infection,” neither of which fit any behavioral, affectational, or identitarian metric approved by LGBTQ health actors or queer demographers as data collection about sexual orientation or one of its three elements.[49]

The use of HIV risk hierarchy data to express information about “sexual orientation” by the highest governing document in the domestic response to HIV/AIDS legitimizes uses of the hierarchy to express information about sexual orientation in the broader HIV apparatus and local organizations. In legitimizing uses of HIV risk hierarchy data to report out "sexual orientation" data, *NHAS* provides part of the groundwork for data utilization strategies that treat HIV risk hierarchy data and behavioral data as data about "sexual orientation."

This position is, of course, opposed by LGBTQ health actors, which Sean Cahill of Fenway confirmed to me in an interview. I asked him about this issue, and he said "I think they could ask the questions in a better way…I think AIDS service organizations funded by the Ryan White program should be asking their clients how they currently identify because, like I said, what happened 20, 30 years ago may not correspond with how you identify today." However, in implying that HIV risk hierarchy data gathered "20, 30 years ago" could constitute sexual identity data at the time of its collection, Cahill unwittingly reproduces the practice he is trying to push against regarding uses of hierarchy data to infer orientation. This slippage highlights how many complex histories and discourses overlay with and inform one another in this space, an effect of what Andrew Pickering characterizes as "the mangle of practice" and what John Law characterizes as "mess."[50]

Consider another example. A high-ranking official at the Georgia Department of Public Health (GDPH) told me, unambiguously and without doubt, that the HIV prevention program collects sexual orientation data. However, except in one re-linkage-to-care program aimed at people living with HIV who have dropped out of care and agree to be "re-linked" with the assistance of health department staff, GDPH does not collect structured data about identities or attractions – only behaviors, using CDC's risk assessment form (which doubles as a sexual history). Many agencies in metro Atlanta that collect detailed behavioral data deliberately avoid discussing sexual identity unless it is brought up by the client presenting for services, let alone record this data. This is usually not for homophobic reasons, but because bringing up gay identity is perceived as potentially causing a negative reaction in clients and as a possible deterrent to regular testing or honest conversations between testing personnel and individual clients.

Or take the case of Andy Butler, a prevention specialist at We Have a Heart, Inc., which promotes itself as the premier transgender social service agency in Atlanta, and is largely funded through HIV prevention and support services grants. Andy told me that the organization collects sexual orientation data. However, the agency does not ask questions about sexual identity. Rather, they ask about behaviors in the past 12 months, per CDC's HIV testing form, which does not include a field called "sexual orientation" or "sexual identity":

> **SM**: Is it your understanding that We Have a Heart collects sexual orientation data on clients?
>
> **Andy**: We do.
>
> **SM**: Here? [points to form where only behavioral data are collected]
>
> **Andy**: Yeah, correct, on the consent form. That's all on there. As far as when we go over the risk factors, we ask them basically, "When's the last time they had sex." If it's a man, we don't automatically assume that they're gay.

Andy is not incorrect in saying that his agency collects sexual orientation data. They collect behavioral data, and these are (per the IOM definition) data about orientation: behavioral data are data about one of three elements that, gathered in any combination, constitute sexual orientation data collection. In saying "we don't automatically assume that they're gay," Andy is in fact readily acknowledging that they do not collect "sexual identity" data. However, in his reality and the methods utilized by We Have a Heart, Inc. (which can be contraposed to Sean Cahill and Fenway Health's), the non-collection of identity data does not disqualify the organization from claiming that they collect sexual orientation data.

Zina Age of Aniz, Inc. offers another example. Zina insisted during our conversation at her agency's offices – repeatedly, and without any doubt – that Aniz collects structured data about sexual orientation when it enrolls new member-clients, and that her agency only uses "MSM" – for "men who have sex with men" – in communications with funders, and not with clients, because "MSM" does not reflect the vast majority of gay and bisexual men's identities. Zina even uses deploys the framework of "programming" to describe how she trains her staff not to use "MSM" for this reason – implying inflexibility and rigidity in the manner of "program requirements" connected to funding in public health jargon or computer programs which literally break if code is improperly written or executed.

> **Zina Age, CEO of Aniz, Inc.**: My staff is programmed: "MSM" means "Morehouse School of Medicine" [a well-known medical school in Atlanta]. So, we're either talking about "you gay, straight, or bisexual." That's how we talk about it at Aniz, Incorporated. We don't say "the MSM population." The only time we use "the MSM population" is when we have to do it for funding.

In saying this, Zina is articulating her agency as LGBTQ-affirming, and asserting her belief (stated explicitly elsewhere in our interview) that the "men who have sex with men" category is stigmatizing to gay and bisexual men, and especially to Black gay and bisexual men.

"MSM is what? You identify yourself by where you stick your private parts?" Zina said incredulously during our interview at her offices on Forsyth Street in Downtown Atlanta, modeling an interaction that she had with an audience from a recent roundtable panel discussion. "MSM" is a category for which Zina – like many others in both the LGBTQ health and HIV worlds – has little patience, except insofar as she must use it strategically to secure funding. Hence, her staff are trained only to use the term when they have to do it for funding, and not in clinical encounters. The method she uses to reinforce this is by telling them that (at her agency), "'MSM' means 'Morehouse School of Medicine'" – something inappropriate (or, more precisely, probably totally irrelevant) to bring up when talking to a member-client about their health needs.

However, based on the forms provided to me by Zina and her staff, during the intake process, her agency does not collect structured data about any of the three elements that define sexual orientation. Rather, they collect HIV risk hierarchy data, and no categories in the HIV risk hierarchy match any gold standard metrics related to sexual orientation - even behaviors, and even though these data are sometimes expressed as being data about orientation. This does not mean that providers at Aniz are not having conversations with clients about their sexualities. However, from the perspective of data collection and the three-part gold standard, the organization is not collecting structured sexual orientation data at intake.

For this reason, the case of Aniz is particularly interesting. It demonstrates that the collection of HIV transmission factor data is not only sometimes used to infer data about sexual orientation (in any of its three elements) and to express these data. In some instances, HIV transmission factor data also exist in the world as data about sexual orientation at the point of collection. The collection of HIV transmission factor data materializes sexual realities that are rooted in practitioners' belief that they are collecting data about sexual orientation or sexual identity.

The Informatics View at Fenway

Sometimes, when data that should be in a patient record are not there – particularly for health informaticists – what data get to count as being about orientation (or, as it were, are *not* about orientation) is dependent on perspective, context, and what data are available to populate missing structured data fields. I had an opportunity to test this in a unique way at Fenway, during a conversation with an informaticist at the organization. This is because Fenway is a Ryan White grantee and is therefore required to collect HIV risk hierarchy data for many of its patients. Fenway is also, of course an LGBTQ-focused FQHC that has collected robust SO/GI data for many years (since long before national standards existed). I wondered: under what circumstances might HIV risk hierarchy data and SO/GI data (particularly SO data) be transposable with one another from an informatics perspective, for the purposes of either reporting to federal funders or completing patient profiles for internal quality assessments.

Quinn Monk, an Informatics Manager at Fenway, explained that, in certain circumstances, in order to complete annual Ryan White Services Reports that require HIV risk hierarchy data for every client, Fenway would use a client's SO/GI data as the starting point for a chart review process to populate the patient's HIV risk hierarchy field for funding reports:

> **SM**: Would you ever use a client's SO/GI data to fill this field out? [I point to the HIV risk hierarchy Quinn is showing me on a laptop screen, for a "mock patient" in Fenway's EHR]
>
> **Quinn**: Good question. Yes. We do. We do occasionally do that. In the rare circumstances where the provider has not filled out the [HIV risk hierarchy] data, though that is very rare…
>
> **SM**: And [the HIV risk hierarchy] is a different field than the sexual history [which is also different from SO].
>
> **Quinn**: Yes…
>
> **SM**: So, you're saying that if a client, who's a gay man, doesn't have the risk factor field filled in, you…would occasionally – probably not very often – pull his SO/GI data to populate an MSM risk factor?...
>
> **Quinn**: So, we would go a step further and do a chart review for that person [and look for] a chart note written by the provider perhaps at their first visit that said, "This person is MSM, they have been with the same partner for X number of years, this is when they were diagnosed." So, if the provider is indicating that the person is MSM, that's when we would – and if they also have the SO/GI data completed that suggests that they might also still be MSM, yeah, we would default to that.
>
> **SM**: So, the SO/GI data would be the first step of the chart review?

> **Quinn**: Right. If they have SO/GI data, and no risk factor completed that would flag us to do a chart review.

Therefore, at Fenway, identity-based SO/GI data are (along with other contextual clues a from patient's chart) sufficient information to allow Quinn to populate an "MSM" risk factor in a patient's HIV risk hierarchy. This means that Quinn feels that they cannot only infer behavioral data from SO, but also that they can infer how someone became HIV positive from their SO ("In the rare circumstances" when the HIV risk factor data are not filled out), and when other context clues from the chart seem to confirm this.

However, for Quinn, things do not cut in the other direction, and there was no ambiguity about this at all.

> **SM:** Would you ever use HIV risk factor data or behavioral data [from the sexual history template] to populate someone's SO/GI fields?
>
> **Quinn:** No.

That was that. Quinn also affirmed the common view at Fenway and in the LGBTQ health movement that, in order to qualify as collecting sexual orientation data, an organization would need to be collecting data about sexual identity or self-identification.

> **SM**: So just in your view, if a clinic or organization is collecting detailed data about sexual behaviors but not identities, are they collecting sexual orientation data?
>
> **Quinn**: No, I don't believe that they are. I think in order to be really understanding where a patient sits in the realm of health risk, and social risk, and the types of factors that would affect you every day, whether it's your physical health, or your emotional health, or your financial health, or whatever, you would need to know orientation and social identity, and also, behavior…
>
> **SM**: So, for someone to qualify as collecting orientation data they have to be asking about identities too?
>
> **Quinn**: I would say so.

My conversation with Quinn reveals a distinct way of conceptualizing how HIV data and data about sexuality can inform one another – one that is rather widespread in the LGBTQ health movement. SO data – data about self-identification – are a special class of data that must be collected by itself and no other data about behaviors or HIV risk factors can be used to populate it. However, identity-based SO data can be used to fill in other fields – namely, HIV risk factor – that do not necessarily have anything to do with how a person self-identifies or even their recent sexual behaviors. When, where, and for what reasons certain data elements are transposable with others is not just a matter of what various data fields or categories mean, conceptually, but also depend on (A) their availability in the first place, (B) the technologies available to actually do the work of transposition and interpretation (an EHR is easier than comparing fields in a lengthy or thick paper chart), (C) the training of the individual(s) doing the work and organizational policies that are in place to do so, and (D) a set of background assumptions on the part of the person working with the record.

Foreclosing and Facilitating Sexual Multiplicity in Biomedicine through Standardization

In his article "Sexualizing Governance and Medicalizing Identities: The Emergence of 'State-Centered' LGBT Health Politics in the United States," Steven Epstein says that it has been in LGBTQ health actors' interest in federal policy to argue for an understanding of sexuality primarily rooted in identity categories for the express purpose of avoiding discussions about sexual behaviors in policymaking forums. Employing poetic understatement, he writes that

> It can be argued, in fact, that the political viability of state-centered LGBT health politics has depended substantially on the avoidance of explicit discussion of sexuality. In the corridors of Washington, it is far less threatening to speak of 'sexual orientation as a demographic variable' than it is to speak of fellatio or fisting.[51]

In addition to being a political decision rooted in the history of LGBTQ visibility politics and potentially an assessment of political practicality in the way that Epstein suggests, it can also be argued, in fact, that the decision to invest in a single-factor SO question was a *technical* one.

It was easier for Fenway and CAP to test and validate a one-element SO question than a two- or three-element question. The more variables that are added to a survey or a hypothesis, the less likely a positive outcome or confirmatory result is to be produced. Further, in successfully arguing for single-element SO data collection, Fenway was not *only* engaged in the flattening of a three-part concept called "sexual orientation" into a single field, or an infinitely complex array of forces called "sexuality" into one thing. In introducing a single-field SO standard, the Fenway and CAP-led coalition also opened up a multiplicity of avenues for understanding the sexual health of patients and populations. Learning about a patient's sexual identity, from a clinical or informatics standpoint, can open the door to much more, such as conversations during clinical visits about sexual behaviors and attractions, or the population of other missing fields in a patient's chart (as Quinn's use of SO data to initiate chart reviews for HIV risk hierarchy data shows). So too, of course, can asking patients about sexual behaviors or HIV risk factors. The issue I am most interested in is *when*, *why*, and *for what reasons* certain data get to function about "orientation," and which do not. Standards substantially affect this state-of-affairs – particularly national standards that are sweeping and affect the entire healthcare industry by mandating that all product developers modify their products to include certain features or fields.

Software Studies scholar Alexander R. Galloway has written about how technological protocols – a kind of standardization – facilitate free action utilizing logics of perfect control. The Internet, for example, only functions because of Internet Protocol (IP) and HyperText

Transfer Protocol (HTTP), which all websites and Internet-based functionalities must be built within in order to function.[52] SO/GI health IT standards are "protocological" in this way. In flattening the collection of data about "sexual orientation" and "gender identity" – phenomena that are, on the one hand, biomedically far more complex than even a multi-factor combination of demographic and clinical metrics can capture and, on the other hand, infinitely complex in reality – the standards incorporated into the U.S. health IT infrastructure by Fenway and CAP's grand coalition stage a multiplicity of different uses of SO and GI in health contexts. The availability of SO/GI fields in EHRs and exchange standards change the parameters around which organizations can build up and sustain specific ways to utilizing and managing data about sexuality, gender, and HIV. They both facilitate and foreclose sexual multiplicity in the practice of biomedicine at all scales and in all infrastructures where they are present.

IV. NEClinic: An Interdisciplinary Team from a Multi-Site Health Center in New England Reflects on Implementing SO/GI

This clinical case study considers NEClinic, a 14-site Federally-Qualified Health Center (FQHC) in a New England state with an associated Disparity Groups Institute. NEClinic was, with Fenway, a leader in a collaborative network of FQHCs that tested the implementation and rollout of SO/GI questions after they were incorporated into annual reports during 2016. At the 2017 Annual Meeting of the American Public Health Association, I saw a presentation by Dr. Joseph Abbas, the lead clinician in the SO/GI implementation project, reflecting on the process. When I realized that the full team he led was also in the audience, I approached him afterward and asked if we could do a group interview.

Six of us (including me) gathered chairs and sat in a semi-circle outside of the conference presentation room at the Georgia World Congress Center and spoke for 45 minutes – one other member of the NEClinic team went to another conference session. Team members present included: (1) Dr. Abbas, the lead physician, (2) Christine Henderson, the Director of the NEClinic Disparity Groups Center and Quality Improvement Lead on the SO/GI project, (3) Karen DeVries, a quality improvement facilitator at the Institute, (4) Michelle Iannucci, a research assistant, and (5) Mila Sorento, another research assistant.[53]

I will start the case study with an anecdote shared with me during the interview that is somewhat moving and demonstrative of how SO/GI implementation can be a wellspring for other LGBTQ-affirming outcomes beyond increased LGBTQ patient visibility:

> **Christine Henderson, NEClinic Disparity Groups Institute Director**: We actually had a staff person who came out as transgender, who had lived for years and years believing that our agency would have a negative take on their life that they led outside of the health center. And that had a huge impact…You had patients who had been patients of ours for so long, who we believed to have a really strong relationship with and engage well, and then to find out that they were--
>
> **Dr. Joseph Abbas**: It was humbling. I had patients I'd taken care for years, who then all of a sudden identified as trans patients! *And I was floored*. I'm like, “I've been taking care of you for years!” But I guess I realize – and I was priding myself for being culturally sensitive and competent – and then I realized that *I never asked the gender questions*. And so here we are – I had three or four patients that identified as trans, and I had no idea.

For NEClinic, at least, claims that SO/GI implementation (A) cannot be done in the absence of systemic organizational transformation and (B) leads to positive outcomes that extend well beyond the collection of the data itself bore out. The organizational transformations required to begin collecting and utilizing SO/GI data led to whole-organization reforms for this safety net health center, which spans the entire state and serves a large portion of the state’s uninsured and under-insured population.

Much like many healthcare organizations throughout the country, NEClinic worked closely with Fenway Health to implement their SO/GI processes. Therefore, NEClinic’s style both follows and diverges from Fenway's. Unlike Fenway, NEClinic did not originate as an LGBTQ-serving facility. It is a general safety-net care and services provider. Therefore, successful implementation of SO/GI data collection required – as Fenway's training materials for health centers suggests – systematic LGBTQ cultural competency trainings among all staff in the clinic, in addition to the entry of SO/GI fields into the EHR, data collection into the clinical workflow, and new informatics practices at NEClinic's Disparity Groups Institute. This required buy-in and leadership from the top managers of the organization, which the team leaders secured (at least in part) because LGBTQ health and SO/GI data were considered "sexy," from a health disparities and health informatics perspective:

> **Christine**: Let's be really honest and frank: it's a hip topic. It was very much in the national news. And our health center prides ourselves on being on the cutting-edge.
>
> **Dr. Abbas**: It got on the radar of the Performance Improvement Workgroup! which every single big leader at the [12-site] agency is on.
>
> **Christine**: Monthly!
>
> **Dr. Abbas**: *Monthly!* It was on their radar.

Clearly, getting on the monthly meeting agendas of this leadership committee, which included leadership from individual sites within the NEClinic network was key in securing the organizational buy-in necessary from every NEClinic site to implement organization-wide SO/GI data collection. NEClinic's Institute had to build an implementation program that could be easily tweaked by personnel to work for every individual clinical site and then be fitted within the different workflows of each physical clinic within the large organization.

NEClinic was not implementing SO/GI with the primary aim of publishing research. Publications – such as the presentation at the 2017 APHA meeting – would be a secondary outcome. Therefore, the level of systematic process-documentation included in NEClinic's

SO/GI implementation was not as thorough as some institutions' that I reviewed, which built SO/GI data collection primarily to secure funding for publications resulting from the study of the process and outcomes. However, the team did undertake significant pre-planning and assessment work involving patient focus groups. The findings from these focus groups led NEClinic to deviate significantly in their implementation of SO/GI from Fenway's guidance and other LGBTQ cultural competency curricula.

For example, Fenway's materials recommend providing patients the ability to self-report their SO/GI from home via a patient EHR portal and/or at intake, in the waiting room, before the clinical workflow begins. Sean Cahill, Director of Health Policy Research at The Fenway Institute, confirmed this to me when I interviewed him in late 2017, when he described the organization's preferred data collection workflow (see, Figure 3.3).

> **Sean Cahill:** Our preferred thing is either to ask the question through a patient portal, which is when you log in to a website and email your doctor to say you want a prescription refilled or to schedule an appointment or something. And when you're doing that the patient portal can ask you some questions and say, "we're gonna update your demographic information." That would be one way.
>
> The other preferred way would be a "patient report outcomes tablet," which is basically like an iPad [in the waiting area]. There's a lot of reasons to believe that those kind of more confidential, private ways of asking sensitive questions are more effective…whether you're asking about substance use or domestic violence or HIV treatment adherence or sexual orientation and gender identity, you're probably gonna get more people to respond honestly if you ask those ways.

Cahill's statement is notable not only for providing the specific parameters Fenway recommends for clinical SO/GI data collection, but also for simultaneously placing SO/GI in the very different categories of "demographic information" and "sensitive questions…about substance use or domestic violence or HIV treatment adherence" in the same statement. This raises the question of precisely what kind of data objects SO/GI are, or perhaps, *when* SO/GI are permitted to function as “demographic information” versus a special class of “sensitive” data akin to HIV status.

In addition to recommending disclosure of SO/GI before the clinical workflow begins, Fenway’s educational materials and other LGBTQ cultural competency curricula that I reviewed during fieldwork also generally insist on there being physical markers of LGBTQ safety or friendliness in the clinic, such as rainbow flags behind the front desk, gender-neutral restrooms, and LGBTQ media in the lobby. The results of NEClinic’s LGBTQ focus groups, however, led the team to make a different set of decisions.

> **Christine**: We did run focus groups. So, we actually went to patients and asked them for their feedback on certain things. For instance...Giving the survey in the medical visit, that was unanimously. *There was no one who wanted it offered at registration*. Everybody said they preferred [the data to be collected in the clinical workflow]. Every patient...
>
> **SM**: Which is decidedly – that's not what Fenway recommends…
>
> **Christine**: Right, exactly. Which was a challenge, because we were going against the only best practice we actually had to rely on. But it ended up working for us and our patients.

NEClinic faced a similar reaction from patients regarding gender neutral bathrooms and LGBTQ symbols in the lobby area. The team told me that LGBTQ patients said word-of-mouth was far more important than physical LGBTQ symbols in the clinic, and that these symbols could in fact be alienating.

> **Christine**: They said… “Why would you single us out as a group that you focus on? Why wouldn't we just be able to assume that you're open...” And they really spoke to word-of-mouth being so much more important than a rainbow flag, and in some ways, that almost felt like an isolating factor... And then one of our patients who we're very familiar with was like, “Well, that's like, are you gonna put a Puerto Rican flag up there so that Puerto Ricans know that they can go there? Why would you put a rainbow flag?” And it was unexpected…
>
> We were ready to lobby our agency to put it on our letterhead. To do *everything*! And we were shocked when we realized – –

> **Dr. Abbas**: We were thinking at this point: “I don't think it would be *harmful*.” I mean, *to me*, I would always see a rainbow flag and feel like, "Okay. Safe place." Right?...
>
> **Christine**: They said they would rather have a tagline like, “All Are Welcome” – something very general that didn't isolate a certain group.
>
> **Dr. Abbas**: Which is what we ended up doing in terms of our mission statement for our sensitive population. So, the idea is, "Just be inclusive, but not necessarily sort of point us out…” And the same thing with the bathrooms. We thought, just have single use bathrooms, they're obvious. Why do you need a different sign on it? Just as long as there is a single use bathroom, you can go in the single use bathroom.
>
> **Christine**: Yeah. And our trans groups were hilarious about the bathrooms. They were like, “You can have a men's and women's bathroom. I'm gonna use whatever bathroom I think I wanna use.” They said: “the only problem would be if someone stopped me or made some kind of [issue].” But they really didn't feel very strongly about unisex bathrooms.

Some of NEClinic’s decisions go against almost everything that folks are trained to think about in LGBTQ cultural competency, and in gender and sexuality studies. An “all are welcome” tagline sounds a lot like the line “we treat all patients the same here,” which cultural competency trainers often use as a point of entry to argue for why clinics need to engage in specific practices to meet the health needs of their minority patients. To use academic jargon from cultural studies, it could even be interpreted as a repurposed form of “neoliberal colorblindness” that is a violent erasure of difference that is particularly pronounced in the contemporary historical moment.[54] However, that is not the only way to read “All Are Welcome,” and would be especially ungenerous. This is particularly so, given that NEClinic felt more bound to what their patients said was best for them than they did to Fenway’s guidance, and therefore followed the patients’ lead.

NEClinic described problems in utilizing SO/GI data in advanced ways, such as translating structured SO/GI data into information about correct pronouns for patients. The clinic also wanted – as part of the structured SO/GI rollout process – to begin collecting detailed structured data about sexual behaviors using a template in their EHR in order to make their informatics potential even greater. However, integrating this into the EHR was too expensive – not from an organizational perspective within NEClinic, but because of the high price given to them by their EHR vendor to build the template:

> **Dr. Abbas**: Karen and I have been sort of working on that [chuckle] quite a bit, yeah. We haven't gotten there yet...because we're just starting on the next step. This actual risk assessment is gonna be set up hopefully to train all the providers to do it on every patient, and then depending upon how they answer, it can either stop really immediately, or you can start to sort of go into a little bit more in-depth questionnaire that way. And it is overwhelming... Because there's so many questions that we're supposed to be asking, so we divide it up into three sections, so that way providers can use it as they will. It isn't structured data; it isn't social history.
>
> **Karen, Quality Improvement Facilitator**: Right. It's in the same field as the SO/GI questions, and it could technically follow those questions, but we can't queue it to come up based on responses to the SO/GI questionnaire. Even developing the SO/GI questionnaire as what we call the "Smart Form," the minimum is $5,000 from the vendor that we would have to pay, and we just don't have the resources for that. And then this sexual risk assessment that we built, we actually had them price it out.
>
> **Dr. Abbas**: It was $45,000, $50,000?
>
> **Karen**: It was multiple thousands of dollars, yeah, tens of thousands.

Barriers to effectively implementing and utilizing SO/GI and other data about sexuality and gender are often laid at the feet of organizations or providers that are resistant or "not ready." However, hurdles take appear in a wide variety of forms, including prohibitive cost from EHR vendors.

V. From "Identity Management" to "Data Ontology Management" in the SO/GI Assemblage

A major area of friction regarding sexual orientation and gender identity (SO/GI) pertains to what kinds of data objects "sexual orientation" and "gender identity" are – especially structured SO/GI collected in surveys, medical records, and other data sets (as opposed to unstructured data about sexuality and gender collected in free text or other areas of a medical record). Owing to the desire among LGBTQ health experts, queer demographers, and advocates to normalize SO/GI data collection, SO/GI are often discussed as structured demographic data that should be collected in any context where information like name, date of birth, and race are collected. This includes human resources records, personnel or client satisfaction surveys, and other non-health or research contexts where individuals are asked about demographic attributes as part of the normal data collection process.[55]

To aid in the normalization of SO/GI data collection, in both the clinical and survey research contexts, SO/GI advocates such as The Williams Institute and Fenway go to great lengths to insist and to empirically demonstrate that patients, survey respondents, and people generally are comfortable with SO/GI data collection. These organizations, academic researchers, and large institutions expend resources to cognitively test individuals' affective experience of answering the questions, solicit respondents for their thoughts about being asked, and to report respondents' "high levels of acceptability" in answering SO/GI questions.[56] Advocates and scientists do this work not only to develop validated metrics, but also because SO/GI have long been considered taboo questions to ask on surveys and in other contexts such as medical encounters and employment records. SO/GI data are associated with (empirically and historically justifiable) concerns that collecting these data potentially skew survey results, makes respondents uncomfortable, causes individuals to not respond "honestly" about SO/GI or other questions that follow on a survey, and/or that the availability of data in datasets could lead to after-the-fact discrimination. In asking about individuals' "levels of acceptability" in responding to SO/GI questions as normal demographic data, SO/GI advocates like Fenway and The Williams Institute are working yet another angle to normalize the collection of these data: the angle that sexual and gender minorities and even heterosexuals and cisgender folks genuinely do not mind being asked about their sexual orientation and gender identity, and even that they appreciate it, understand why an institution would want to inquire about it, and are aware of the potential benefits of collecting the data for them as individuals and for more altruistic purposes.[57]

However, many SO/GI proponents who work to de-exceptionalize SO/GI in this way will also insist – sometimes even in the same conversation where they make arguments about the acceptability of routine SO/GI data collection as part of demographic attributes – that SO/GI data are "sensitive" health data that (A) fall into the special category of "Protected Health Information," and (B) require special data collection procedures to ensure that data are collected in a "private" fashion where the individual feels comfortable and will answer "honestly." During my fieldwork, I met few practitioners who provided consistent answers about the ontological status of sexual orientation and gender identity data as either "simple demographic data" or "sensitive health data." Whether SO/GI were perceived to be sensitive or not depended on the context of their collection. In another common refrain, SO/GI simply oscillated haphazardly between "sensitive clinical data" and "normal demographic questions" with little consistency, or appeared as both at the same time. Recall, for example, Sean Cahill's statement placing SO/GI in both the "sensitive" and "demographic" categories in his answer to my question about Fenway's preferred mode of data collection.

At this point, readers will be unsurprised to learn my position that this ontological uncertainty and flux is a feature of SO/GI's existence, not a quirk or something to be clarified or corrected. Further, I show that SO/GI's enactment as either especially sensitive data or routine demographic information is not haphazard or random, but depends on the assemblages in which the data are collected, conceptualized, and utilized.

From “Strategic Outness” in Queer Life to the Strategic Management of SO/GI Data Ontologies

In his 2011 article “‘You will always have to “out” yourself’: Reconsidering Coming Out Through Strategic Outness,” sociologist Jason Orne proposes the framework of “strategic outness” to articulate how LGBTQ people engage in practices of identity management related to their sexualities and genders that make them “out” in some situations, but not in others. As many queer writers and theorists have noted, coming out is not a one-time event, and many LGBTQ people are not “out of the closet” in all contexts. Rather, coming out is something that queer people must do repeatedly, and a great deal of sexual and gender minorities are out to some people or organizations in their lives, and not to others. This requires individual queers to engage in strategies that are catered to their own lifeworld regarding when and how they disclose their sexual and gender minority status, or what aspects of their identities they choose to reveal. Orne calls this “strategic outness.”[58]

For example, a transgender person may be fully out as trans to everyone in their social and professional life, but may strategically decide who to tell whether they have pursued medical transition through surgery or hormones. Similarly, a gay man may be out as gay but keep their status as single or partnered from coworkers or landlords. Members of Leather or BDSM communities may be open about their membership in kinky subcultures to their “vanilla” friends, but often hold their specific sexual predilections close to the vest, only sharing them with others in their subset of the kink world. People living with HIV also engage in strategic outness. Disclosure of one’s serostatus is a matter of great consequence for many people living with HIV. Some folks only very selectively share this information (perhaps just with their medical providers), while for others people living with HIV, being poz (an identity category that emerged from HIV positive cultures) is a central and public part of who they are in nearly all contexts. For a great number of people living with HIV, it is somewhere in the middle: people are strategically out to some (perhaps their lovers, family, and doctors), but not to others (perhaps their employers or landlords, owing to the very real possibility of discrimination). When and how to disclose one's serostatus is central to debates over the criminalization of HIV transmission and the sexualities of people living with HIV.[59]

The litany of examples I have just provided constitute "identity management strategies." There is a large body of literature on identity management in sociology, anthropology, scholarship on racial passing and stigma management, and other fields.[60] Herein, I build conceptual bridges between identity management scholarship (especially Orne's "strategic outness"), the philosophical theory of "identity in the concept" from Gilles Deleuze's *Difference and Repetition* (wherein concepts are understood to take on certain characteristics or "identities" through their repeated use in one or more ways), and approaches from data studies (especially Yanni Alexander Loukissas' methodological exhortation taken up in this dissertation to turn away from analyses of "data sets" to consider the "data settings" where data acquire meaning).[61] I articulate how SO/GI stakeholders and health practitioners engage in kinds of strategic negotiations in their professional practice regarding the ontological status of SO/GI data as especially sensitive data or not. These strategies have the effect not only of "managing" SO/GI data but also of producing new SO/GI data ontologies that are bounded by time and place. They also resemble those that LGBTQ people and other marginalized people engage in during their everyday lives regard to their identities and "outness," as they move through different zones where it might be more or less safe to be "out" to those around them.

I call the tactics that health actors use to determine when, why, and for what reasons SO/GI materialize as either sensitive health data akin to HIV status or non-sensitive demographic data akin to date of birth or race "data ontology management" strategies. The concept of data ontology management is particularly relevant to SO/GI data and on display when SO/GI data are being utilized, because the ontological status of SO/GI is frequently shifting and regularly contested: as being either "sensitive" or not, as being "clinical" or "demographic." However, data ontology management has applicability in many other areas – specifically, in any situation in which an actor must make considered determinations about the conditions in which data (or a particular kind of data, like SO/GI) might transmute from being "sensitive" to "routine demographic" data, or be enacted in a particular institutional milieu as one or another data class.

Deleuze uses "identity in the concept" partly to refer to "the formal identity which corresponds to simple logical blockage": specific uses of a concept that, when repeated over time in discrete instances, give a concept consistency and meaning (an identity).[62] Put otherwise, through a concept's regular, routinized, repeated, and consistent usage in a particular way, it acquires an identity. A concept's identity extends not just to its conceptual content (e.g. the gold standard definition of "sexual orientation" as a three-part amalgam of identities, attractions, and behaviors), but also to the formal characteristics that the concept acquires through its use (e.g. whether "sexual orientation" is non-sensitive demographic data akin to date of birth or protected health information akin to information about experiences of domestic abuse).

As I have explored in this dissertation and in this chapter, concepts often possess multiple identities. I have shown how "sexual orientation" and "HIV risk factors" are constituted differently from organization-to-organization or from discipline-to-discipline, and play a role in producing different methods of utilizing data, and thus sexual realities, in specific milieus. These differences in usage occur because of how practitioners are trained to think about concepts, the technologies they use to measure and enact concepts in practice, the social movements they are situated within (e.g. the HIV/AIDS movement or the LGBTQ health movement), and a multiplicity of other factors which cause the concept to materialize in a specific way.[63] The identities that concepts like “sexual orientation” and “gender identity” acquire in practice – through acts of cognition, by discursive deployments by human actors using technologies, and their existence in sociotechnical infrastructures like electronic health records (EHRs) and health IT standards – deeply shape the material constitution of sexuality and biomedical practice in bounded times, places, and discourse communities. In the case of SO/GI, its identity as sensitive data, routine demographic information, and clinical data do not merely cause confusion that ought to be resolved. Rather, the ability of SO/GI data to exist in the world as one or the other of these data classes – to take on one or the other conceptual identity or even to possess more than one in the same time and place, with the same set of actors working in the same network – reveals how the sociotechnical contexts in which data are regulated, collected, stored, and utilized shape the ontological status of those data at least as much (or more than) the conceptual content of a category in a gold standard, index such as a health IT nomenclature, or authoritative definition in a textbook.

SO/GI in the 2015 EHR Certification criteria published by the Office of the Coordinator for Health Information Technology (ONC) are an interesting case where SO/GI take on both identities: as non-sensitive demographic data and protected clinical data. In EHR certification criteria, SO/GI were deliberately excluded from the Common Clinical Data Set (CCDS), despite the fact that the Fenway Institute and the Center for American Progress-led coalition requested their inclusion in this data set: the most critical such data set in the health IT regulatory landscape in the United States. SO/GI are instead in the “demographics” section of the “Base EHR Definition.” The CCDS, as its name implies, is a “clinical data set.” However, in addition to containing clinical information such as medication allergies, smoking status, immunizations, medical implant data, and laboratory test values, the CCDS also contains demographic data elements. These include name, race and ethnicity, date of birth, and sex (male/female/unknown).[64] In the universe of binding health IT product certification criteria in U.S. health IT policy, SO/GI are "demographic" data that do not merit inclusion in the main "clinical data set" that governs other demographics data elements which are – clinically speaking – in some cases less relevant than knowledge of a patient's sexual orientation or gender identity. SO/GI in this context are only "clinical data" because of their inclusion in medical records and health IT infrastructures, not because they are "clinical" in the same way that laboratory test results constitute or can be said to be clinical data. Further, structured SO/GI in EHR certification criteria are just one way that data about sexuality and gender are recorded, and a far more "demographic" modality of recording information about sexuality and gender than a clinically-oriented approach such as sexual history fields, anatomical inventories documenting what gender-affirming procedures transgender patients may have had, or history of sexually transmitted infections. There are no ONC-endorsed national health IT standards for these clinically important data about sexuality and gender, but there are for demographic SO/GI.

Further, while it is currently in-line with best practices to ask about demographic "SO" data at intake, several HIV agencies where I conducted fieldwork also have patient self-report detailed questions about sexual history at intake, before the clinical workflow begins. The National AIDS Education and Services for Minorities (NAESM) agency in Southwest Atlanta, which primarily serves Black gay, bisexual, and same-gender loving men is one such site. NAESM does not ask if patients identify as gay or bisexual on intake paperwork: so, they do not collect standardized "SO." However, some of the behavioral questions that NAESM asks at intake are, per the three-part gold standard definition, data about sexual orientation (e.g. **"I have/had sex with** (check all that apply): Male __ Female __ Transgender M/F __"). Other NAESM intake questions are about sexual health or sexuality more generally (e.g. "In the past 12 months, have you had STD/HIV talks with a potential sexual partners?"). At NAESM, these questions are asked on a single form alongside fill-in-the-blank demographic questions about ""name," "date of birth," "age," "race," and "gender" (so the agency also does not collect standardized, structured "GI" data in the modality recommended by Fenway or survey researchers like The Williams Institute).

When asked if they collected data about sexual orientation at intake, a Deputy Director at NAESM responded in the affirmative. As I show in previous sections, LGBTQ health practitioners would contest the Deputy Director's assertion, owing to the non-collection of sexual identity data in the "SO" modality. However, clinically speaking – per the Institute of Medicine's definition– NAESM does collect sexual orientation data. Demographically speaking, though – from both LGBTQ health and health IT perspectives – NAESM is not collecting SO data. While sexual identity questions with fields such as "gay or lesbian," "heterosexual/straight" and "bisexual" are variously framed as both "demographic" fields and as "sensitive clinical data," it is difficult to imagine a circumstance at a social service agency or healthcare provider in which questions about sexual behaviors would ever be treated as a demographic characteristic, rather than clinically-informative data about the sexuality or recent sexual history of a patient.

The ontological status of SO data in clinical contexts – as "demographic" and/or "clinical" and/or "sensitive" – is shaped not only by practitioners' understandings of what constitutes a demographic attribute, but also by which of the three specific SO elements that an agency (A) is actually collecting, (B) understands itself to be collecting, and (C) how those elements are situated along the continuums of "demographic" to "clinical" and of "routine" to "sensitive."

Given all of this, does NAESM collect structured data about sexual orientation? Yes. However, does NAESM collect structured *demographic* data about sexual orientation? No.

The answers to these questions are less about the content of the SO data that NAESM is collecting than they are about how the specific SO elements that they are collecting are positioned within the broader discursive fields that determine what constitutes "clinical" data (something biomedically informative, actionable, and private) versus "demographic" data (something written onto the subjectivity of the person answering the question both by themselves and the culture in which they live).

SO/GI's multiple conceptual and formal identities give way not only to different biomedical sexualities and sexual realities in practice, but also to varied data ontologies that shape how the data exist in the world in their contexts and settings, how they inform decision-making by providers, the ways that the data collection instruments shape disclosures by patients, and even disclosures between different providers when making referrals or transferring data about a patient from one agency to another.

In some situations, SO/GI are not clinical or health data, per se, but are "sensitive." Employment records or workplace surveys administered by human resources departments or other internal actors in a company or firm are a grey zone which illustrate how this can be the case. In the context of employment records, SO/GI data are certainly not "clinical" in the same way that they are in a medical record. However, these data – especially gender identity data – are related to biomedicalized identities that individuals possess. They are also "demographic." The Human Rights Campaign (HRC, a major gay rights lobby) includes "optional questions on sexual orientation and gender identity" as a mark in firms' favor, on all "[d]ata collection forms that include employee race, ethnicity, gender, military and disability status — typically recorded as part of employee records."[65] Even in the non-clinical, non-health context, SO/GI take on many of the same ontological characteristics that they do in medical records: as demographic data that ought not be required conditions of employment or participation in workplace initiatives (HRC explicitly says that SO/GI should be "optional"). They are therefore "sensitive" data that merit some degree of control by the disclosing employee.

The question of the ontologies produced by SO/GI becomes more complex when one considers how the data shape clinical conditions when they are transmitted from one entity to another. The future of SO/GI in the health IT ecosystem will largely hinge on whether SO/GI are required in interoperability standards. Interoperability standards are presently non-binding criteria included in the *Interoperability Standards Advisory*, published annually by ONC. However, as I discuss in the conclusion of this chapter on "SO/GI's Uncertain Future in Health IT," interoperability standards are set to become binding certification criteria for the vast majority of health IT products in 2018 and beyond. This follows the path laid out in the 2015 *Interoperability Roadmap*, statements by ONC, and the consensus of the health IT community, the leaders of which envision all health data as existing on a trajectory toward exchangeability, liquidity, and accessibility to parties granted appropriate access. This automated interoperable future poses a major challenge for SO/GI stakeholders and the LGBTQ health community. While there is firm consensus that SO/GI data should be collected in health contexts, there is currently no consensus at all about under what circumstances it is appropriate for a provider to transmit a patient's SO/GI to another provider. In fact, it is fiercely contested. In my fieldwork, I regularly had conversations with LGBTQ health educators – especially those focused on trans health – who were very invested in SO/GI data being subject to strict controls by the patient.

Unresolved questions abound in this space. During an emergency event where EHR data are pulled over a health information exchange into an EHR being used in an ambulance or Emergency Room, or during the course of a referral from a primary care provider to a specialist, what business does a paramedic, Emergency Room triage nurse, podiatrist, allergist, or ophthalmologist have knowing a patient's SO/GI, unless the patient themselves has requested that these data be disclosed electronically during a transfer of records, or has opted to proactively disclose their SO/GI to the specialist themselves? These are crucial questions, and ones that LGBTQ health advocates will need to build consensus about as an increasingly interoperable future in healthcare begins to take shape and SO/GI begin (with varying degrees of consistency) to be transferred between providers as part of normal referrals, hand-offs, and automated EHR data population processes. SO/GI data are clinically informative, even and especially in unexpected contexts such as ophthalmology. Gay and bisexual men who use the recreation inhalant "poppers," for example, have been known to experience a specific kind of maculopathy (or damage to the retina) owing to changes in the chemical formula used to manufacture the drugs, following attempts to ban the substance in Europe. However, it is unlikely that a specialist's office will have the level of LGBTQ cultural competency training of even a non-LGBTQ specialist general family practice, and many doctors are simply queer- and transphobic. When the clinical value of demographic SO/GI outweigh the value of the data remaining private will often not be apparent until a specific disclosure itself is made. Advocates and practitioners must build new norms with this in mind.

Alternative models for health data management exist in the form of nascent health data cooperatives that would offer menu-like options for patients to control what data are sent between clinical organizations, as an alternative to current “view/download/transmit” functions in EHRs and health information exchanges, which generally do not allow for either patient control of what data are transmitted between providers or even meaningful provider controls of what data are sent between systems or over an exchange network. Giving patients and providers more mechanisms to control the flow of data, while a stated priority in documents such as the *Federal Health IT Strategic Plan*, is not the driving priority of the health IT community: getting data to more easily move between systems is the primary motive. In addition to creating more opportunities for individuals – both patients and providers – to control the movement of data in ways that they determine are best for them, the introduction of controls such as these would also open up new modalities for data ontology management on the part of sexual and gender minorities and all patients.

Conceptualizing and Managing Sexual Orientation Data Ontologies: A Diagrammatic Approach

Below, I offer a diagram to help readers gain a handle on the complex tangle of sexual orientation data ontologies that exist in the world (or potentially exist) and how they are managed by health practitioners, particularly in clinical practice, LGBTQ health, and HIV contexts. The chart provides a mapping of relations between overlaid concepts that exist in conceptual and practical friction with one another in the everyday work of sexual orientation data ontology management, with an emphasis on health milieus. In the column headings, I present six different classifications: SO in health IT (sexual orientation primarily as a technical standard), sexual orientation (as a measurable three-part concept and object of knowledge and intervention), each of sexual orientation’s three conceptual components (identities, attractions, behaviors), and “HIV risk hierarchy.” In the rows, I ask questions pertaining to the ontological status of the specific kinds of sexuality data that I have explored herein; for example, whether a particular kind of data are “clinical,” “sensitive,” “demographic,” whether subject to biomedical intervention or “off-limits,” or standardized.

I frame the diagram as a set of “Coordinates for Sexual Orientation Data Ontology Management.” I intend it to be useful for social scientists and humanists whose research requires them to understand or articulate the constitution of sexuality and sexual orientation as objects of knowledge in particular times and places. I also intend the diagram to be useful to health practitioners and others who work with sexual orientation data and who seek to engage in reflective exercises regarding how their own practices of sexual orientation data management both require certain kinds of ontological management strategies and themselves produce novel (or at least situationally particular) sexual orientation ontologies, biomedical sexualities, methods of utilizing data related to sexuality and HIV, and sexual realties.

[figure is presented on the following page]

Figure 3.4. Coordinates for Sexual Orientation Data Ontology Management

	Sexual Orientation	**Sexual Identity**	**Sexual Behaviors**	**Sexual Attractions**	**“SO” in Health IT**	**HIV Risk Hierarchy**
Formal definition:	“Identities, Attractions, and Behaviors”	One of three elements of “sexual orientation”	One of three elements of “sexual orientation”	One of three elements of “sexual orientation”	Taxonomic equivalent of “sexual identity”	Most likely cause of HIV transmission at time of initial diagnosis
Is it demographic data?:	Usually	Usually	Sometimes (e.g. “MSM”)	Almost Never	Yes	Often
Is it clinical data?:	Sometimes	Sometimes	Often	Sometimes	Yes, because it is in a health record	Yes
Is it sensitive data?:	Sometimes	Sometimes	Usually	Sometimes	Sometimes	Yes
Is it sexual orientation?:	-	Almost Always	Sometimes, Not Usually	Sometimes	It is the taxonomic equivalent of “sexual identity”	Often, but only by inference
Is it an identity?:	Almost Always	-	Rarely, and Sometimes Provisionally (e.g. “identify as MSM”) to Sometimes (e.g. fister, kinky)	Sometimes (e.g. “Same-Gender Loving”)	Usually, but it depends on the patient’s understanding of themselves	Rarely, and Sometimes Provisionally (e.g. “identify as MSM”)
Is it a behavior?:	Not necessarily	Not necessarily	-	No	Often, but only by inference	At least once, but more often by inference (e.g. “MSM”)
Is it an attraction?:	Usually	Almost Always	Not Necessarily	-	Usually	Sometimes, but only by inference
Is it acceptable for a health worker to proactively try and change or affect it for a patient?:	**No**	**No**	Under many circumstances (e.g. encouraging use of prophylaxis, when behaviors could “harm,” or are perceived as “risky”)	Under certain circumstances (e.g. when the desires could “harm,” or are extremely taboo i.e. incest)	Only if the patient asks for the field be changed, or changes it themselves	Rarely. An individual could report additional risk factors later in life, thus retroactively changing their risk factor in some datasets.
Is it associated with a national health IT standard?	Yes	It is called “SO”	No	No	Yes	No
Do validated data collection best practices exist?	Yes	Yes	Yes	Yes	Yes	Yes

V. Conclusion: SO/GI's Uncertain Future in Health IT

In this chapter, I have explored how SO/GI became incorporated into the United States' "nationwide interoperable health IT infrastructure." I have also explored some of the regulatory and definitional tensions that currently structure discussions and uses of SO/GI data in health IT systems, primarily regarding in what circumstances SO/GI are "sensitive health information" such as HIV status or "demographic data" such as date of birth and race.

I have also explained how the standardization of SO in U.S. health IT has flattened it into a single, identity-based variable in many settings, as opposed to a three-part definition encompassing "identities, attractions, and behaviors." However, I have also shown that the introduction of a single-variable, identity-based SO field into EHRs and health IT standards has opened a multiplicity of possible interpretations and uses of SO data. Finally, I have shown how specific clinics use SO/GI implementation processes, data collection about sexuality (including SO data, other data about sexuality, and sexual behaviors, identities, and attractions), and HIV data to create different methods and strategies for using data about sexuality, gender, HIV status, and related information to address health disparities among sexual and gender minorities and people living with HIV.

In providing this overview of current SO/GI standards and uses of data about sexuality, gender, and HIV, I have tried to provide a synthetic account of the current state of queer health informatics in the United States and the material existence of sexual orientation and gender identity as concepts in several areas of biomedical practice. The diagram that I offer at the end of the last section presents my findings in a single place, diagrammatically – allowing readers to work playfully with various iterations of SO data and sexuality data in their various forms to consider how they exist in relation to one another in various times, places, and in different technological infrastructures.

I conclude with a note about SO/GI's uncertain future. In February of 2018, following the interoperability mandate of the 21st Century Cures Act of 2016, the Office of the National Coordinator for Health Information Technology (ONC) released a draft document called the *Trusted Exchange Framework and Common Agreement* (TEFCA) for public comment. One element of TEFCA was something called the *United States Core Data for Interoperability* (USCDI), which listed the data elements that would be required to flow over new classes of health information exchange networks that would be certified under new criteria established by TEFCA when it became law. The draft USCDI did not include SO/GI. The reasons for SO/GI's non-inclusion (whether technical or political) were unclear and will require their own analysis in the future. However, in early 2018, SO/GI advocates, led by Fenway – and with technical guidance from me – submitted a public comment supporting the inclusion of SO/GI in the USCDI.

In February of 2019, when this dissertation was being completed, ONC released a Notice of Proposed Rulemaking and the USCDI during the annual meeting of the Health Information Management and Systems Society of North America (HIMSS). The proposed USCDI does not include SO/GI data elements. The public comment period on the proposed rule was active when this dissertation was defended, during which time a campaign to lobby for SO/GI was being planned and executed by advocates. While the future of SO/GI in health IT is presently unclear, the story of these standards is far from settled. Rather, it is both ongoing (in the daily use of the standards) and to be continued in the changing federal regulatory environment that determines the status of the standards in health IT certification requirements – which are, in some respects, central to the future of sexual and gender minority wellbeing and to the future of sexuality and gender themselves.

References for Chapter 3

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[1] For historical examples, see, Howard Goldberg, "Gay Movement Looks for Strength in Numbers Via Census, Surveys," *The Associated Press*, June 27, 1991; Phyuong Ly, "Be Counted in Census, Groups Urge Gay Live-Ins," *The Washington Post*, March 12, 2000; Aaron Rodriguez, "#CantEraseUs: HRC FOIAs Trump Administration Over Elimination of LGBTQ Data," *Human Rights Campaign Blog*, March 29, 2017, https://www.hrc.org/blog/hrc-foias-trump-administration-over-elimination-of-lgbtq-data. See also, Sean R. Cahill and Harvey J. Makadon, "If They Don't Count Us, We Don't Count: Trump Administration Rolls Back Sexual Orientation and Gender Identity Data Collection," *LGBT Health* 4, no. 3 (June 2017): 171–73, https://doi.org/10.1089/lgbt.2017.0073.

[2] For an historical overview of LGBTQ visibility politics, see, Larry P. Gross, *Up from Invisibility: Lesbians, Gay Men, and the Media in America* (New York: Columbia University Press, 2001).

In the health context, see, Harvey J. Makadon, "Improving Health Care for the Lesbian and Gay Communities," *New England Journal of Medicine*, March 2, 2006, 895–97. This article by Makadon, a Harvard Medical School and Fenway Health clinician who led the way in building the new consensus in LGBTQ health and the addition of sexual orientation and gender identity questions into the national health IT infrastructure in the 2010s, opens with a personal narrative about his own experience of feeling invisible as a gay man in the healthcare system and coming out to his personal doctor. This is a narrative that Makadon would reproduce in innumerable contexts in the decade that followed, many instances of which I recount or cite in this chapter.

[3] Epstein calls "inclusion" a "biopolitical paradigm," and defines that concept as "frameworks of ideas, standards, formal procedures, and unarticulated understandings that specify how concerns about health, medicine, and the body are made the simultaneous focus of biomedicine and state policy." See, Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago, IL: University of Chicago Press, 2007), 17.

I do not adopt Epstein's terminology. However, his conceptualization of a biopolitical paradigm vis-à-vis minority inclusion in clinical trials and other areas of federal health policy governing biomedical research could be easily extended to the kind of incorporation that I document herein.

[4] I refer readers to the dissertation's Appendix for a more detailed discussion of the source material involved in the new consensus. For a partial selection of key documents, see, United States Institute of Medicine (IOM), *The Health of LGBT People*; Institute of Medicine (U.S.) et al., *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary* (Washington, D.C: The National Academies Press, 2013); The Joint Commission, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community* (Oak Brook, IL: The Joint Commission, 2011); HHS LGBT Issues Coordinating Committee, "Advancing LGBT Health & Well-Being: 2015 Report," Annual (Washington, DC: HHS, December 2015); Office of Minority Health, "LGBT Data Progression Plan: Improving Data Collection for the LGBT Community," 2011; Three reports from the Federal Interagency

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Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys (FIWGSOGI), "Current Measures," "Evaluations," and "Toward a Research Agenda for Measuring Sexual Orientation and Gender Identity in Federal Surveys: Findings, Recommendations, and Next Steps" (Washington, DC: OMB, October 20, 2016); NIH Sexual and Gender Minority Research Coordinating Committee, "NIH FY 2016-2020 Strategic Plan to Advance Research on the Health and Well-Being of Sexual and Gender Minorities" (Washington, DC, September 10, 2014).

[5] I extract the notion of multiple marginality from Kimberlé Creshaw's articulation of intersectionality in "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (July 1991): 1241, https://doi.org/10.2307/1229039.

[6] On "data friction," see, Paul N. Edwards, *A Vast Machine: Computer Models, Climate Data, and the Politics of Global Warming*, First paperback edition, Infrastructures Series (Cambridge, Massachusetts London, England: The MIT Press, 2010), 83-5.

[7] See, note 4, above. On the notion of a "gold standard," see my comments in the introduction and Stefan Timmermans and Marc Berg, *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care* (Philadelphia, Pa.: Temple University Press, 2003), http://public.eblib.com/choice/publicfullrecord.aspx?p=496404.

[8] One such document is: American Medical Association, "Resolution 212: Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation" (American Medical Association House of Delegates, September 30, 2016), https://assets.ama-assn.org/sub/meeting/documents/i16-resolution-212.pdf.

[9] Health Resources and Services Administration (HRSA) Bureau of Primary Health Care (BPHC), "Program Assistance Letter: Approved Uniform Data System Changes for Calendar Year 2016 (PAL 2016-02)," March 22, 2016, https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/pal201602.pdf.

[10] In April 2010, President Obama issued the "Presidential Memorandum – Hospital Visitation." In addition to requiring hospitals that received federal funds to allow partner visitation for lesbian and gay couples, the memo also directed the Secretary of HHS to

> Provide additional recommendations to me, within 180 days of the date of this memorandum, on actions the Department of Health and Human Services can take to address hospital visitation, medical decision-making, or other health care issues that affect LGBT patients and their families.

This directive would become the legal basis for a huge range of actions at HHS regarding LGBTQ health, including data collection and the establishment of the HHS LGBT Issues Coordinating Committee by Secretary Kathleen Sebelius (the former governor of Kansas), who also delivered a series of addresses on LGBTQ health issues during her tenure. See, Barack Obama, "Presidential Memorandum - Hospital Visitation" (Washington, DC: The White House,

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April 15, 2010), https://obamawhitehouse.archives.gov/the-press-office/presidential-memorandum-hospital-visitation.

[11] IOM, *The Health of LGBT People*, 10; ONC, "A Ten-Year Vision," 2.

[12] NIH, "Strategic Plan to Advance Research on the Health and Well-Being of Sexual and Gender Minorities."

[13] For treatments of this topic, see, Jennifer Fishman, Laura Mamo, and Patrick Grzanka, "Sex, Gender, and Sexuality in Biomedicine," in *The Handbook of Science and Technology Studies*, ed. Ulrike Felt, Fourth edition (Cambridge, Massachusetts: The MIT Press, 2017), 379–406; Patrick Grzanka, *The "Born This Way" Wars: Sexuality, Science, and the Future of Equality* (Cambridge, UK: Cambridge University Press, forthcoming); Patrick R. Grzanka, "Queer Survey Research and the Ontological Dimensions of Heterosexism," *Women's Studies Quarterly* 44, no. 3/4 (Fall 2016): 131–49; Tom Waidzunas, *The Straight Line: How the Fringe Science of Ex-Gay Therapy Reoriented Sexuality* (Minneapolis: University of Minnesota Press, 2015).

[14] IOM, *The Health of LGBT People*, 27-9. See also, Sexual Minority Assessment Research Team (SMART), "Best Practices for Asking Questions about Sexual Orientation on Surveys" (Los Angeles, CA: The Williams Institute, November 2009), 1-17; Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys (FIWGSOGI), "Current Measures."

[15] IOM, *The Health of LGBT People*, 27

[16] I explain this at greater length in other sections of this dissertation; however, see, Jeffrey Weeks, *Coming Out: Homosexual Politics in Britain from the Nineteenth Century to the Present* (New York, NY: Quartet Books, 1977), 9-44; Gayle Rubin, "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality," in *Deviations: A Gayle Rubin Reader* (Durham: Duke University Press, 2011), 137-8; Michel Foucault, *The History of Sexuality, Vol. 1*, trans. Robert Hurley (New York, NY: Vintage Books, 1978), 103-115.

[17] The evolution of "sexual orientation" as a concept has yet to be written. Its definitional status is strangely taken-for-granted in much writing in queer theory and sexuality, as being conceptually coextensive with individual human "sexuality" as a central feature of subjectivity beginning in the late 19th Century.

The most comprehensive histories of sexual orientation as a concept are presented along with attempts to better measure and understand it, and come from primarily from the discipline of psychology. A genealogy of contemporary sexual orientation as a concept associated with metrics would likely begin with the writing of Stephen Morin, Michael Shivley, and John DeCecco in the 1970s and 80s, and extend to Grzanka's recent research and that of Sari van Anders. See, John DeCecco and Michael G. Shively, "From Sexual Identity to Sexual Relationships: A Contextual Shift," *Journal of Homosexuality* 9, no. 2–3 (1984): 1–26; Michael G. Shively and John DeCecco, "Components of Sexual Identity," *Journal of Homosexuality* 3, no. 1 (Fall 1977): 41–48; Sari M. van Anders, "Beyond Sexual Orientation: Integrating Gender/Sex and Diverse Sexualities via Sexual Configurations Theory," *Archives of Sexual*

Behavior 44, no. 5 (July 2015): 1177–1213, https://doi.org/10.1007/s10508-015-0490-8; Patrick R. Grzanka, "Queer Survey Research and the Ontological Dimensions of Heterosexism," *Women's Studies Quarterly* 44, no. 3/4 (Fall 2016): 131–49; Patrick R. Grzanka, Katharine H. Zeiders, and Joseph R. Miles, "Beyond 'Born This Way?' Reconsidering Sexual Orientation Beliefs and Attitudes.," *Journal of Counseling Psychology* 63, no. 1 (2016): 67–75, https://doi.org/10.1037/cou0000124. However, this genealogy is speculative. The history of sexual orientation requires its own rigorous and independent analysis; such an inquiry could likely constitute a subfield within the history of sexuality.

[18] IOM, *The Health of LGBT People*, 25-7.

[19] Fenway Institute, "Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records," March 2016, http://www.lgbthealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf.

[20] ONC, "Interoperability Roadmap," 2015.

[21] Fenway Health, "Fenway Health Comments on Stage 2 Proposed Meaningful Use Guidelines (CMS-0044-P)" (Fenway Health, May 7, 2012), http://thefenwayinstitute.org/documents/Meaningful_Use_Guidelines_Fenway_Health_comment_summary_.pdf.

[22] Interview with Sean Cahill, Director of Health Policy Research at The Fenway Institute.

[23] Institute of Medicine (U.S.) et al., *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary* (Washington, D.C: The National Academies Press, 2013), 55-58.

I apply a convergent approach to stakeholder theory, conceptualizing stakeholders who engage in health IT policy as operating with a shared set of professional norms, while also calling attention to the constructedness, fungibility, relational nature, and ultimate contingency of those norms. See, Thomas M. Jones and Andrew C. Wicks, "Convergent Stakeholder Theory," *Academy of Management Review* 24, no. 2 (April 1999): 206–21.

See also, Sara Rubinelli and Per Maximilian von Groote, "Stakeholder Dialogue as Deliberation for Decision Making in Health Policy and Systems: The Approach from Argumentation Theory," *American Journal of Physical Medicine & Rehabilitation* 96 (February 2017): S17–22; Kathrin M Cresswell, Allison Worth, and Aziz Sheikh, "Actor-Network Theory and Its Role in Understanding the Implementation of Information Technology Developments in Healthcare," *BMC Medical Informatics and Decision Making* 10, no. 1 (December 2010).

[24] Harvey J. Makadon, "Project Title: National Training and Technical Assistance Cooperative Agreements (NCA), National LGBT Health Education Center" (Health Resources and Services Administration, 2010), https://grants.hrsa.gov/2010/web2External/Interface/Common/PublicWebLinkController.aspx?GrantNumber=U30CS22742&WL_WEBLINK_ID=1.

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[25] Sean Cahill et al., "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers," ed. Garrett Prestage, *PLoS ONE* 9, no. 9 (September 8, 2014): e107104, https://doi.org/10.1371/journal.pone.0107104; Fenway Health and Center for American Progress, "Do Ask, Do Tell: A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings," April 2014, DoAskDoTell.org. See also, Sean Cahill and Harvey Makadon, "Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities," *LGBT Health* 1, no. 1 (March 2014): 34–41, https://doi.org/10.1089/lgbt.2013.0001.

[26] Fenway Health, The Center for American Progress, and 103 other signatories, "Public Comment on Stage 3 Meaningful Use Proposed Rule CMS-3310-P, Published March 30, 2015," May 29, 2015, http://fenwayfocus.org/wp-content/uploads/2015/06/CMS-Stage-3-final-rule-Fenway-CAP-public-comment-FINAL-052915.pdf?__hstc=185075638.95700bb649c0d9e3416b37ba4dfd1211.1540240778791.1542729453525.1548602708781.5&__hssc=185075638.1.1548602708781&__hsfp=4058140573.

[27] Regarding a public's capacity to act, see Michael Warner:

> A public can only act in the temporality of the circulation that gives it existence. The more punctual and abbreviated the circulation, and the more discourse indexes the punctuality of its own circulation, the closer a public stands to politics.

"Publics and Counterpublics," in *Publics and Counterpublics* (New York, NY: Zone Books, 2002), 96-7. This is the sort of goal-oriented public that Fenway and CAP assembled in their public comment.

[28] Fenway Health, The Center for American Progress, and 103 other signatories, "Public Comment on 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications Published March 30, 2015," May 29, 2015, http://fenwayfocus.org/wp-content/uploads/2015/06/ONC-Health-IT-Certification-Criteria-rule-Fenway-CAP-public-comment-FINAL-052915.pdf?__hstc=185075638.95700bb649c0d9e3416b37ba4dfd1211.1540240778791.1542395506811.1542729453525.4&__hssc=185075638.2.1548113274427&__hsfp=4058140573.

[29] Office of the National Coordinator for Health Information Technology (ONC), "Federal Register Volume 80, Number 200 (Friday, October 16, 2015)" (Department of Health and Human Services, October 16, 2015), https://www.govinfo.gov/content/pkg/FR-2015-10-16/html/2015-25595.htm.

[30] Sean R. Cahill et al., "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health," *LGBT Health* 3, no. 2 (April 2016): 100–102, https://doi.org/10.1089/lgbt.2015.0136.

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[31] On the normal, multi-phase piloting and evaluation processes that standards must go through within private standards-setting organizations and then ONC before becoming "national standards" in EHR and health IT certification criteria, see, Dixie B Baker, Jonathan B Perlin, and John Halamka, "Evaluating and Classifying the Readiness of Technology Specifications for National Standardization," *Journal of the American Medical Informatics Association* 22, no. 3 (May 2015): 738–43, https://doi.org/10.1136/amiajnl-2014-002802.

[32] Ibid.

[33] Fenway et al., "Public Comment on 2015 Edition."

[34] See, David Valentine, *Imagining Transgender: An Ethnography of a Category* (Durham: Duke University Press, 2007), 37-50, 149-155.

[35] See, for example, Christoph Hanssmann, "Passing Torches? Feminist Inquiries and Trans-Health Politics and Practices," *TSQ: Transgender Studies Quarterly* 3, no. 1–2 (2016): 120–36.

[36] IOM, *The Health of LGBT People*, 26-7. On "conceptual neighborhood," see, Gilles Deleuze and Félix Guattari, *What Is Philosophy?*, trans. Hugh Tomlinson and Graham Burchell (New York: Columbia University Press, 1994), 19-25. The finding about transsexuality requiring self-identification also comes from analysis of provider education materials produced by Fenway and Georgia-based transgender health advocates.

[37] Fenway et al., "Public Comment on 2015 Edition."

[38] Fenway Institute and Center for American Progress, "Public Comment on Draft Interoperability Standards Advisory Released January 28, 2015," May 1, 2015, https://www.healthit.gov/sites/default/files/comments_upload/public_comment_interoperability_standards_advisory_comments_050115.docx.

[39] IOM, *The Health of LGBT People*, 27-9. See also, SMART, "Best Practices for Asking Questions about Sexual Orientation," 1-17; Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys (FIWGSOGI), "Current Measures of Sexual Orientation and Gender Identity."

[40] Cahill et. al., "Do Ask, Do Tell," 2014

[41] See the composition of the IOM LGBT Health Report's official author, the "Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities," listed in the front-matter of the report. It lists both Judith Bradford and Harvey Makadon of Fenway as members, see, IOM, *The Health of LGBT People*, 2011. *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health* and other publications by Fenway affiliates are also cited throughout the IOM report. See, Harvey J. Makadon et al., eds., *The Fenway Guide to Enhancing the Healthcare of Lesbian, Gay, Bisexual and Transgender Patients*, 1st ed. (Philadelphia, PA: American College of Physicians Press, 2007); for the second edition, released after the 2015 IOM report, see, Harvey J. Makadon et al., eds., *The Fenway Guide to Lesbian,*

Gay, Bisexual, and Transgender Health, Second edition (Philadelphia: American College of Physicians, 2015).

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[44] Ibid., 14.

[45] As of 2016, SO/GI data collection and reporting were requirements for annual Uniform Data System (UDS) reports required by all FQHCs and similar community health centers. See, HRSA, “Program Assistance Letter.”

[46] The Fenway Institute, “Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Taking the Next Steps,” March 30, 2016, 4 http://www.lgbthealtheducation.org/wp-content/uploads/Collecting-SOGI-Data-in-EHRs-COM2111.pdf.

[47] “Progress notes” are individual entries in a patient’s chart that providers fill in during a visit to a clinic.

[48] Emerson Rosenthal, “Nine Inch Nails Fans Get a Hand-Burned Art Book: Artist Russell Mills Made ‘Cargo In The Blood’ to Commemorate His Collaboration with Trent Reznor, Creating 2,000 Limited-Edition Art Books, Each One with Its Own Original Artwork,” *VICE*, March 29, 2016, https://www.vice.com/en_us/article/pgq8bg/nine-inch-nails-cargo-in-the-blood-interview.

[49] The various data collections instruments used to collect HIV risk hierarchy data in the surveillance and care contexts do capture data about sexual behaviors. However, they do not match the gold standard measurement for behavioral data collection as laid out in the 2011 IOM report or elsewhere. This is not the case in HIV prevention programs in the United States, however, where CDC’s risk assessment form used during testing events does include questions about sexual behaviors in the last twelve months that match the recommended behavioral data elements in surveys and sexual histories that are published by groups such as The Williams Institute and Fenway.

[50] John Law, *After Method: Mess in Social Science Research* (London; New York: Routledge, 2004), *passim*; Andrew Pickering, *The Mangle of Practice: Time, Agency, and Science* (Chicago, IL: University of Chicago Press, 1995).

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[51] Steven Epstein, "Sexualizing Governance and Medicalizing Identities: The Emergence of 'State-Centered' LGBT Health Politics in the United States," *Sexualities* 6, no. 2 (May 1, 2003): 131–71, https://doi.org/10.1177/1363460703006002001, 161.

[52] Alexander R. Galloway, *Protocol: How Control Exists After Decentralization* (Cambridge, MA: MIT Press, 2004), 6-11, 40-5.

[53] I am interested in the work of memory at the intersection of the history, social study, and practice of biomedicine in relation to sexuality, gender, and HIV. In this vein, see, Alexis Shotwell, "'Women Don't Get AIDS, They Just Die from It:' Memory, Classification, and the Campaign to Change the Definition of AIDS," in *Against Purity: Living Ethically in Compromised Times* (Minneapolis: University of Minnesota Press, 2016); Deborah B. Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago, IL: The University of Chicago Press, 2009), *passim*.

[54] Michael Omi and Howard Winant, "Colorblindness, Neoliberalism, and Obama," in *Racial Formation in the United States*, Third edition (New York: Routledge/Taylor & Francis Group, 2015), 211–44.

[55] See, for example, this technical guidance document from a major LGBTQ rights organization: Human Rights Campaign Foundation, "LGBTQ Self-Identification in the Workplace" (Washington, DC: Human Rights Campaign Foundation, 2018), https://assets2.hrc.org/files/images/resources/HRCF_LGBTQ_Self-Identification_One_Sheet_2018.pdf?_ga=2.132702222.1009633835.1552277721-832773089.1551321682.

[56] Cahill Et al., "Do Ask, Do Tell"

[57] Ibid.

[58] Jason Orne, "'You Will Always Have to "out" Yourself': Reconsidering Coming out through Strategic Outness," *Sexualities* 14, no. 6 (December 2011): 681–703, https://doi.org/10.1177/1363460711420462.

[59] See, Trevor Hoppe, *Punishing Disease: HIV and the Criminalization of Sickness* (Oakland, California: University of California Press, 2018); Françoise Barré-Sinoussi et al., "Expert Consensus Statement on the Science of HIV in the Context of Criminal Law," *Journal of the International AIDS Society* 21, no. 7 (July 2018), https://doi.org/10.1002/jia2.25161; Prevention Access Campaign, "Risk of Sexual Transmission of HIV From a Person Living with HIV Who Has an Undetectable Viral Load: Messaging Primer and Consensus Statement," July 21, 2016, https://www.preventionaccess.org/consensus.

[60] See especially: Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Simon & Schuster, 1963); Erving Goffman, *The Presentation of Self in Everyday Life*, Anchor Books (New York, NY: Doubleday, 1990).

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[61] Yanni A. Loukissas, *All Data Are Local: Thinking Critically in a Data-Driven Society* (Cambridge, MA: The MIT Press, 2019), 1-11; Gilles Deleuze, *Difference and Repetition*, trans. Paul Patton (New York: Columbia University Press, 1994), 16, 212, 220-1.

[62] Deleuze, *Differene and Repetition*, 16.

[63] In *Difference and Repetition*, Deleuze calls uses of a concept "actualizations," and writes that "actualisation takes place in three series: space, time and also consciousness. Every spatial-temporal dynamism is accompanied by the emergence of an elementary consciousness which itself traces directions, doubles movements and migrations, and is born on the threshold of the condensed singularities of the body or object whose consciousness it is," 220.

[64] Office of the National Coordinator for Health Information Technology (ONC), "2015 Edition §170.315(a)(5) Demographics" (Washington, D.C, September 21, 2017), https://www.healthit.gov/sites/default/files/170%20315%28a%29%285%29%20Demographics_0.pdf; Office of the National Coordinator for Health Information Technology (ONC), "2015 Edition Common Clinical Data Set (CCDS) Reference Document" (Washington, D.C, February 18, 2018), https://www.healthit.gov/sites/default/files/ccds_reference_document_v1_1.pdf.

[65] Human Rights Campaign Foundation, "LGBTQ Self-Identification in the Workplace" (Washington, DC: Human Rights Campaign Foundation, 2018), https://assets2.hrc.org/files/images/resources/HRCF_LGBTQ_Self-Identification_One_Sheet_2018.pdf?_ga=2.132702222.1009633835.1552277721-832773089.1551321682.

Chapter 4: CAREWare in Atlanta: A Regional Interoperable Health IT Infrastructure, the Workers Who Operate It, and Some Ontological Implications

I. Introduction

In this chapter, I posit that the Fulton County Ryan White Program's deployment of a piece of software called CAREWare in the Atlanta metropolitan area provides an ideal opportunity to study a regional interoperable health IT infrastructure that resembles the nationwide health IT ecosystem envisioned by the Office of the National Coordinator for Health Information Technology (ONC) for the entire United States. Fulton County's build of CAREWare also reflects more widespread issues in uses of health information technologies, both within individual organizations and when health entities are required to collect and exchange data over a common infrastructure. These include the various kinds of labor that make such systems function, including – in the case of CAREWare – huge amounts of low-waged labor performed predominantly by women of color using paper forms to facilitate interoperability between IT systems. By centering these forms of work, this chapter further problematizes utopian notions of digital automation in healthcare examined in chapter two.

The region considered is the 20-county "Atlanta Eligible Metropolitan Area" or "Atlanta EMA" – a Health Resources and Services Administration (HRSA) HIV/AIDS Bureau designation for jurisdictions funded under Part A of the Ryan White program for "areas that are most severely impacted by the HIV Epidemic."[1] The Ryan White Program is the federally-funded, locally-administered payer of last resort for HIV-related medical care in the United States. CAREWare is software maintained by the HRSA HIV/AIDS Bureau to aid Ryan White-funded agencies in collecting client level data, completing mandatory annual reports, and engaging in ongoing quality management activities. As discussed in the introduction, owing to the public health prevention, surveillance, and clinical safety net infrastructures that have been developed in the United States specifically to manage and govern the HIV epidemic, the national HIV data infrastructure has long been at the cutting-edge of new uses of health IT systems to improve planning and the delivery of care and prevention services. This is attributable to the top-down management of these programs by the Centers for Disease Control and Prevention (CDC) and HRSA within the Department of Health and Human Services (HHS), a structure which makes the integration of systems across domains and the alignment of key metrics (such as viral load and HIV risk factors) more straightforward than integration in other domains. HIV infrastructures are therefore ideal for examining innovations in uses of data and new forms of network architecture as the nationwide interoperable health IT ecosystem has developed. This includes an explanation of how advances in automation and interoperability in healthcare are materially constituted, and are often made possible by analog or manual processes.

Fulton County's deployment of CAREWare lays bare a wide range of challenges and other phenomena that stem from the development of large technical systems and other information infrastructures, both in HIV practice and healthcare generally. This is, in part, because CAREWare in Fulton County is an under-supported technology that is deployed in a resource-poor environment: the public health infrastructure in metro Atlanta. It therefore "breaks" or fails to function especially frequently, and in so doing, to quote Geoffrey Bowker and Susan Leigh Star, "becomes visible" and reveals the inner workings of the infrastructure.[2] Issues that rise to the surface following a close examination of CAREWare include the various kinds of labor required to make the infrastructure function, problems of uncertainty about data quality (both in

CAREWare and the other clinical and public health IT systems to which it is connected), disparate understandings of what the infrastructure is and what it does among actors in the network, the human aspects of interoperability processes (which are often assumed to be automated and fully digital), and ethical and organizational issues pertaining to the exchange of health data over a network in which actors are both not invested in sharing data and view each other with varying levels of skepticism.

An examination of CAREWare using multi-site ethnography, methods of infrastructural inversion, healthcare organization studies, actor-network theory, and health policy analysis strategies provides an opportunity to study issues that are critical to understanding the revolution in U.S. health IT that has taken place during the 2010s. However, studying CAREWare also offers the chance to consider many central topics that infrastructure studies and data studies scholars have identified as critical problem areas in those fields.[3] An inquiry into CAREWare in Fulton County reveals the various kinds of unseen, analog labor (disproportionately done by women of color) that make the interoperability revolution possible: a phenomenon I call "this digital health revolution called their backs," in an homage to *This Bridge Called My Back*, a foundational text in queer theory, women of color feminisms, and queer of color critique.[4] In the conclusion, I argue that a close, empirical study of CAREWare in Fulton County reveals that the quality and truth-value of Ryan White data and clinical data held in health IT systems comes not primarily from clinicians who attest to the value of data, but often equally from generally lower-waged quality assurance workforces who ensure the validity of data entered into these systems. These interventions open new avenues into imagining healthcare's programmable futures: futures in which the epistemic authority, the economic value, and the clinical value of data are further dispersed among actors in the healthcare system's various networks, rather than vested primarily in medical providers.[5]

II. CAREWare in the Atlanta EMA

The interaction below is between me and Michael Zales, the data manage of MetroATLCare, a large HIV/AIDS Service Organization (ASO) in metro Atlanta first introduced in chapter two. He describes how the organization must still build processes to manually enter data from its paper intake forms and EHR into CAREWare, even after substantial investments of resources and time to change this state-of-affairs. This investment came in the form of a Health Resources and Services Administration (HRSA) Special Project of National Significance (SPNS) grant focused on building automated interoperability between MetroATLCare's EHR and CAREWare using Health Level 7 (HL7) exchange standards, the dominant set of health IT exchange standards globally.

> **Michael**: Right now, our [SPNS-funded HL7] interface is not operational…technical, technological differences so to speak with the Fulton County IT department. Long story short: they upgraded to a new Windows 2012 server and there's been a lot of compatibility and connection issues associated with maintaining the interface…In the meantime, until we get our interface going [with an internal CAREWare server held by MetroATLCare], the only other option we've had is to actually create these spreadsheets of patient names, the service received, and then we translate that to the CAREWare sub-service name and are having people manually enter that…
>
> **SM**: Even after all this investment you're still having to do everything manually?
>
> **Michael**: At this point [in June 2017], as of December [2016], we were put in a position of having to manually enter the data, which not only is a very tedious frustrating task, there's also room for error. And honestly, even [with the HL7] interface, there was room for error because you're dependent again upon human interaction with how they're charting and people using the agreed-upon note types in order for us to be able to precisely understand what type of service was being provided. So, our plan today is to attempt to sort out that PDI [Provider Data Input Process], to get that information from [the EHR] and into [a local] CAREWare [server in the MetroATLCare facility], when it'll probably take maybe 30 minutes [to then send to Fulton County's CAREWare server] as opposed to a team of people spending all day doing it.
>
> **SM**: Right – which is what you've been doing since December?

> **Michael**: Right. And…the other part of this is that CAREWare is insanely slow now. As far as opening a patient profile it can take up to three to five minutes just to get the chart to open to where you can then enter data into there.

This conversation showcases not only the difficulty of making health IT systems interoperate in an automated fashion, but also problems that are specific to CAREWare in Fulton County: that it is slow to load, that local CAREWare servers operated by Ryan White-funded agencies do not interface easily with EHRs used by those organizations, that Fulton County's build of CAREWare will not easily integrate EHR data even after automated feeds are established, and that even if CAREWare would interface easily with EHR systems, issues pertaining to data quality would persist because of inconsistent entry.

Despite the hurdles, six months of cumbersome manual data entry that had to be undertaken simultaneously with the effort to roll out automated reporting through the SPNS project, and the insistence from Fulton County CAREWare manager Greg Nowitzki that MetroATLCare's automated HL7 feed will "never work" (as recounted in chapter two), Michael – hopeful as ever about the programmed vision of automated interoperability – speaks about a future where this will no longer be the case. Michael envisions a future for MetroATLCare when a scaled-back version of the organization's SPNS health IT project and HL7 feed will at least allow for basic demographic data to flow automatically from his organization's EHR into a local CAREWare server operated by MetroATLCare, and then easily to Fulton County. Even though this would not fulfill the original aim of the SPNS project to directly interface between MetroATLCare's EHR and Fulton County CAREWare, implementing this "Plan B" initiative (what Michael characterizes in a more optimistic light as "phase two") would make data reporting to Fulton County's CAREWare servers far less organizationally cumbersome.

> **Michael**: I will discuss with you our interface through our SPNS Project. It was sort of like a phase two. We have enabled, where…the majority of basic demographics will

> interface from our [EHR], which is where the patient profile is built, to send a message and then upload to CAREWare [on an internal MetroATLCare CAREWare server, thus facilitating a semi-automated reporting process to Fulton County's CAREWare servers].
>
> **SM**: So, who enters these [paper intake] forms into CAREWare [right now]?
>
> **Michael**: That would be – [pause] – I do that…
>
> **SM:** So, *you* manually enter these data into CAREWare?
>
> **Michael**: Yes.
>
> **SM**: Wow.
>
> **Michael**: Yep.

If the promise of automated interoperability is what Michael works toward when he dreams about interoperability, the reality of interoperability for him has been that he puts in a great deal of work to achieve it, while at the same time having to build manual and analog processes and – in some cases – even do data entry himself. The promise of automated interoperability – at least as he imagines it – remains a dream deferred.

In any of the circumstances – hand-entry or seamless flow over an HL7 feed – data still get translated from one system to another and transmitted to funders: the Fulton County Ryan White office and HRSA. In either case, a kind of interoperability emerges: one that is either more automated or more manual, analog, and labor-intensive. Further, no matter how automated or analog/manual data transmission processes between systems might become, achieving interoperability will always necessarily rely on human processes, organizational investment, and data governance decisions with institutional support. Whether data move *easily* to, from, and/or between CAREWare and other systems in the EMA, CAREWare is an interoperable health IT infrastructure that spans the region.

CAREWare as a Regional Interoperable Boundary Infrastructure in the Atlanta EMA

During my two-plus years of fieldwork in Atlanta's HIV community, CAREWare appeared as a major source of frustration among health executives, county bureaucrats, data managers, and an array of others in the metro area's HIV care and support services apparatus. A vast array of different people with varying professional roles interact with the software, and their comments about it usually pertain to its problems. Further, even individuals who never actually touch the program usually have precise secondhand complaints. "Ugh, CAREWare," approximates the affect associated with the software, at least in fieldwork interviews. There is a shared understanding about how difficult CAREWare is to work with. However, this exasperation is also – often begrudgingly – paired with a recognition of how valuable its reporting functionalities can be to inform clinical or organizational operations, quality improvement practices, or regional planning. Frustration is often twinned with a hopeful discourse about how much better CAREWare could be, if only sufficient resources were invested both in the software and in the HIV/AIDS safety net infrastructure more generally. It also bears mentioning that Ryan White data are some of the most complete and high-quality longitudinal clinical data in the U.S. healthcare system: a fact recognized by the Office of the National Coordinator for Health Information Technology (ONC) and reflected in the national *Ryan White Data Report*, which is released annually by HRSA.[6] CAREWare has played a major role in ensuring the quality of data, being utilized in about half of all funded jurisdictions.[7]

CAREWare was first launched in 2000 by the HRSA HIV/AIDS Bureau, and has been developed, maintained, and made freely available by a small staff at HRSA and a contractor based in New Orleans called Jeff Murray's Programming Shop (jProg). Its primary function has always been to facilitate annually-required Ryan White Service Reports (RSRs) to HRSA, and in some jurisdictions, to facilitate ongoing data monitoring, reporting, and planning at the regional level. This includes the Atlanta EMA, where Fulton County requires all agencies that receive Ryan White funding to use CAREWare for reporting purposes – both to the county for ongoing monitoring and to HRSA. However, in its nearly-20-year existence, CAREWare has grown to encompass many functions it did not originally have, expanding along with health IT in the United States. CAREWare's expansion, in many ways, parallels the expansion of the health IT infrastructure in the country. Despite this, very little has been written about the software itself other than a few articles by those who built and maintain it. My exposition of it here is thus a somewhat of a "revelatory case," in that it is an examination of an infrastructure that has heretofore gone relatively unexplored in the academic literature.[8]

In Fulton County, CAREWare functions as what Bowker and Star call a "boundary infrastructure," which is "[an] infrastructure [that] serves multiple communities of practice simultaneously, be these within a single organization or distributed across multiple organizations."[9] CAREWare functions in both ways. It is a tool utilized within organizations for quality assessments, for generating external reports to funders, and it is a network that links all funded agencies to the Fulton County Ryan White office. It is also used internally by the Fulton County Ryan White office for quality management activities and for external reporting to HRSA.

CAREWare is not an EHR or client management software, although it can function in this way for small agencies. However, few choose to utilize it in this fashion. Per Steven Jones, a Deputy Director of a small agency in Southwest Atlanta that focuses on providing support services and substance use counseling to people living with HIV (largely to street-based sex workers), his team prefers to use Microsoft Excel to record data. Excel assures high quality data collection at a very low cost. The agency is small enough to not require client management software or an EHR, which would be much more expensive than a Microsoft Office license.

Jones's staff then does their best to translate data from Excel into CAREWare manually. However, working with CAREWare is an experience that Steven struggles to make sense of. This is not for lack of trying or expertise in data quality assurance or the Ryan White system, but because an adequate explanation has never been provided to him about why the software is so beset with problems.

"Something's wrong with it," Jones told me toward the end of an interview, in a disquisition that echoes similar comments made to me about CAREWare by HIV care professionals in the metro area from both large and small agencies:

> **Steven Jones, agency Deputy Director:** I'm not a CAREWare expert, but from what I've been able to get from CAREWare, I'll say it was 50% efficient. The reports that it spit out to me are 50% true, most of the time…I just went through that with my third-quarter report to Ryan White. CAREWare was saying one thing, my internal data was saying something completely different – *and my internal data I know is true*. We didn't cook the books or anything, but CAREWare wasn't capturing the information.
>
> And I've talked to the CAREWare expert [Greg Nowitzki from Fulton County], and he admitted that it was a problem that was ongoing and that they was trying to fix. But hell, I've been hearing that! I've been working for agencies funded by Ryan White for the last 10 years – the last 15 years – and this problem is ongoing… And even locally, the CAREWare manager [Greg], is about to leave, at a time when we're just beginning to think we're making some headway into getting this stuff synchronized. So, you got another learning curve for somebody else to come in, and I don't know what the hell to expect.
>
> **SM**: I know that data reporting is really important for keeping your grant. Is that a source of anxiety?
>
> **Jones:** It's frustration, not anxiety. It is what it is, and certainly it would close down us without the Ryan White funding. But I'm 67. It is what it is. I'm gonna do the best that I can, and I'm gonna ask for technical support as much as I can. With this CAREWare, the system itself: *there's something wrong with it*. There's something wrong with the system, that, as of yet, Fulton County has not been able to get an expert in here that could manage it right. And I'm not saying it's [Greg], I'm just saying that they haven't had adequate support staff.

Despite the many problems that come with using CAREWare and the difficulty in building automated processes that interface with the software and other systems, CAREWare in the

Atlanta EMA is an actually-existing, service area and disease state-specific, multi-function health IT infrastructure. It is an open platform specifically built for HIV service providers funded by the federal Ryan White program. Further, it is a boundary infrastructure that is – in principle and, despite barriers to realizing its full potential for automated reporting, in reality – interoperable with other health IT products.[10]

In a 2016 article in the *Journal of the American Medical Informatics Association*, CAREWare's long-time manager John Milberg describes the system as "a longitudinal electronic patient health information system designed to assist providers of HIV/AIDS care in a range of daily clinic, monitoring, quality, and reporting activities," and as "a comprehensive health information system that can run as a stand-alone installation or a fully networked application connecting multiple care providers." He goes on to characterize CAREWare as an interoperable system, saying that:

> While the initial impetus for its use was primarily reporting to HRSA, enhanced functionality, ability to generate performance measures, ***ease of customizability and interoperability***, and overall reliability have greatly expanded the application's utility so that 77% of survey respondents reported that they use the application on a daily basis. CAREWare networks, connecting providers of care in large geographic areas, contribute to better care coordination, patient follow-up, and more complete and efficient data reporting.[11]
>
> (emphasis mine)

Milberg's insistence that CAREWare is interoperable is not false. It merely showcases that interoperability lives more on a spectrum defined by degrees of automation than in any stable definition. The two most prominent definitions of "interoperability" are those used by the Health Information Management and Systems Society of North America (HIMSS): "the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged" and the Institute of Electrical and

Electronic Engineers (IEEE): “the ability of two or more systems or components to exchange information and to use the information that has been exchanged.”[12] While actors in health IT often treat “interoperability” as coextensive with “automation,”[13] it is notable that these formal definitions are rather indifferent to the question of whether interoperability is facilitated by human actors and large amounts of labor or “seamlessly,” through highly-functional implementations of mature interoperability specifications and organizational processes.

In practice, interoperability is a process and a matter of degree more than it is an end-point or identifiable state. It is therefore more useful to speak about degrees of automated interoperability – or processes that lead to greater, smoother, or faster interoperability – than it is to speak about interoperability’s “achievement.” I have already discussed several variously automated and manual approaches to interoperability and its futures. We will now explore some less-automated styles, as part of a broader exposition of CAREWare in the Atlanta EMA. Through this analysis, a fuller understanding of interoperability’s realities will materialize.

III. This Digital Health Revolution Called Their Backs: Black Women’s Labor and Not-So-Paperless Digital Transformations in Healthcare

In “Indigenous Circuits: Navajo Women and the Racialization of Early Electronic Manufacture,” digital studies scholar Lisa Nakamura explores promotional materials produced by the Fairchild Corporation about a semiconductor plant in New Mexico that opened in 1965, and the history of the factory on the Navajo reservation. The company deliberately touted how it utilized Navajo women’s skills in weaving intricate fabric patterns to manufacture computer chips.[14] The labor of lower-waged women of color – indigenous women, in Nakamura’s case (one of several such studies in emergent feminist histories of computing) – is thus revealed to be central to the history of contemporary computer hardware.[15]

During my fieldwork, I discovered that this is also true, in many respects, of the contemporary digital health revolution – both generally, and specifically in metro Atlanta's public health and HIV safety net. Automated interoperability, seamless reporting or data transfers between systems, and the promise of digital utopianism in healthcare are not only predicated on the achievement of visions that will never fully materialize in reality, but are often also (in the limited way that these visions are achieved) illusions sustained by the labor of workforces dominated by women of color charged with the day-to-day work of data quality assurance in healthcare organizations. In metro Atlanta's HIV infrastructure, these are predominantly teams of Black women. I explore several such teams herein.

The Self-Described "Data Divas" at The Infectious Disease Clinic of a Major Public Hospital System

I conducted fieldwork at an institution in Atlanta colloquially referred to within the HIV community as "The IDC": The Infectious Disease Clinic of a large public hospital system. The IDC is in its own building and operates with a large degree of autonomy from "Main Hospital" – the term that IDC employees refer to the central hospital building downtown and to the hospital system's administrative apparatus.[16] With over 6,000 patients, the clinic often claims to be the largest facility of its type in the United States. Nearly all its patients have a diagnosis of AIDS (advanced HIV disease), are youth, or are pregnant women or new mothers. The building is a grand and foreboding stone structure that formerly belonged to a mainline protestant denomination and was donated to the hospital system in order to open The IDC. The structure is situated on a hill overlooking two main thoroughfares situated squarely between one of the largest public housing developments in the southeast in the rapidly-gentrifying Old Fourth Ward neighborhood and Midtown, Atlanta's historic gay neighborhood, which is in late-stage gentrification as of early 2019.[17] Main Hospital itself is in the very heart of downtown Atlanta, barely viewable over the Midtown tree-line from The IDC's third floor conference room.

During early-stage interviews with IDC leadership – and after two years of being immersed in federal health IT policy discourses about data liquidity, automated interoperability, and various discourses promoting the "digital health revolution" the U.S. healthcare system was experiencing – I learned something about The IDC that was (at the time) astonishing. All the data reported to the Ryan White program by this relatively well-resourced institution – a performance site for some of the most consequential clinical trials in the history of HIV/AIDS and home to an advanced, multi-site HIV disease registry at the cutting edge of secondary uses of EHR data for biomedical research – was manually processed on paper, and then entered into CAREWare by hand by a team of three Black women who called themselves the "Data Divas." When Rebecca Joubert, The IDC's Data and Grants Manager, told me this, I realized that these women's labor was what enabled this storied institution to function.

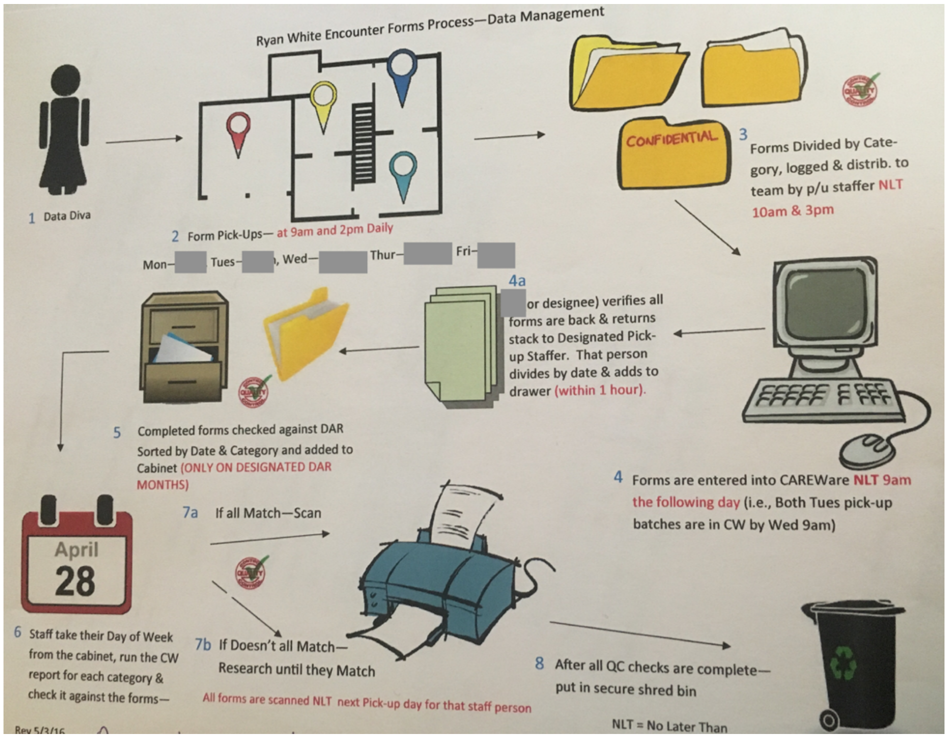
Figure 4.1. The IDC Towers Over Midtown

The full data team is made up of five women: The Data and Grants Manager (the only white member of the team), the Deputy Manager, and three Data Technicians (the “Data Divas”). This team is primarily responsible for ensuring that data from paper “Ryan White Encounter Forms” that are generated by departments during intake and clinical visits are correctly filled out by providers and translated into CAREWare. In addition to working with paper encounter forms, the Technicians also use The IDC’s EHR to conduct confirmatory inquiries and quality assurance processes. Their labor and their coordination with clinical departments to ensure data quality form the basis of all the data reported from this facility to Fulton County and HRSA about its 6,000-plus patients, which makes up nearly half of all clients served by the Ryan White program in the Atlanta EMA.

The three Data Technicians work in a small suite in The IDC situated in the back corner of a windowless basement, next to the clinic’s dental facility. The suite where they work is protected with a passcode on the door, ensuring that the data is kept secure and is accessible only to a few people with proper authorization. Behind the passcode-protected door, each Data Diva has her own small office with a computer and door that is connected to the larger common area. During half of a lunch hour, I had the chance to ask them questions that would illuminate how they worked with CAREWare, paper forms, and the hospital’s EHR, and also how they understood their work in the larger informational ecologies of The IDC and Atlanta Ryan White program.

During the interview, I sought to hear the Data Technicians reflect on their work-processes described to me by their managers, the Data and Grants Manager (Rebecca) and her Deputy (Natasha Smith). The IDC data team is an incredibly busy group of women. They have multiple sets of daily and weekly deliverables involving the collection and processing of several hundred patient forms and accompanying quality assurance processes. This does not leave much room for error or time off without falling quickly behind. I worked to understand the exact mechanics of how they did the grueling, repetitive, and also complex work of moving mountains of paper within the building, bringing the paper forms back downstairs into their secured area, then dividing the forms by subservice category, running quality assurance (QA) processes on forms (which could mean sending forms back to providers or departments for confirmation one or more times), manually translating the content of the forms into CAREWare through their individual computers, running a secondary QA check through the Deputy Manager, storing the forms in the appropriate file cabinet, running a secondary match the following week, running a tertiary quality check on the paper forms, then scanning forms into a secure database to create a PDF file for long-term reference, and then again moving the papers into a secure shred bin. Figure 4.2 contains a diagram of that workflow, given to me by the Data and Grants Manager:

Figure 4.2. The Data Divas' Workflow, Created by the Data and Grants Manager


Ryan White Encounter Forms Process—Data Management

1 Data Diva

2 Form Pick-Ups— at 9am and 2pm Daily
Mon–[redacted] Tues–[redacted], Wed–[redacted] Thur–[redacted] Fri–[redacted]

3 Forms Divided by Category, logged & distrib. to team by p/u staffer NLT 10am & 3pm

4 Forms are entered into CAREWare NLT 9am the following day (i.e., Both Tues pick-up batches are in CW by Wed 9am)

4a [redacted] or designee) verifies all forms are back & returns stack to Designated Pick-up Staffer. That person divides by date & adds to drawer (within 1 hour).

5 Completed forms checked against DAR Sorted by Date & Category and added to Cabinet (ONLY ON DESIGNATED DAR MONTHS)

6 Staff take their Day of Week from the cabinet, run the CW report for each category & check it against the forms—

7a If all Match—Scan

7b If Doesn't all Match— Research until they Match

All forms are scanned NLT next Pick-up day for that staff person

8 After all QC checks are complete— put in secure shred bin

NLT = No Later Than

Rev 5/3/16

Before the interview, I examined the paper intake form furnished to me by the primary intake staff person, reviewed my interviews with IDC providers and the Data and Grants Manager, and looked over every different kind of Ryan White Encounter Form used by the medical providers (given to me by Rebecca), each of which listed the subservices offered, ranging from “Initial Primary Care Visit” to “Nutritional Assistance Counseling.”

The interview was overseen by the Data and Grants Manager and Deputy Manager. As the Data and Grants Manager walked me down the hallway from her third-floor office in The IDC’s leadership suite, to the elevator, and down to the basement level, I imagined the many thousands of times the Data Divas had walked these same hallways, carrying papers, nodding “hello” to people making their way around the building, heading toward their office area in the lower level. After Rebecca keyed in the door code, we walked into the Data Technicians’ shared offices. They each came out of their individual offices into the common area, and we gathered chairs around, began introducing ourselves, and went through the informed consent process.

I first asked them to explain their jobs to me in a sentence or two. Michelle Anderson – who was celebrating her 40th anniversary working in the hospital system and her 24th year as a Data Technician at The IDC – spoke first. She referred to the paper sheets that her she and the other women collect and assess every day simply as “the work.”

> **Michelle Anderson**: The work is first picked up from each department. Then it's come back and sorted. Then once it's sorted, then it's entered into CAREWare.

Patricia Pearson then gave a longer explanation. What Michelle boiled down to “sorting,” Patricia expounded upon in some greater detail:

> **Patricia Pearson**: Normally we pick up twice a day from this department, nine o'clock in the morning and two o'clock in the afternoon. So, we go around all the different departments in the clinic and pick up all the forms, the different forms that we're using. So, we come down, we sort it by category and each one of us have different stack that we

> are working on. So, when we sort them by category, we give everybody their different stack.
>
> So, that's when we go in and try to input them in the computer. In the process of inputting them in the computer, we might find some of them that are blanks, some of them that the doctors don't sign and things like that. I mean, *with some of them that are completely blank!*
>
> So, we'll take *those forms* back to the departments where we get them from. And then we continue entering the rest of the papers we pick up for that day. If we don't finish it on that day, of course, it could go on the next day. And also, sometimes CAREWare is down. So, when CAREWare is down, that will slow us down. But, if CAREWare works well, most likely we'll be able to put the forms that we pick up from that particular day in. And then we have up to the next day to do a report with all that is done. We're supposed to run a report. And from that report, we QA [run "quality assurance" processes on] the forms with the report. And when that is done, we have to scan it into the system [to create an archived PDF].

Michelle then spoke again, noting that the process of gathering, translating, "running QA" on the paper encounter forms, and getting the data into CAREWare could also sometimes involve comparing data on the paper sheets with data in The IDC's EHR.

> **Michelle:** Sometime I also have to refer to [the EHR], too…when stuff is missing.
>
> **Patricia:** If we need to, right.

Everybody nodded. The process of getting data on paper into CAREWare at The IDC is not only one that requires translation of data from paper encounter forms to CAREWare screens, but also movement and verification between screens (from EHR to CAREWare). What I thought was a one-to-one translation between two systems – with multiple intermediary QA checks that had the potential to create looping effects within the workflow – revealed itself to be a more complicated process of verifying data on paper and data not on paper ("when stuff is missing" or when "*some of them are completely blank*") with data in a third IT system, the EHR. Paper forms revised using EHR data would then be translated manually into CAREWare by one of the Technicians.

Occasionally, data from paper sheets or CAREWare would be used to populate the patient's incomplete EHR chart.[18]

> **Me**: Gotcha. Okay, I'll make a note of that. And Marianne, how about you?
>
> **Marianne**: Because, you know, for us to go in to [the EHR], we have to come out of CAREWare. And you might not be able to get back in it. [group laughter]
>
> **Michelle**: Yeah, that's true.

Michelle and Marianne had brought up a very common gripe: CAREWare as a walled garden or closed environment that blocks users from opening other programs when it is open.

CAREWare as Both Closed Environment and Open Infrastructure

I had heard this complaint many times, and would encounter it many more, in almost any discussion of CAREWare with an individual who regularly worked with it. A major feature of Fulton County's build of CAREWare is that the user cannot do anything else on their computer when the application is open. This is a function of CAREWare's main security feature, which requires users to login to the software (sometimes called "the portal") using a Virtual Private Network (VPN) that sequesters their machine from other networks to which it is connected. The VPN also disallows users from accessing any other programs on their computer while it is running.

CAREWare is thus simultaneously – at different times and for different users – a highly customizable and relatively open infrastructure as well as a "walled garden." The *Oxford Dictionary of Social Media* defines a "walled garden" as a mostly-negative term opposed to openness, but also as a security feature:

> typically a pejorative term referring to an online or mobile service to which only members have access, its users also being in some sense 'locked in', with their options limited by the service provider...As a criticism it is usually applied to the big players dominating the market (another restriction and a potential threat to the common good): among others, Facebook, Google, and the Apple operating system and App Store have all

> been widely referred to as walled gardens. The contrast is with open access systems. **Occasionally the reference is to an environment offering greater safety and security to its users.** [19]
>
> (emphasis mine)

CAREWare is an interesting case in that it is freely available and highly customizable, but also a closed system. At least in Fulton County, it is *both* an open infrastructure and a hermetic environment. A major 2019 update – CAREWare 6 – is set to remedy this by creating a browser-based interface for CAREWare, although whether this will affect the Atlanta EMA's deployment of CAREWare is unclear. During fieldwork, I learned that the pace of technological adoption in healthcare is extremely uneven, even when directives are provided by federal agencies. Whether a clinic or other healthcare organization is working with the latest update is often more dependent on the capacities of its staff than on the availability of technological upgrades by their vendor(s), or even the requirements of a federal, state, or local policy.

However, as of 2018, users of CAREWare in the Atlanta EMA and funded organizations must organize their work around the fact that they have no access to any other software applications while CAREWare is open. Quality management, IT, and informatics teams deal with these workflow limitations through a variety of strategies.[20] Some of these involve investing in additional technological resources, such as giving key personnel two computers: a dedicated "CAREWare machine" and another computer for other purposes. Other strategies simply require data personnel to work in creative ways to translate data from another piece of software, such as an EHR, to CAREWare using one machine. This requires multiple logins and logouts which take a great deal of time (on the order of hours for just a handful of logins when CAREWare is running slowly), and sometimes the use of extra paper sheets to record data from one system (normally an EHR) into written form, and then into CAREWare from the paper sheet (a two-step translation).

Consider two large organizations that have dealt with CAREWare's status as a walled garden quite differently, to suit their specific needs. At AID Atlanta, the Vice President for Quality and Compliance (Belinda McCarney) only gets one computer; however, the Data Specialist beneath her (Nancy Johnstone) is afforded two, because her work requires her to translate data between two different EHRs and CAREWare (a process I describe in greater detail below). At The IDC, however, the Technicians only get one computer each while Rebecca, the Data and Grants Manager gets two. These different arrangements are attributable to actors' different roles within the organizations, decisions pertaining to resource allocation, and the structure of the information and care ecologies at each site.

AID Atlanta: One Computer for the Boss, Two for the Data Specialist

AID Atlanta is a multi-site clinic and one of the oldest and largest HIV/AIDS Service Organizations (ASOs) in the U.S. Southeast. The organization has been through a series of changes of leadership and ownership that have created a complex internal information ecology.[21] The organization uses two different EHRs, CAREWare, and several other reporting infrastructures utilized by housing agencies, the Georgia Department of Public Health (DPH), county-based HIV prevention programs, and CDC. In 2015, AID Atlanta was affiliated with the AIDS Healthcare Foundation (AHF), a massive (and sometimes controversial) multinational ASO in what was widely perceived to be an acquisition.[22] Whatever the precise nature of the merger was, it deeply reshaped the informational ecology at AID Atlanta.

After the affiliation, AID Atlanta decided to retain its existing EHR for its non-clinical case management services, but to adopt AHF's EHR for its clinical operations. Data from both

EHRs must make their way into CAREWare to generate single all-agency Ryan White reports. The non-clinical EHR data are entered manually by Nancy, the Data Specialist. Clinical EHR data, however, are entered by clinic staff in Atlanta and are then "pushed" into CAREWare by AHF informatics staff based in Los Angeles using a "Provider Data Input" process.[23] Belinda McCartney, AID Atlanta's Vice President for Quality and Compliance, has access to both EHRs and to Fulton County's CAREWare servers on her single machine. She is also charged with running parallel clinical and non-clinical assurance processes to ensure the quality of Ryan White data delivered at regular intervals to Fulton County and annually directly to HRSA through CAREWare. She also uses data from all three systems to engage in ongoing quality improvement work, and is a quality management leader in the Atlanta EMA and Ryan White community. CAREWare functioning as a walled garden often gets in her way.

Belinda told me about how the CAREWare VPN limits what she can accomplish, both during a workday and with the data in the software:

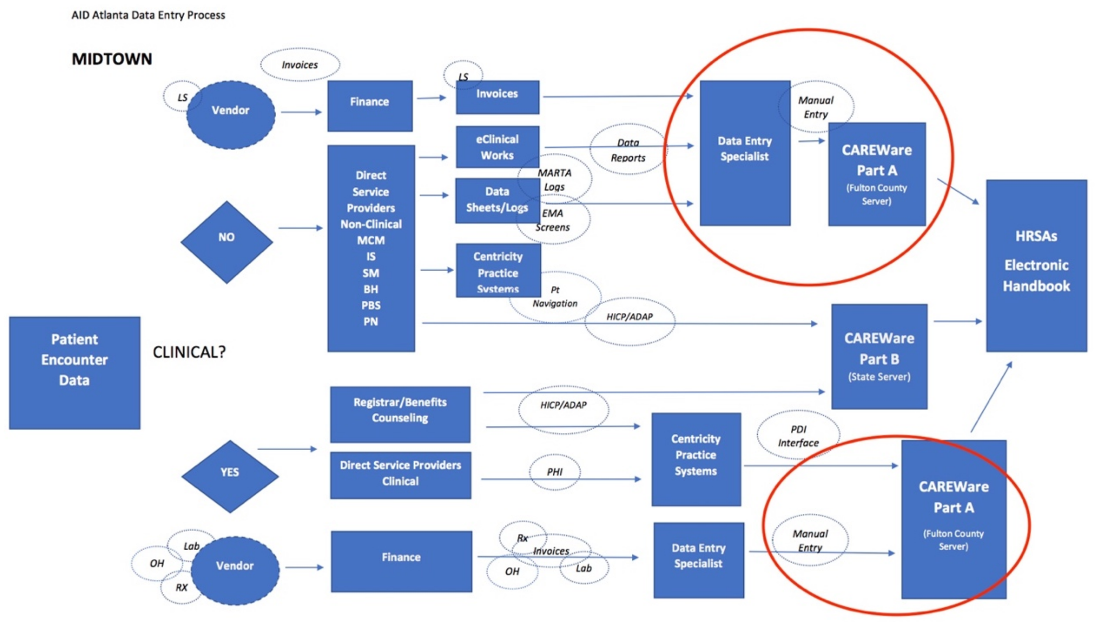
> **Belinda McCartney, VP of Quality and Compliance at AID Atlanta:** I don't run reports as often as I'd like to because you have to get on VPN so you can't do anything else, and it takes a really long time to run the simplest reports. So, it just seems like CAREWare is a bit antiquated and I don't know if there's a plan for updates or improvements for the system. It's what we have to do, and we just have to figure out how to make it work and deal with some of the deficiencies and delays.

Her limitations in running reports are largely attributable to the fact that she does not have a second computer on which to continue other work while generating them. She described sitting and waiting for long periods for reports to generate, unable to do any other work during what can be an unpredictable process ranging from just a few seconds to the better part of an hour. Belinda will sometimes ask Nancy, the Data Specialist at AID Atlanta, to run specific reports for her, when Belinda needs to use her computer in a time-crunch but also needs to generate a report. This is especially true around March of every year, when annual Ryan White Service Reports

(RSRs) are due to HRSA, or if Belinda has other grant-related deadlines but still needs to run regular CAREWare reports.

However, Nancy's primary job as the Data Specialist is to manually translate data from AID Atlanta's non-clinical EHR that is used for case management, and other financial and billing information, into CAREWare. To do this, she works with two screens at nearly all times, using her eyes and two keyboards to translate data into CAREWare data that have already been entered into the EHR by case managers. Unlike the Data Technicians/Divas at The IDC – who work in their own contained and passcode-protected area of the building – Nancy works in the basement level of AID Atlanta in a large room of cubicles mostly occupied by case managers.

Figure 4.3. Data Flow at AID Atlanta's Main Clinical Site in Midtown
Provided by AID Atlanta, with red circles added by me indicating manual entry by Nancy



Because Nancy's primary task is to manually translate data from an EHR to CAREWare, rather than from paper sheets to CAREWare (as is the case at The IDC), only having access to one computer would make her job far more frustrating, if not impossible to do in a 40-hour workweek. However, a one-computer workflow for Nancy would also raise larger quality assurance issues that could call the quality of the data into question. This could also raise bigger ontological problems for the organization. Without accurate data, AID Atlanta could not bill Fulton County, report data to funders, or know how many patients they served, and how they served them. It would quickly become difficult to function as an organization without a firm understanding of that information. Using only a single computer would require Nancy to perform so many logins, logouts, manual translations, and quality checks without the ability to compare screens in real-time using her eyes that the process would be difficult to track. “A” to “B” comparisons would be excruciating, and revisions would take a very long time. Therefore, at AID Atlanta, the employee lower on the organizational hierarchy is given more technological resources – at least from the perspective of hardware – than her boss.

Back to The IDC: One Machine for Each Technician, Two Machines for the Boss

The situation is somewhat reversed at The IDC. At The IDC, Rebecca Joubert, the Data Quality and Grants Manager who oversees the Data Technicians (the self-described Data Divas) has two computers on two separate desks: a “CAREWare machine” dedicated to running reports and monitoring quality assurance processes in CAREWare as they move forward, and another computer dedicated to her other work, such as grant-writing, working in The IDC’s EHR, and sending emails. Rebecca’s office is in the leadership suite on the third floor of The IDC. She sits in a rotating office chair, flipping back and forth between two desks that she is situated between.

The Divas, however, are allotted only one computer each. This can prove problematic and cumbersome, especially when paper CAREWare Encounter Forms used by IDC providers are not properly filled out, are delivered “*completely blank*,” or (for some other reason related to quality assurance) one of the Technicians must go into The IDC’s EHR to confirm or populate information on an encounter form by cross-referencing it with data in a patient’s chart.

> **Patricia Pearson, Data Technician**: If something is not right on the form, we have to close CAREWare and we have to close it all the way down, before we can get access to [the EHR]…So, because of that, we could stack stuff [problematic paper forms] aside, so we don't lose our CAREWare. Then, perhaps, towards the end of the day, we could go into [the EHR] and try to fix those things [in one batch of work].

After describing the existing process, Patricia discussed how beneficial it would for her to have a second machine.

> **Patricia**: Any form we need to check, we stack them aside. So, we cannot go back [into CAREWare]. Like, that's what even Marianne was saying, we wish we have another computer that we can go into [the EHR], so we work on CAREWare here [gestures left], we work on [the EHR] here [gestures right].

However, Rebecca, the Data and Grants Manager verbally noted that this was not a possibility.

Improving CAREWare?

At the end of the group interview with The Divas and their bosses, I asked "If there was something you could improve about CAREWare, what would it be?" The response was typical of those who work with the software on the data entry and/or quality assurance level:

> **Patricia, Technician**: Change the whole thing,
>
> **Rebecca, Manager**: Change the whole thing! [group laughter, agreement, and cross-talk]
>
> **SM**: What was that, Ms. Michelle?
>
> **Michelle Anderson, Technician**: I said the downtime. You know, how it goes out [chuckle].

Michelle's comment echoed an earlier complaint from Marianne, the newest team member:

> **Marianne**: I was in another department upstairs. Now I thought [the EHR] was bad [laughter] because it could go down on you in a heartbeat. But when I got down here, and this thing don't work – *they don't have a backup!* You just gotta wait and see if it's gonna come back up. That's kind of messed up. You need a backup in case it go down…but it's nothing you can do when they go down – just wait. You never know when it's gonna go down. It just stops.

Data Friction in CAREWare

In addition to complaints about the software breaking frequently (the sort of quotidian technological failures that are built-in to programmed visions of total automated interoperability), a common gripe among people who work with CAREWare – and especially among those who are charged with data entry or generating reports – is that they are unable to run reports or sometimes even work with the software during busy hours. This is an effect of what Paul Edwards calls “data friction”: “the costs in time, energy, and attention required simply to collect, check, store, move, receive, and access data.”[24]

Data have materiality. They are objects, stuff, things: bits and bytes that must flow over actual wires and circuits connected to electrical grids. On a local network, such as Fulton County’s deployment of CAREWare, this means that the software runs predictably slower or faster at different times of the day, in addition to going down *un*predictably (and with no backup, to Marianne’s disbelief).

> **Patricia Pearson**: Exactly, yes, yes. [laughter] You see, if I come in early in the morning, I could do more work from 7 o'clock to 8 o'clock [than I could the rest of the day]. I think it's like they turn it off at 8 o'clock, or something is happening between 8:00 and 8:30 And *definitely* after 4:30. I don't know if whoever's going home turn it off or do something before they leave. Yesterday, from 4:30 to 5:30, it was so slow I turn it off before 5 o'clock. Just turn it off and find something else to do. That's how slow it is. It's like they are turning it off at a certain time somewhere. I don't know what...
>
> **Rebecca Joubert, Data Quality and Grants Manager**: Or it's just too many people on the server in the peak hours of the day. I think that's when everybody is in using it and it slows down much more. Early in the morning, you say you can get it done a lot faster because there's not as many people probably using it. Yeah.

CAREWare and Data Uncertainty

The problem of uncertainty looms large in STS and critical data studies – and equally so in the practice of data science and clinical data quality assurance. In this dissertation, I have discussed issues pertaining to the quality of CAREWare data and clinical EHR data, with particular attention to the fact that the quality of clinical data are generally regarded as suspect by practitioners and researchers, even though these data also are recognized as valuable for informing clinical practice and improving patient outcomes. I have also discussed strategies of “data ontology management” used by practitioners in determining the clinical, conceptual, and economic value of certain data classes. Those of a more utopian bent in health IT treat clinical data as “the future of biomedical knowledge” – and secondary uses of clinical data for biomedical research are on the rise. As I mention earlier in this chapter, The IDC itself – in addition to being a site where many influential clinical trials are performed – is the institutional home of a multi-site HIV disease registry project that uses aggregated EHR data from multiple healthcare organizations in Atlanta to conduct secondary research. The disease registry is an infrastructure that causes its managers serious organizational headaches and requires constant tweaking or tuning, despite being an example of highly automated interoperability and more smoothly functional on a day-to-day basis than CAREWare. CAREWare data themselves are regularly matched against HIV surveillance data held by the Georgia Department of Public Health (GDPH), which is a secondary re-use of CAREWare data.[25]

However, CAREWare produces an even more extreme kind of ontological uncertainty regarding the data held in the system that goes beyond data quality. For reasons that no interlocutor could explain to me (except to express their puzzlement or frustration), neither the software or its underlying database of clients can produce a consistent number of total clients served across different kinds of reports.

CAREWare affords users the ability to produce different kinds of "canned" reports, where the variables selected for output are predetermined, as well as custom data reports. The two main reports utilized are the Ryan White Data Report (RDR), which is generally used only for internal assessment work, and the Ryan White Services Report (RSR), which is the basis for annual reports submitted to HRSA but is also sometimes used for organizational quality assessments. Further, at Fulton County, Ryan White program managers can produce reports directly from the back-end CAREWare database using Structured Query Language (SQL). Fulton County CAREWare managers and epidemiologists employed by the county are not limited by the VPN or the software's interface in the same way that agency personnel are at sites such as The IDC, MetroATLCare, and AID Atlanta.

However, direct access to the underlying database does not mean that Fulton County has a clear picture of the patient population. Fred Thoreau, a Ryan White manager at Fulton County who has worked in the system for over two decades, told me the following:

> **Fred Thoreau, Fulton Ryan White Program Lead**: I get confused on some of the intricacies within CAREWare, in that we may run a custom report where we are looking at all of the data to determine viral load suppression, using the same time period, and the same agencies, and we will get one number. We then use HRSA's canned report and we get a different number…HRSA has some already-developed reports in the quality management section… you get a different number than if you run using the same data, asking the same stuff on your own, you get a different number than that, and I don't understand how…
>
> If we run an RDR and an RSR and the canned reports, we get different numbers… So, if we ran the RDR, we'd get a different number than if we run the RSR. And we'd get a different number than if we just did our own report [using SQL and the underlying database] to come up with a set of numbers.
>
> I don't understand what it's excluding or what it's pulling in some that is not in the other. But there's a lack of consistency that becomes problematic.

Fred, a good-humored man, confirmed that this leads to a situation in which the program genuinely does not know how many clients it serves.

> **SM:** How does it become problematic? Just because then you don't really know what your baseline is?
>
> **Fred**: Right. How many did we actually serve? Did we serve 13,000? Did we serve 14,000? Did we serve thirteen-five? I don't know! [hearty chuckle]
>
> And it's not necessarily an issue of [agencies] still entering client data [after a reporting year has closed]. Like, if I ran it for [2014], and '14's closed, nobody's still going back and doing the data collection…I would get different numbers each time.

There is only so much quality assurance, double-checking, data cleaning, and debugging that local actors in a network can do before they run into higher-order problems in the network that are outside of their control. How these problems are constituted is different for each actor depending on where they are situated in the network.

For Steven Jones, the Deputy Director of the small agency in Southwest Atlanta whose team uses Excel and does their best to get data into CAREWare, only to achieve a result that is "50% true," this means accepting the limitations of Fulton County's ability to provide technical assistance. The same is true for Michael Zales of MetroATLCare, even though his technical abilities as a systems administrator are significantly more advanced than the Jones's, and even though his organization received substantial funding and technical assistance from HRSA to solve their CAREWare woes. Such barriers prevent organizations from maximizing the full utility of the software and create various forms of uncertainty: about how many clients they served, about the quality of the data they will report through CAREWare, and in several other respects (such as hours spent wrangling with data that can contribute to a lack of work/life balance or excessive workloads in the buildup to reporting deadlines).

For Ryan White executives and CAREWare managers at Fulton County – who do not experience many of the issues experienced by agency personnel – their higher-order problems come primarily from HRSA. If there are three major reports which claim to produce a number that reflects the total number of clients served, and three different numbers come out every time staff run those reports, with no apparent resolution to this problem in the here-and-now or on the horizon, what else is left to do but chuckle and chock up these fundamental uncertainties to irresolvable problems caused by higher-ups in the network?

Data Sharing and Information Blocking in the Atlanta EMA: Collaboration Using Aggregated Numbers, but Little Exchange Between Agencies

During fieldwork in Atlanta from 2016-2019, Fulton County attempted to execute a "rapid entry" program that would allow Ryan White-funded agencies to share basic client-level data with one another over the EMA-wide CAREWare network. This encompassed simple, structured information such as eligibility enrollment and demographics. The aim of the Rapid Entry initiative was to allow clients to easily go from agency-to-agency within the Atlanta Ryan White system.

Movement between agencies occurs frequently for people living with HIV who rely on the Ryan White program, because different agencies provide different services. For example, for all clients who enter case management, a document called the "EMA Screening Tool" is used to determine whether they require other services.[26] Through a series of questions arranged in columns, case managers generate a number of different scores that determine whether a client requires mental health or substance use counseling, legal assistance from the Atlanta Legal Aid AIDS Legal Project, housing assistance, or other relevant services.

This rapid entry project –for which I attended technical assistance sessions led by Greg Nowitzki, the Fulton County CAREWare manager – was, in the words of Michael Zales of MetroATLCare, "a shitshow," and was never fully implemented due to agencies guarding their data or not implementing appropriately revised informed consent forms that would allow for the sharing of data. This is a practice that the Office of the National Coordinator for Health Information Technology (ONC) and 21st Century Cures Act of 2016 refer to as "information blocking": deliberately not sharing patient data with patients or other healthcare providers when it is in the interest of patients to do so (or when they want the information shared), usually (but not always) because sharing data is perceived to take away from an organization's edge in a competitive market.

In the Atlanta EMA, the lack of rapid entry protocols adopted by all agencies and practices of information blocking create significant barriers to entry and continued engagement in care for clients. If a client must receive services from four different agencies, not only must they physically make it to each agency (a serious barrier of its own), they must also present enrollment paperwork each time they appear at a new agency. This includes documents that one does not typically keep on one's person (and which can be difficult to acquire for many who are, for example, houseless), such as proof of income, residency, HIV status, date of HIV diagnosis, proof of uninsured status, and sometimes other data.

Collaboration using aggregated EMA-wide numbers from CAREWare is a different story. This sort of data sharing happens routinely through the Metropolitan Atlanta HIV Health Services Planning Council (also called the Atlanta Ryan White Planning Council), an independent entity from the Ryan White Office (but also housed within Fulton County) that serves as a gathering place and kind of public sphere for agency personnel, people living with HIV (who, by federal statute, must be represented on the council), and community members who wish to serve on it. The Planning Council directs the Fulton County Ryan White Office about what services and outcomes ought to be prioritized. The Quality Management Committee of the Planning Council meets monthly in a basement conference room of The IDC not far away from where the Data Technicians work, and – working with Fulton county staff – uses aggregated data in a multiplicity of ways that allow the committee to assess service gaps and pursue EMA-wide quality improvement projects. In addition to setting local standards of care that are informed by the baselines set by HRSA and the *National HIV/AIDS Strategy*, the committee pursues at least two such projects per year.

However, aggregating CAREWare data for planning purposes is data sharing of a different order than direct, agency-to-agency data exchange about specific clients. CAREWare can facilitate agency-to-agency data sharing easily, from a technical perspective. Fulton County

IT staff would simply need to activate permissions that would allow for data to move between different agencies' builds of CAREWare. The county administers and controls the software and this functionality centrally. However, the organizational politics involved in the corralling of agencies in Atlanta to do the work necessary to allow the county to activate this functionality – such as writing data-sharing agreements and modifying patient consent forms or introducing new forms related to data exchange – has proven difficult, even for data as simple as intake and enrollment information. This is in part because many of the agencies are (at base) distrustful of one another, because they work in a resource-poor and highly competitive environment. However, this is not the only reason. A lack of data sharing is also attributable to the fact that brokering agreements and altering internal consent processes can be organizationally cumbersome for agencies. As interlocutors repeatedly told me, the problem in getting data to move is usually not only or even primarily an issue related to the software itself, but of organizational buy-in, investment, governance practices, and getting these issues "on the radar" of leadership.

III. Conceptual and Material Terrains of Ryan White Data: Where Do Clinical HIV Data Exist and Who (or What) Ensures Their Quality and Truth Value?

Speaking conceptually and literally, clinical data, their quality, their economic value, and their truth value do not exist stably or in one place. The data (and their meanings) live in secured rooms that are dedicated to storing paper files or servers on-site at healthcare organizations. Large such facilities that exist off-site from clinical organizations are called "data centers" or "server farms." Sometimes, now, where data live is simply called "(the) cloud."[27] Whether secured rooms where personnel work to key in and store data or sequestered areas of databases, clinical data are stored away in zones designed to keep them hidden from view, safe, secure, and accessible only to those with the appropriate permissions.

In one of my first fieldwork interactions after signing a Memorandum of Understanding with the Fulton County Ryan White Office, I interviewed Greg Nowitzki, the county CAREWare Manager. When I asked if I could see the servers where Fulton County Ryan White data were stored, Greg said, in his usual way (but in not so many words), “no way.”

> **SM:** Those servers [where CAREWare data are stored] – do you know where they are? Obviously, you probably know where they are, but are they in the building, or are they out on a server farm?
>
> **Greg**: I don't know...I'm not 100% certain, but…I believe that we have the servers housed in the building over there [at Fulton County’s main IT facility] in a secure environment, and then we back them up off-site.
>
> **SM:** Gotcha.
>
> **Greg**: I'm relatively certain that's how we do it. That being said, I've never actually asked that. So, we may actually house servers off-site too. So, we may do both, but I've never actually asked that. I've never needed to physically see the servers.
>
> **SM**: Cool. Well, that's also something I'd be interested in taking a look at, if that would be –
>
> **Greg**: – yeah. I've been doing this for a while, for some years, and I've never seen the servers... [light chuckle]
>
> **SM:** Yeah.
>
> **Greg:** No company really lets you visually see the servers, 'cause…typically there's a real security risk of somebody being able to do that. So, typically they keep it…Very restricted, usually with a keypad and...
>
> **SM**: My experience, going to a server farm in the past…required a biometric scan.
>
> **Greg**: Yeah, yeah. And I have never been to a server farm.
>
> **SM:** I've only been to a server farm because, growing up, my step-father worked in tech. I went into work with him once when he was doing that, and that's how I got to see it. But other than that, I've only ever seen pictures…

> **Greg:** Yeah…I'll bet you there's probably two people over there that can physically access our servers… 'cause don't forget, in that same – wherever they're housed – in that same room: the jail servers. So not only do you have our servers with the HIPAA requirements and all that level of security, you also have the jail servers, the court servers, as well as just other county stuff. I mean, there's a lot of people out there that would really like [chuckle] to hack the courts. You know?
>
> **SM**: Yeah, that's a really good point, yeah.

Having worked for months at that point to gain the trust of, and access to, the staff of the Fulton County Ryan White program, I didn't pursue the question of physically accessing Fulton County's servers any further, lest somebody get the wrong idea of what I was up to.

I was, in fact, just trying to follow the materiality of the data I was working to understand: to physically – per the suggestion of infrastructural ethnographers R. Stuart Geiger and David Ribes – follow the traces of the network as far and deep as I could so that I could analyze the flows, people, and stuff (what STS scholars often refer to as "matter") that constituted the network.[28] I wanted to sense, to feel, to listen to the whirring and humming of the machines, and to touch the notions of "data security" and "quality" as they were reified in the software, network architecture, and the built environments of the data centers and storage areas that held up the infrastructure I was so determined to get to know. This was going to be the difficult part, I thought. What the data contained in the infrastructures "actually said" or referred to, I surmised, would be much more simple. This was in part because these were clinical data associated with standards and best practices. However, this was not the case. The reality of where the quality of clinical data and their various values and meanings come from is far more complicated.

Clinical data are only valid, the story goes, because their veracity is attested to by clinicians with medical credentials, even if others are involved in the collection of the data, the assurance of the quality of the data, and utilization of the data in health IT systems. Oftentimes these clinicians are doctors. However, in HIV care infrastructures, these providers are increasingly Physician Assistants and Nurse Practitioners. This is an effect, on the one hand, of the increasing role of "mid-level" providers in clinical medicine and, on the other hand, of a growing shortage of new Infectious Disease doctors.[29] To reemphasize: provider attestation is the ultimate source of value for clinical data. The truth-value of these data ultimately rests with clinicians who verify patient services in EHRs and other systems, even if those data are entered by another person in the clinical workflow.

However, people who work in the field know that this is not, strictly speaking, true. If one follows the data as they move, as they transmute and are translated between systems, and as practitioners talk about these process from their own situated vantages, it becomes clear that the source of clinical data's epistemological validity – or, in healthcare parlance, its *quality* – does not ultimately lie with clinicians.[30] It lies equally in the labor put into assuring the quality of data by workers who are constantly inputting, cleaning up, tweaking, filtering, and doing quality assurance (QA) work on the data that providers often bungle or which become polluted during the transfer between systems owing to technical or human error. These workers often don't have college degrees. They are predominantly women and women of color. They work long, thankless hours in windowless basements. They are not, generally speaking, well-paid.

Consider the following dramatization of this reality of where the value of Ryan White data come from, from my fieldwork at The IDC. The IDC data team – the Divas/Technicians and their managers – told me story after story of how they would need to send forms back to providers to be corrected. The Technicians, in particular, detailed how much of a burden it was to get corrected forms back from some departments who took a long time to send the sheets back to the data team, and how much of a pleasure it was to work with departments like intake (overseen by a longtime AIDS activist), which returned “QA’d” forms in a timely fashion.

> **Marianne Tate**: Now that I know a little more about what I'm doing, it's not bad. But it's like, you have to go and retrieve the paper. That's my issue...if I don't have all the sheets that I need for them to write a report, then I have to go and find the sheets. That is time-consuming. And, if the providers would sign them and do the right thing about them, we wouldn't have to take them upstairs. But we always have a lot we take upstairs. And I took some upstairs last week and I just got them back. Now, I took them upstairs two weeks ago and I just got them back. So, it's taking them too long to sign it, put it where it's supposed to be so we can get it. So, I have to hold the reports. I have to hold the paper work until I get maybe one or two sheets of paper. And I mean, I don't understand that. Because they get a package. All they gotta do is sign it and check. It shouldn't take them no three weeks to do that.
>
> **Patricia Pearson**: Well, some of... The signing and some of the providers hold on to the papers. When we say providers, not only the doctors, though. The nurses – they hold on to these papers and give us very, very late and that would throw us off completely.

Consider another example: a large, systematic quality assurance (QA) project the Divas and their managers had to undertake when providers had been mis-entering data on their Ryan White Encounter forms.

> **SM**: We were talking about a couple of projects that you all have had to do…There were two examples I remember…One was when providers had been entering something wrong for a long time, and it messed up the report, and then you all had to go back and change every individual patient service category. And then another one was when, actually, something in CAREWare changed and it caused you all to have to do the same thing. Do you recall what those were? Maybe Rebecca can give more [context]?
>
> **Rebecca Joubert, Data and Grants Manager**: I was talking about the [Minority AIDS Initiative] report that [The Deputy Manager] ran recently. A whole bunch of patients showed up as initial primary care visit in the 12 months. But when you look back, they were old patients. They've been coming a long time, but they dropped out and they were re-enrolling. But the providers marked them as “initial primary care visit.” In [the Deputy Manager’s] report, they showed up like they were brand new patients. In order to fix that so that when you run a report next time, they don't incorrectly show as new patients in that year, somebody has to go in and change all of the initial primary cares to re-enroll intake so that you don't have that ongoing problem.

This is just one of many such projects where The IDC’s data team has had to send forms back to departments for revision, either to fix systematic errors or errors that appear sporadically. The shuttling back and forth of mis-entered forms by the Technicians is a major part of the labor and data assemblage that keeps The IDC up and running, and the quality of its data high enough to receive very large Ryan White grants year-over-year.[31]

However, when I asked a provider who maintains a practice at The IDC – one of the top Infectious Disease doctors in Atlanta – he told me that he had never had a form sent back to him for correction. To his credit, he went even further than this, saying that he had even never received instructions on how to fill out Ryan White Encounter forms and did not know how to fill them out:

> **IDC physician**: Now, what I will tell you, is that, I will say, from a provider standpoint, I actually have very little guidance on how to fill this form out. You can see that there's different types of visits here [motions to checkboxes]... So, sure, I know what a “new patient visit” is, but what's the difference between a “comprehensive primary care” and “interim primary care” visit, I really don't honestly know, and so I tend check those somewhat haphazardly. I have a pretty good sense, but it's one of those things where we have no idea, we don't get any feedback in terms of is there a quality difference between which of those we're checking, 'cause most of us probably actually do a “comprehensive primary care visit” at most of our visits, but maybe check in an “interim primary care visit.” But no, I've never gotten it back from the data team to say, "Something's not right here."

Given the workflow as described to me by the data team and represented in diagrams of the data workflow made by the Data and Grants Manager in Figure 4.2, I do not know how this is possible. I could venture some guesses. It could be that nurses are vested with power to correct provider errors (which would lie outside of normal best practices in health data quality assurance per my understanding), or something else, such as the Data Divas always using this providers’ EHR notes to correct his errors. Or, maybe, this provider just gets it right every single time – which, based on his own account and descriptions from the data team, seems highly doubtful. No matter the case, it is clear that there is something queer going on in the data workflow of America’s largest AIDS clinic.

In the case of clinical Ryan White data generally – and, it would seem, much clinical data in the healthcare system– their quality and the source of their authority does lie partly (*perhaps* even primarily) with providers who attest to their veracity. However, materially speaking, the actual quality of these data – and therefore what the data mean in practice, or the biomedical ontologies they produce – are *deeply* reliant on processes outside of providers' control.[32] The epistemological validity of clinical data are locatable all across the network, including in lower-waged actors such as the Data Technicians at The IDC. That is an open secret that ought to be brought out and utilized to rethink the nature of clinical data, their quality, and their truth value in a transformed national health IT ecosystem.

Displacing the source of epistemic validation for clinical data in the way that I suggest could potentially open a new range of conversations about the value of other forms of expertise, of labor, and could even further advance the goal of making clinical data even more useful for providers and patients. This work, if taken up by healthcare organizations and policy professionals, has the potential to transform their own practices to their benefit and to bring about new healthcare ontologies related to data quality, uses of health data, and other issues such as providing just and equitable compensation for work performed via recognition of its importance in new ways. Reframing where the value of health data come from has the potential to aid in the work of achieving interoperability in whatever style actors in their respective networks might want to, specifically because it will reveal – in different ways – what these data are and what they mean, both materially and conceptually speaking.[33]

References for Chapter 4

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[2] Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, MA: MIT Press, 2000), 35; This chapter is also hugely informed by Martin French's article "Gaps in the Gaze: Informatic Practice and the Work of Public Health Surveillance," *Surveillance and Society* 12, no. 2 (2014): 226–42.

[3] See, Andrew Iliadis and Federica Russo, "Critical Data Studies: An Introduction," *Big Data & Society* 3, no. 2 (December 2016): https://doi.org/10.1177/2053951716674238.

[4] Cherríe Moraga and Toni Cade Bambara, eds., *This Bridge Called My Back: Writings by Radical Women of Color*, 2. ed., 7. printing (New York, NY: Kitchen Table, 1983).

[5] I of course refer to the same "visions" of total programmability that I expound upon at length in the second chapter of this dissertation, in which I draw from Chun, *Programmed Visions: Software and Memory* (Cambridge, MA: MIT Press, 2011), 9.

[6] See, Office of the National Coordinator for Health Information Technology (ONC), "Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and EHRs (Draft for Comment)" (Washington, DC, December 14, 2018), http://bit.ly/2soJOwW, 41-2.

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[7] John A Milberg, "Development, Use, and Integration of a Nationally-Distributed HIV/AIDS Electronic Health Information System," *Journal of the American Medical Informatics Association* 23, no. 6 (November 2016): 1190–94, http://bit.ly/2H9gUuO

[8] On CAREWare, see, Milberg, "Development, Use"; John Milberg et al., "Improving HIV/AIDS Services Through a Network-Based Health Information System," *AMIA Annual Symposium Proceedings*, 2003. On the genre of the revelatory case, see, Robert K. Yin, *Case Study Research: Design and Methods*, Fifth edition (Los Angeles: SAGE, 2014), 51-7.

[9] Bowker and Star, *Sorting*, 271; see also, Eric Dagiral and Ashveen Peerbaye, "Making Knowledge in Boundary Infrastructures: Inside and Beyond a Database for Rare Diseases," *Science & Technology Studies* 29, no. 2 (2016): 44–61.

[10] There is currently a collapse happening between the subfields of "platform studies" and "infrastructure studies" that is itself reflective of the fact that platforms that were formerly disconnected from networks are increasingly networked and are thus taking on the characteristics of infrastructures. This is reflected in the movement between my own discussions of CAREWare as both a "platform" and an "infrastructure." See, Jean-Christophe Plantin, Paul N. Edwards, and

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Christian Sandvig, "Panel Session: Cage Fight: Infrastructure Studies vs. Platform Studies," (November 2015). Also, see the subsection below, "CAREWare as Both Closed Environment and Open Infrastructure."

[11] See, Milberg, "Development, Use," 1191-3. I had the chance to interview John by phone, to meet him at the 2017 ONC Annual Meeting, and (since at least early 2016) have received a consistent stream of technical assistance guidelines and updates from John via archived webinars in HRSA's TARGET Technical Assistance center and in real-time through the CAREWare listserv.

[12] Health Information Management and Systems Society of North America (HIMSS), "HIMSS Definition of Interoperability" (HIMSS, April 5, 2013), http://bit.ly/2M7WWzn; Software & Systems Engineering Standards Committee, "Interoperability," *IEEE 610-1990 - IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries* (IEEE, 1990).

[13] Don Rucker, "Achieving The Interoperability Promise Of 21st Century Cures," *Health Affairs Blog*, June 19, 2018, http://bit.ly/2AFo6ZV; Douglas Fridsma, "Interoperability vs Health Information Exchange: Setting the Record Straight," *Health IT Buzz* (blog), October 14, 2013, http://bit.ly/2syoS6V; Megan Daugherty Douglas, "Almost-Standard Gauge: Misadventures in Interoperability" (June 11, 2016).

[14] Lisa Nakamura, "Indigenous Circuits: Navajo Women and the Racialization of Early Electronic Manufacture," *American Quarterly* 66, no. 4 (2014): 919–41, https://doi.org/10.1353/aq.2014.0070.

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[19] Daniel Chandler and Rod Munday, "Walled Garden," *Oxford Dictionary of Social Media*, 2016, http://bit.ly/2sn27T2.

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[20] "IT," "informatics," and "quality management" will often be distinct departments or individual roles at larger agencies such as The IDC, which is connected to the larger Main Hospital system and has access to its IT resources as well as the IT resources of a major university that partners with The IDC for research purposes. The Fulton County Ryan White Program had – at various times during my fieldwork – a Quality Lead charged with quality improvement projects, a community epidemiologist who was able to conduct advanced informatics work, and a CAREWare Manager in addition to general county IT resources. All of them work with CAREWare, but fill different roles in the broader Ryan White infrastructure in the Atlanta EMA.

However, at small and mid-sized agencies many of these roles (IT/informatics/quality) will be overlapping or shared. For example, at MetroATLCare, Michael Zales fills all three roles, but has off-site IT support from his EHR vendor, support from CAREWare contractors on matters pertaining to the organization's SPNS grant, and from a firm they use for cloud-based storage of EHR data. For Steven Jones, the Deputy Director of the small agency in Southwest Atlanta, he oversees all the IT, informatics, and quality management roles with a very small staff.

[21] "AID Atlanta History Timeline," https://www.aidatlanta.org/document.doc?id=474.

[22] Christopher Glazek, "The C.E.O. of H.I.V.: Michael Weinstein's AIDS Healthcare Foundation Treats and Enormous Number of Patients - and Makes an Enormous Amount of Money. Is That Why so Many Activists Hate Him?," *The New York Times Magazine*, April 26, 2017, https://www.nytimes.com/2017/04/26/magazine/the-ceo-of-hiv.html; Dyna Dagby, "AID Atlanta 'Joins Forces' with AIDS Healthcare Foundation," *The Georgia Voice: The Premier Media Source for LGBTQ Georgia*, June 19, 2019, https://thegavoice.com/news/atlanta/aid-atlanta-acquired-by-aids-healthcare-foundation/.

[23] I interviewed a Los Angeles-based AHF informatics professional assigned to AID Atlanta by phone. In the process of interviewing him and John Milberg, I gained an appreciation of just how different various jurisdictions' deployments of CAREWare are from one another. CAREWare merits further, comparative, cross-jurisdictional study.

[24] Paul N. Edwards, *A Vast Machine: Computer Models, Climate Data, and the Politics of Global Warming* (Cambridge, Massachusetts London, England: The MIT Press, 2010).

[25] On "tuning" as a concept used to describe how practitioners work within the limitations set by technologies, and are forced to fix these technologies' everyday failures: see, Andrew Pickering, *The Mangle of Practice: Time, Agency, and Science* (Chicago, IL: University of Chicago Press, 1995), 14-15. I conducted multiple interviews with members of the team that runs this disease registry project, based at a university in Atlanta with offices in The IDC.

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[28] R Stuart Geiger and David Ribes, "Trace Ethnography: Following Coordination through Documentary Practices," in *2011 44th Hawaii International Conference on System Sciences* (2011 44th Hawaii International Conference on System Sciences (HICSS 2011), Kauai, HI: IEEE, 2011), 1–10, https://doi.org/10.1109/HICSS.2011.455.

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[30] In using the term "situated" here, I refer to the specific way in which Donna Haraway uses the term to rearticulate "situatedness" as a mode of seeing that imparts special perspective informed by training and one's subject-position. See, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective," in *Simians, Cyborgs, and Women: The Reinvention of Nature* (New York: Routledge, 1991), 183–202.

[31] On labor and data assemblages, see, Rob Kitchin, *The Data Revolution: Big Data, Open Data, Data Infrastructures and Their Consequences* (Thousand Oaks, CA: SAGE Publications Ltd, 2014), 1-26.

[32] As cited in previous chapters, my use of ontology is primarily informed by Annemarie Mol's. See, "Ontological Politics. A Word and Some Questions," *The Sociological Review* 47, no. 1 (May 1999): 74–89, https://doi.org/10.1111/j.1467-954X.1999.tb03483.x, *passim*; Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002), *passim*.

[33] Martin French, David Ribes, and Ribes' coauthors are among a cohort of scholars in critical studies of health IT who have contributed mightily to such a project. See, Martin French, "Gaps in the Gaze: Informatic Practice and the Work of Public Health Surveillance," *Surveillance and Society* 12, no. 2 (2014): 226–42; David Ribes and Thomas A. Finholt, "The Long Now of Technology Infrastructure: Articulating Tensions in Development" 10, no. 5 (May 2009): 447–73; David Ribes and Jessica Beth Polk, "Organizing for Ontological Change: The Kernel of an AIDS Research Infrastructure," *Social Studies of Science* 45, no. 2 (April 1, 2015): 214–41, http://bit.ly/2SOPuvG.

Chapter 5: The “HIV Care Continuum” and “Data to Care”: Sanguine Frameworks for the Governance of HIV

I. Introduction

In this chapter, I describe the “HIV Care Continuum,” a framework for managing HIV disease at the individual and jurisdictional levels that has become dominant both transnationally and domestically in the United States since 2013. Adoption of the Care Continuum as an HIV management strategy accelerated following President Barack Obama’s launch of the HIV Care Continuum Initiative by executive order in 2013.[1] Since that time, federal, state, and local HIV prevention, care, and surveillance programs funded by the U.S. Department of Health and Human Services (HHS) have been expanded or built to manage HIV disease using the HIV Care Continuum as their grounding model.

As operationalized by HHS, the HIV Care Continuum is a closed narrative in five stages.[2] Stage 1, “Diagnosed with HIV,” means that an individual has received an HIV-positive diagnosis. Stage 2, “Linked to Care,” means that the individual has scheduled their first medical appointment. Stage 3, “Engaged or Retained in Care” means that the individual has reported HIV-related bloodwork following a medical visit. Stage 4, “Prescribed Antiretroviral Therapy” means that a person living with HIV has started a regimen of antiretroviral medications designed to suppress HIV virus in their body, or to reduce their “viral load.” Stage 5, “Achieved Viral Suppression” means that the last viral load count for that person in that calendar year was below 200 copies/ml of blood, a level at which they are noninfectious, or “undetectable,” and thus “untransmittable.”

Figure 5.1, below, is a visual representation of the HIV Care Continuum from HIV.gov, a federal clearinghouse for HIV-related information intended to function as an educational resource for the public, policymakers, public health workers, clinicians, and other stakeholders.

Figure 5.1. Visualization of the HIV Care Continuum from HIV.gov[3]

The Care Continuum is a closed narrative because, once someone is diagnosed with HIV, they are never able to leave it. This is true in both a narrative sense, and literally – particularly from the perspective of HIV surveillance systems operated by state departments of public health.

If an individual "drops out of care," they revert to Stage 1 (diagnosed). Then, when they re-engage in HIV-related medical care, they are said to have been "re-linked" and move to Stage 2 (linkage). When their first round of labs from HIV-related bloodwork are reported, they are then "engaged" in care (Stage 3). If they report a second set of labs within a given period (generally 12 months), they are said to be "retained" in care (Stage 4). When their viral load becomes suppressed following the prescription of antiretroviral therapy (a metric that changes, but is now usually marked at less than or equal to 200 copies of HIV per milliliter of blood), they have "achieved viral suppression" and are listed as "suppressed" in HIV surveillance data (Stage 5). The inability to leave the HIV Care Continuum once diagnosed with HIV is not only true in surveillance, but also in other domains of HIV practice such as care, prevention, research, and planning. In these domains, progress is measured using the Continuum as a framework for monitoring individuals' disease-course and treatment efficacy. The Continuum is also applied to populations and is used within jurisdictional planning efforts to control or "End" the HIV/AIDS epidemic there. Since it came to prominence in 2013, the HIV Care Continuum has come to dominate almost every area of HIV practice, moving people and groups living with HIV toward individual and collective viral suppression and untransmittability.

A Scalable Framework

The Care Continuum has transformed the management of HIV across scales. It is a framework used by clinicians and individual people to conceptualize their own HIV disease. At the jurisdictional level, state and local health departments use the Care Continuum to measure progress in the management of their local HIV/AIDS epidemics. At the organizational level, clinical organizations and researchers use the Continuum as a framework to measure how well they are serving their patients or how they are progressing toward meeting overall goals. It is also the orienting metric at the national level, whereby branches of HHS such as CDC and the Health Resources and Services Administration (HRSA) aggregate jurisdiction-level Continuum data to generate national Care Continuum data. CDC and HRSA also build technical assistance programs for stakeholders to learn how to put the Continuum to use in their work in states, localities, and healthcare organizations.

The Continuum is also increasingly the dominant framework used to conceptualize and manage HIV transnationally. In addition to research on the use of Care Continuum frameworks in U.S. federal health policy, the state of Georgia, and metropolitan Atlanta, I conducted immersive fieldwork at two international public health and HIV conferences for this dissertation: the 2017 American Public Health Association annual meeting in Atlanta and the 2018

International AIDS Conference in Amsterdam. I also undertook health policy analysis focused on the Care Continuum as a governance model in international HIV work. I do not consider the transnational uptake of the Care Continuum other than to note that it is also the dominant governing framework for the management of HIV/AIDS outside of the United States, where it is also frequently called "the Cascade."[4]

The HIV Care Continuum and its metrics are employed by global civil society and advocacy organizations such as the International AIDS Society (IAS) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), global public health agencies such as the World Health Organization (WHO) and the European Centers for Disease Control and Prevention (ECDC), and the inclusion of a Continuum-driven approach is a central component of major funding streams that support HIV/AIDS programs in the developing world. This includes the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), which requires funded countries to include "Cascade" approaches in their national HIV/AIDS strategies. Some of the cascades/Continuums used in international public health work – and other emergent ones in the domain of research – extend beyond the management of HIV disease and people living with HIV and include prevention efforts targeted at individual people or groups who are more likely to become HIV-positive. This is also true of recent research in biomedical HIV prevention, where a "PrEP Continuum of Care" is emergent.[5]

The HIV Care Continuum is a narrative framework for conceptualizing the course of care for a person living with HIV that is used by providers, health educators, and people living with the virus. The HIV Care Continuum is used by providers and organizations to work with patients, and to educate patients and their family members on the management of their HIV. Clinical organizations and public health departments use both workforce education and patient engagement strategies to impart knowledge about the Continuum to stakeholders as a way of instructing program managers and people living with or affected by HIV about the management of the disease. The HIV Care Continuum exists in this way, as a narrative engine in the minds and work of practitioners.

However, literally speaking – at the level of the data infrastructures used to manage HIV in the United States – once a new individual case of HIV is reported to a state department of public health (DPH), that individual enters Stage 1 of a very specific iteration of the HIV Care Continuum: the HIV Care Continuum in the domain of HIV surveillance and HIV surveillance systems operated by state departments of public health.

This is not just entry into a narrative of care provision that will be employed by teams of providers and perhaps the individual person living with HIV in conceptualizing their own care process in an ideal progression toward viral suppression after being linked to, engaged in, and retained in medical care. Rather, entry into the HIV Care Continuum in the domain of surveillance is a material entry into a specific data assemblage made up of interlinked HIV data infrastructures in clinical, surveillance, and prevention domains. In these HIV data assemblages, state and local health departments operationalize the HIV Care Continuum by using clinical Electronic Laboratory Report (ELR) data that are sent by testing laboratories to state HIV surveillance offices every time an individual living with HIV receives bloodwork. People living with HIV ideally get HIV-related bloodwork done twice or more per year, following current standards of care. This is reflected in the narrative's definition of being "retained in care," which requires two blood draws in 12-month period.

In a paradigm called "Data to Care" that launched following the 2013 HIV Care Continuum Initiative, these HIV surveillance data – formerly entirely segregated and stored separately from other HIV data in the domains of care and prevention – can now also be used for prevention purposes. Specifically, they can be distributed to public health prevention personnel to target individuals living with HIV who have been identified as "out of care" for re-linkage interventions. Advanced forms of "molecular HIV surveillance" (MHS) – which use phylogenetic testing methods to identify particular strains of HIV at the individual level and within in a jurisdiction – have also been deployed in all states beginning in 2018.[6] MHS tools are used to trace the emergence of specific "clusters" of HIV and to engage in new forms of "transmission network mapping." These methods allow health departments to determine how specific strains of HIV virus move within a particular jurisdiction, not only at the large-group level, but also within small groups of individuals.[7]

These new strategies for managing HIV disease and HIV data constitute a new mode of governing HIV, both as an individual disease state and a public health problem. These methods have in fact provided a new baseline for this work in a multiplicity of contexts. However, the HIV Care Continuum, Data to Care programs, and MHS also raise serious questions about patient privacy, confidentiality, informed consent, patient autonomy in medical decision-making, and patients' right to access and control the use and exchange of their electronic health information – a stated policy priority of HHS as it builds a "patient-centered" "nationwide interoperable health IT infrastructure."[8] I explore these issues at greater length in the next chapter, which discusses the administration of HIV Data to Care programs in Georgia. However, in this chapter, I describe how federal policies developed primarily by CDC stage uses and exchanges of HIV data that lead to substantive ontological transformations of specific kinds of HIV data simply because they move from one kind of infrastructure to another.

In the Data to Care framework, clinical data that require informed consent for their collection and use by providers are first transformed into surveillance data that do not require informed consent and are not subject to the same privacy restrictions as clinical health data. These same data are then again transformed into HIV prevention data, which likewise do not require informed consent.

Through my exposition of these programs in federal policy and in the State of Georgia in this and the next chapter, I describe them and explain key ethical questions and problems raised by the fact that personally-identifiable HIV data (protected, sensitive, electronic health information) transform and their range of acceptable uses expand simply because they are transmitted between different braches of the healthcare system. Bloodwork data that are collected in a context where informed consent is required (during the provision of clinical care) transmute into data that can be put to a wide range of uses for research and public health planning and prevention without patients' informed consent. This only occurs because the location of the data changes from a clinical setting to a public health infrastructure, via a testing laboratory. I describe how the current paradigm developed with minimal consultation by people living with HIV and little effort to educate both the HIV workforce and people living with HIV that clinical HIV data collected through routine laboratory tests are now used for public health purposes across the United States.

This descriptive work focuses on federal HIV data policy and Data to Care in Georgia, building to the conclusion of chapter six. There, I put forward the foundation for a multi-stakeholder research agenda aimed at assessing current tensions in policy and practice pertaining to uses of HIV data. I do so with an emphasis on possible reforms, potentially by seeking or requiring patient informed consent for secondary reuses of clinical data for public health surveillance and prevention, and/or engaging in more widespread efforts to educate both the HIV workforce and people living with HIV about current practices in order to at least inform people living with HIV about how their engagements in medical care are used for public health purposes.

The Birth of the HIV Care Continuum: Electronic Laboratory Reporting

Since 2013, following the issuance of regulatory guidance to public health departments in the form of a "Dear Colleague" letter sent to state and territorial HIV surveillance systems by CDC that accompanied the launch of the HIV Care Continuum Initiative, all state and territory-based HIV surveillance systems have used Electronic Laboratory Reporting (ELR) infrastructures to collect data from bloodwork drawn during every instance of HIV-related medical care that an individual engages in. Current standards of care recommend that people living with HIV receive HIV-related bloodwork twice per year. If a person living with HIV fails to report bloodwork to their state's HIV surveillance system via a laboratory report, they are eventually flagged as "out of care," "not in care," or as having "dropped out of care."[9]

In this chapter, I describe procedures and technical guidance related to this work that were given to state health departments by CDC starting in 2014 under the auspices of a federal initiative called "Data to Care." In the "Data to Care" paradigm, public health actors are instructed about how to use person-level ELR data held by HIV surveillance systems to construct "out of care" lists. Out of care (or "not in care") lists are indexes of people living with HIV in a specific jurisdiction who have been determined to not be engaged in HIV-related medical care because they have not recently reported bloodwork. In the federal Data to Care framework, health departments are instructed on how to build these lists using HIV surveillance data, and then to enhance individual entries on these lists, and then to remit the lists to prevention programs and healthcare providers to re-link individuals on the out of care lists to HIV care providers.

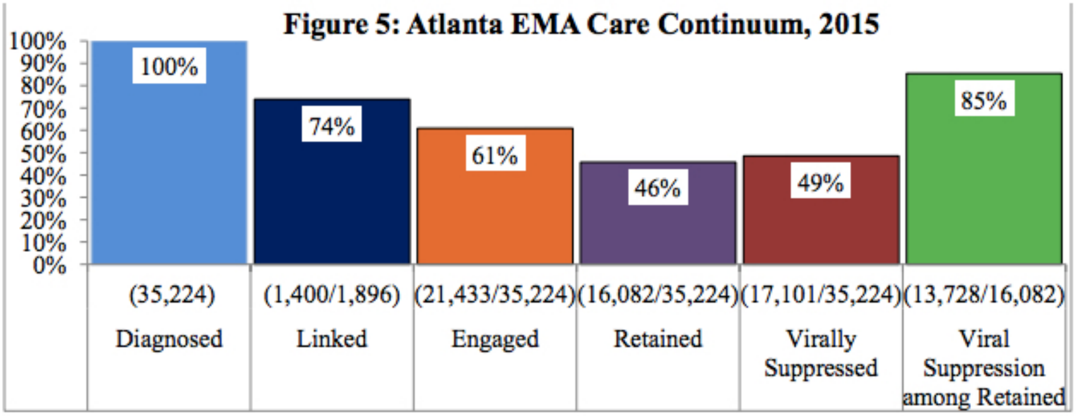
This chapter is focused on describing the federal policy paradigms and technical guidelines that make this approach possible. In the next chapter, I describe how Data to Care has been implemented in Georgia and metro Atlanta. In an ethnographic case study, I describe how the personnel who operate the State of Georgia HIV surveillance system have built an "Out of Care Watchlist" (OWL) for the state. The OWL is distributed through an HIV Health Information Exchange (HIV HIE) to safety net providers in the Atlanta metropolitan area, and to HIV and STD prevention departments in local health districts throughout the state using a prevention infrastructure called the State Electronic Notifiable Diseases Surveillance System (SENDSS).

To review the HIV Care Continuum: if an individual "drops out of care," at the point when they re-engage in HIV-related medical care, they are said to have been "re-linked." When their first round of labs are reported to the state surveillance office, they are said to be "engaged" in care. If they report a second set of labs within 12 months, they are said to be "retained" in care. When their viral load becomes suppressed (a metric that has changed over time, but in 2019 is usually marked at less than 200 copies of HIV per milliliter of blood), they are said to have "achieved viral suppression" and are listed as "suppressed" in HIV surveillance datasets and HIV Care Continuum reports for that jurisdiction. To reiterate just how pervasive the HIV Care Continuum is: political jurisdictions, clinical organizations, and nearly every entity charged with managing a population of people living with HIV in the United States produce their own Care Continuum data reports. The HIV Care Continuum is currently the central metric in the United States' HIV apparatus across all domains of practice.

In public health department or jurisdiction-specific reports, HIV Care Continuum data are generated using ELR data feeds. ELR data allow public health personnel to determine information about rates of linkage, engagement, and retention in care among people living with diagnosed HIV in that jurisdiction. Surveillance personnel will often coordinate with other arms of the public health infrastructure such as local Ryan White programs, interdisciplinary "End the Epidemic" committees, or statewide HIV Integrated Planning entities. State HIV surveillance offices generate Care Continuum reports to help those actors assess their epidemics and build plans, and also receive data from some of these entities.

For example, Figure 5.2 below shows HIV Care Continuum data for the 20-country Atlanta Eligible Metropolitan Area (EMA) served by the Fulton County Ryan White program.

Figure 5.2. Visualization of the HIV Care Continuum in the 20-County Metropolitan Atlanta EMA Using 2015 State HIV Surveillance Data, with Terminological Definitions[10]



Diagnosed = People listed as living with HIV in Georgia in the state's HIV surveillance system
Linked = Linked to HIV-medical care within 30 days of initial diagnosis in 2015 with lab tests reported to the state surveillance system
Engaged = 1 lab reported to the state surveillance system in the last 12 months
Retained = ≥2 labs reported to the state HIV surveillance system in the last 12 months
Virally Suppressed = Last lab reported to the state HIV surveillance system in the last 12 months ≤200 copies of HIV/ml of blood

All the data reflected in this chart, presented in a Fulton County Ryan White grant application narrative to the Health Services and Resources Administration (HRSA) for funding for clinical HIV care and support services, are state HIV surveillance data. These data were generated using

ELR feeds, which are in turn generated when medical providers order routine lab tests for people living with HIV. When writing the HRSA grant application, the Fulton County Ryan White leadership team worked with HIV surveillance personnel at the State Department of Public Health to generate this graphic as part of the epidemiological profile. Its purpose is, in HIV parlance, to "demonstrate" the local epidemic to HRSA in the county's annual reapplication for Ryan White funds.[11]

"Re-linkage" efforts staged and funded by federal Data to Care programs – whereby data held by state and local HIV surveillance systems are sent to prevention and care programs to re-link individuals who have been identified as "out of care" – are the focus of the sections that follow in this chapter. The next chapter is a case study of the State of Georgia's re-linkage strategy, which is a local iteration of these federal programs. The argument and orienting impetus of both chapters is that a close examination of transformations in the management of HIV data in the United States reveals that health IT infrastructures which link formerly-distinct classes of HIV data to one another in the domains of care, surveillance, and prevention have developed with such rapidity and enthusiasm for their potential to bring an end to the AIDS epidemic that their effects on the public health workforce and people living with HIV are currently poorly understood, potentially impinge upon the rights of people living with HIV to control the movement of their HIV data, and require further study. I explore how these infrastructures reveal substantive tensions in HHS policies and recommended best practices regarding the exchange of sensitive health data.

Sanguine Frameworks for Governing HIV

The HIV Care Continuum Initiative and programs built around it that link the domains of HIV surveillance, prevention, and care in part by utilizing new health IT infrastructures has led to a new era in the management of HIV and the proliferation of what I call “sanguine” frameworks for governing HIV. Sanguine HIV management strategies are rooted in driving up rates of viral suppression at the individual and group levels, ultimately toward “sustained viral suppression” at the individual level and toward the multiply signifying end-points of the “End of AIDS,” the “End of the Epidemic” (EtE), or “zero” (“zero new infections, zero AIDS-related deaths, zero stigma”) at the population level.

I call these strategies for managing HIV “sanguine” because they are rooted in the unrealistically optimistic and naïve – or sanguine – promise of a future that has long been promised, but which seems never to arrive: the “End of AIDS” or “Zero” new HIV infections. These goals are so utopian (or, for critics, dystopian in their severe finality) that their failure to ever be fully reached is written into their pursuit. In this future-always-deferred, every individual living with HIV is – incorrectly – imagined as being able to access medical care, physiologically capable of becoming virally suppressed, personally able to take antiretroviral medications every day for the rest of their life, and desirous of viral suppression. Viral suppression is framed as an “achievement,” thereby excluding (and arguably stigmatizing) those who cannot or do not reach it, and rewarding those who can and do with a kind of official approval. Viral suppression marks individuals as compliant or “good” biomedical subjects, “safe” for HIV-negative people to have sex with without having to use barrier protection (“treatment as prevention” or TasP), and individually-empowered actors in the grand drama of “Ending the Epidemic.”[12]

However, in addition to being cruelly optimistic – to borrow a framing from affect theorist Lauren Berlant – the biomedical sexualities and sexual realities produced by the HIV Care Continuum and new frameworks for governing HIV are also *sanguineous*, as in “of, relating to, or containing blood.”[13] The sexual realities that are fostered by the HIV Care

Continuum, Data to Care programs, and "End of AIDS" narratives are defined primarily by the actual or perceived molecular composition of the blood of individuals and populations living with HIV, with an emphasis on measuring viral load and patterns of engagement in HIV-related medical care as predictors of likely infectiousness. Determinations about these critical metrics are made based on data continuously gathered in HIV surveillance infrastructures following clinical bloodwork orders, and these data are used to plan and execute national, state, and local responses to the epidemic.

Collectively, this assemblage of programs and narrative frameworks constitute a genuinely new mode of governing HIV that is unique to the 2010s. It falls in line with developments in contemporary healthcare that Nikolas Rose calls the governance of "life itself," owing to these programs' reach further into the interior molecular structures of the body in order to make determinations about both individual and public health.[14] However, the assemblage of methods for managing HIV that stem from the Care Continuum is also a set of apparatuses for managing and producing sexuality that is unprecedented in the history of sexuality.[15] The reorganization of key elements of the management of sexuality through the continuous measurement of the amount of virus in the blood of a specific group (people living with HIV), and then building clinical and non-clinical interventions around these measurements to empower individuals to reshape their own sexual risk profiles by taking medications and engaging in medical care is not aligned with any style of reasoning or mode of bureaucratic administration that has been used to shape human sexual capacities to this point in history.[16] It is a genuinely new development in the modern sexual system and a key driver of broader reorganizations of what Gayle Rubin describes as the "sex hierarchy" in "Thinking Sex."[17]

Viral suppression ultimately occurs at the individual or person-level, even though it can be measured at the group level, organizationally, or within a jurisdiction by centering rates of suppression. Therefore, the burden of reaching "The End of AIDS" is simultaneously distributed both among the institutions charged with managing the epidemic and among individual people living with HIV.[18] In this model, the individual person living with HIV is frequently framed as empowered to become virally suppressed, and as playing a key role in bringing about the end of the epidemic.[19] HIV virus becomes, to borrow a phrase from musician-cum-philosopher Trent Reznor and artist Russell Mills, "Cargo in the Blood": an indelible characteristic of individual people and populations that must be carefully and strategically managed, a burden continuously offloaded and kept at low levels through regimens of daily antiretroviral medications, and carried with one for the duration of their life.[20]

In the sanguine narratives staged by the HIV Care Continuum, individuals' viral load is framed as "character-building, something that could be destructive" (if virus is not suppressed) or "something that could be positive" (when an individual become virally suppressed and as rates of viral suppression go up at the population level).[21] This is often the framing employed regardless of individuals' ability to access services – a discursive problem that is endemic in a multiplicity of places, including in Atlanta. The emphasis on viral suppression in a context where about half of people have reached this benchmark – and where there is not adequate infrastructure to make up the difference – results in a kind of *de facto* criminalization for those who cannot continuously access medical care or who do not become "undetectable."

"90/90/90" and "Ending AIDS": Companion Discourses of the HIV Care Continuum

Transnationally, the HIV Care Continuum has also manifested in the global 90/90/90 targets released by UNAIDS in 2014, for achievement by 2020. 90/90/90 is similar to the HIV

Care Continuum in its narrative form. The first “90” stands for 90% of people living with HIV knowing their serostatus. The second “90” stands for 90% of people who know their status being prescribed on antiretroviral therapy. The third “90” means 90% of those in treatment being virally suppressed.[22] In 2014, UNAIDS also released a “Fast Track” program for cities to reach corresponding 95/95/95 targets. While the United States requires PEPFAR grantees to build their programs around 90/90/90, these goals have not been adopted domestically. In a co-materialization of American exceptionalism and HIV exceptionalism (“the idea that HIV is an exceptional disease requiring an exceptional response,” per Adia Benton), *The National HIV/AIDS Strategy of the United States: Updated to 2020* (*NHAS 2020*) reaches for the lower domestic target of 90/90/80 by 2020 (a fact rarely noted in discussions of the United States’ domestic response in any context).[23] Reaching any of these targets is often referred to as “Ending AIDS.”[24]

The HIV Care Continuum, 90/90/90, and Ending AIDS are dominant sanguine narratives of care and responsibility that ground the governance of HIV in the fourth decade of the epidemic. They are sanguineous because they are rooted in measuring the molecular content of the blood of people living with HIV on a continuous basis at the individual and population level and because they stage a narrative progression toward the “achievement” of universal viral suppression and “zero new infections.” However, these narratives are also sanguine, in that they are so optimistic that their success is essentially foreclosed. What, for example, does “Ending AIDS” mean in a world where individuals who are given an AIDS diagnosis retain that designation for the rest of their life, as is currently the case? It is, in that sense at least, a contradiction in terms. Further, reaching 90/90/90 is a doomed project in any context without extremely robust systems of universal healthcare and public health. These are realities that proponents rarely recognize in their discourse about "Ending the Epidemic," although a dedicated cohort of practitioners and activists have called the "End of AIDS" into question since it became a drumbeat.[25] Meanwhile, the sanguinity or naïveté of 90/90/90 outside of countries with very well-resourced healthcare systems has borne out in real-world contexts. To date, the only nation-states to reach the 90/90/90 targets are countries with amazingly robust public health infrastructures, and the United States has the lowest rates of any country with a "highly developed" economy with an estimated 55% national viral suppression rate as of 2019.[26]

II. A Brief History of HIV Surveillance in the United States, 1982-

Just as there is no official history of HIV risk hierarchy – but only a *de facto* history as I document in chapter one – there is only a loose national history of HIV surveillance. The history of HIV surveillance is mostly made up of piecemeal accounts created by practitioners, and partial histories that are catered to the needs of specific social scientists or humanists studying some specific aspect of HIV surveillance.[27] However, the absence of a full history of HIV surveillance is also partly a function of HIV surveillance being somewhat difficult to study. The implementation of surveillance program directives from CDC, along with initiatives taken by local health departments beyond the required baseline surveillance requirements set by CDC, vary widely from jurisdiction-to-jurisdiction. However, even though HIV surveillance is not uniform across jurisdictions in the United States, it is a process primarily driven by CDC in a hierarchical fashion. Thus, CDC is the logical institution to begin with when studying HIV surveillance in the United States, with a focus on the policy directives CDC has issued to states about how to conduct HIV/AIDS surveillance.

CDC issues guidance to state and territorial departments of public health about how to conduct HIV surveillance, usually following or in tandem with guidance or "position statements" issued by an organization called the Council of State and Territorial Epidemiologists (CSTE). CSTE is the professional association of epidemiologists, survey researchers, and surveillance professionals employed by departments of public health in states and other jurisdictions. CDC works with CSTE to cultivate consensus among practitioners who are charged with managing state HIV surveillance systems at the state level.[28] Thus, while a private institution – a professional association for epidemiologists at health departments – CSTE performs some public functions and in some respects, resembles a federal agency. CDC directives on HIV surveillance prompt surveillance systems managed by state departments of public health to change, alter, or augment the existing surveillance system in that jurisdiction and/or to change the way that certain data are collected. For example, HIV case surveillance only began in 1997; prior to this, surveillance only captured cases of AIDS.[29] Tracking the progression of cases of HIV to AIDS is still a core function of HIV surveillance systems. However, this is now an embedded element of the HIV surveillance infrastructure that is less important than it was at the time of the introduction of HIV case surveillance in 1997. Later changes to HIV/AIDS surveillance, such as names-based reporting and continuous viral load monitoring in the era of the Care Continuum, were layered on top of these and other functions. As I discuss below, HIV surveillance systems are thus the effect of many waves of regulatory and technical transformation and historical accumulation over time.

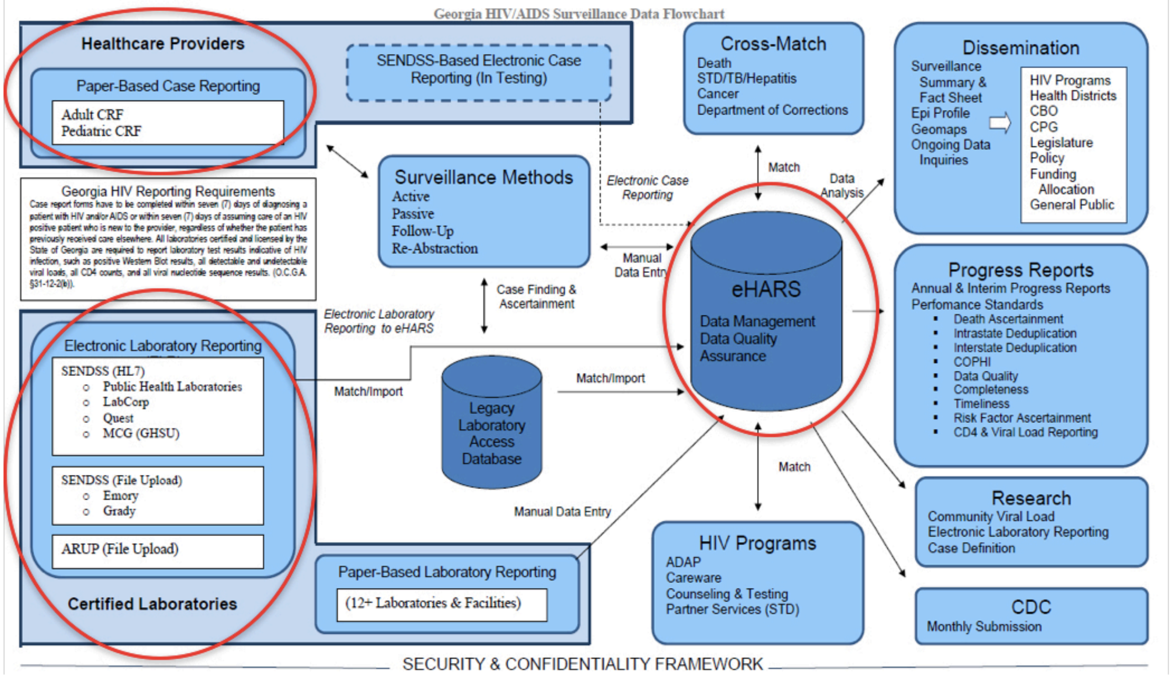
Sometimes, surveillance directives issued by CDC require state departments of public health to enact new regulations using their administrative powers, or sometimes even to work with state legislatures to pass laws to make federal HIV surveillance guidelines legal at the state level. For these and other reasons (such as some state health departments simply moving more slowly to implement changes mandated by CDC), the full implementation of new surveillance methods generally takes a period of years and occurs in a highly uneven fashion. For example, mandatory names-based reporting of new cases of HIV to state surveillance systems was a process that took over a decade to fully complete across every funded jurisdiction, some of which continued to use de-identified codes rather than first and last names until 2008.[30] Further, certain jurisdictions implement new surveillance methods locally without CDC requiring them to do so, and then some of these methods are adopted more widely and/or eventually become required by CDC. For example, while molecular HIV surveillance only became a requirement for state health departments in 2018, several health departments have been conducting some form of molecular HIV surveillance using laboratory data since at least the mid-2000s, CDC has published recommendations about how to conduct molecular surveillance since the launch of the "Variant, Atypical, and Resistant HIV Surveillance" (VARHS) program since 2004.[31] CDC did not require jurisdictions to collect ELR data for HIV care-related bloodwork with an emphasis on viral load until 2013 along with the release of the HIV Care Continuum Initiative, thus facilitating the proliferation of the HIV Care Continuum as the dominant model for governing HIV disease across jurisdictions.[32]

In addition to the uneven implementation of HIV surveillance policies, how HIV surveillance is conducted when the process is complete also varies widely across jurisdictions. In the words of one surveillance interlocutor in Georgia during an interview, "when you've seen one state, you've seen one state." What this epidemiologist meant was that the execution of HIV surveillance – while generally generating similar outcomes or effects in each jurisdiction, per CDC requirements – varies widely from jurisdiction-to-jurisdiction. Given this, generalizations about HIV surveillance are possible from an analysis of policies put in place following CDC guidelines or directives. However, in order to understand how HIV surveillance occurs in a specific place, observations of local, context-bound practices are required. In this chapter and the next, I work to model this kind of inquiry into HIV surveillance in its federal dimensions, as well as ones at the state level in Georgia.

How it Works: Implementing CDC Guidance in State HIV Surveillance

Figure 5.3, below, is a visualization of the Georgia HIV Surveillance System: the state HIV surveillance system that I studied for this dissertation. It was produced by Georgia Department of Public Health (GDPH) HIV epidemiology personnel and is included in some explanatory presentations given by GDPH employees.

Figure 5.3. Visualization of the Georgia State HIV Surveillance System Data Flow Produced by GDPH, excerpted from a PowerPoint presentation



Like all jurisdictional HIV surveillance systems in the United States in 2019, the main source of data about new cases of HIV are Case Report Forms and Electronic Case Report Forms, which report new incidences of HIV. These forms collect detailed information about individuals diagnosed with HIV: data such as name, address, phone number, date of birth, where the individual was diagnosed, whether their initial diagnosis was with HIV or AIDS, and "HIV transmission risk factors" or HIV risk hierarchy data (the subject of chapter one of this dissertation).

The main source of continuous, ongoing surveillance data about individual people living with HIV are Electronic Laboratory Reporting (ELR) data feeds from testing laboratories that are associated with individual cases. These feeds report results from every instance of HIV-related bloodwork drawn in the state, with an emphasis on viral load (for measuring HIV Care Continuum data), CD4-T cell count (for determining when cases have progressed to AIDS), and (as of 2018) phylogenetic data about specific strains of HIV in order to engage in new forms of transmission network mapping and cluster tracing.[33] These ELR data, linked to individual cases associated with first and last names, form the basis of HIV Care Continuum statistics and "Data to Care" activities.

If a name not already in the state HIV surveillance database appears through ELR data reports, or in other secondary sources of data such as periodic "matches" that are performed between clinical Ryan White databases or state Medicaid databases and the state HIV surveillance system, a new entry is generated in the HIV surveillance system. ELR data feeds are thus also a source of data about new cases, in addition to their primary function as continuous streams of data about existing cases. Most new cases of HIV are reported directly by testing agencies or healthcare providers to the state HIV surveillance system using electronic or paper Case Report Forms. However, some private healthcare providers who diagnose people with HIV do not know about the legal requirement to report new cases within seven days of initial diagnosis, or simply neglect to do so. In these cases, a new entry in the surveillance system is generated when bloodwork is ordered by those clinicians and the testing laboratory send the results to the HIV surveillance system. Any information in that ELR report will populate that new case. Then, surveillance personnel – called "surveillance liaisons" – are tasked with consulting other secondary sources of data, following up with diagnosing providers, and/or reaching out to the patient to generate a full case entry. False new cases can also be generated by mis-matches between the data included in ELR feeds and existing entries; these must be investigated and reconciled by HIV surveillance staff on an ongoing basis.

Both sources of data – Case Report Forms and ELR data feeds – are circled in red in Figure 5.3. "eHARS" is also circles in red; it stands for the "Enhanced HIV/AIDS Reporting System." eHARS is CDC-maintained software used by all state, territorial, and local HIV surveillance systems for information management, generating reports, de-duplication work conducted with CDC (such as removing entries when an individual appears in HIV-related medical care in another state), and other purposes.[34] eHARS is the core software infrastructure used to manage all HIV surveillance data and HIV surveillance processes in the United States.

I present the diagram of Georgia's HIV surveillance system to emphasize the complexity of any HIV surveillance system, not so that it can be understood in every one of its specific dimensions. I perform a more detailed close reading of this diagram in the following chapter, when I explain uses of HIV surveillance data for Data to Care activities in Georgia.

However, upon a cursory examination, this diagram shows how HIV surveillance systems receive data from many different sources on both an ongoing and periodic basis. Such an assemblage of layered, nested, and entangled sociotechnical elements and processes, presented thusly, is not designed to be understood in its totality. Rather, like the components of the HIV surveillance infrastructure itself, the diagram representing it must be worked with constantly, on a continuing basis, so that the viewer, operator, critic, or reader, can materialize a partial understanding of what it is, how it is constituted in the world, and its potential and actual effects. This work takes place through the interactive act of utilizing the infrastructure or diagram, or through close examination and analysis. If this work is not done, even an approximation of the whole picture cannot actualize.

Institutional actors' collective decision not to prioritize this kind of holistic approach to educating the HIV workforce, providers, and people living with HIV about HIV surveillance is a major reason why so many of my interlocutors who work with these systems have only a very partial view or understanding of their functionality.[35] Later in this chapter, I discuss this as a kind of "silo-ing" in HIV work, which plays a role in facilitating what I call "infrastructural creep:" the linkage of HIV data infrastructures to one another using technical and organizational methods, or the expansion of infrastructures to take on functions that they did not previously have. The case of "Data to Care," where surveillance data are used in the service of prevention, is the key example I explore here (in federal policy) and in the next chapter (in Georgia).

Return for a moment to the diagram of Georgia's HIV surveillance system above, in Figure 5.3. I recommend readers approach it using an interpretive method employed by software studies scholar Alexander R. Galloway in *The Interface Effect*. Writing about an inscrutable flowchart produced by the U.S. military to depict the War in Afghanistan, Galloway suggests a way of reading indecipherable diagrams such as these – with many lines and nodes – which elude easy sense-making or linear logics. He proposes diagram like this be approached as "an interface:" a kind of interactive environment that allows one to manipulate, explore, and delve deeper "into the society of control," not unlike a computer interface or the screen of a mobile device.[36] Galloway says that

> the high level of detail seems to hinder comprehension rather than aid it. Unlike realism in painting or photography, wherein an increase in technical detail tends to bring a

> heightened sense of reality (at least in the traditional definition of aesthetic realism that has held sway more or less since the Renaissance), the high level of technical detail visible here overwhelms the human sensorium, attenuating the viewer's sense of reality. Rather, like a fractal whose complexity does not decrease when viewed through a magnifying glass, the information contained in the slide does not grow more coherent the longer one inspects it. Eschewing lucidity, the diagram withdraws from the viewer's grasp, effectively neutering its capacity as a vehicle for information.[37]

The HIV surveillance diagram should be approached in this way: not as a visualization to be made sense of in its totality, but as a kind of looking-glass or screen that can be strategically made useful or informative by the viewer, by visually following the various lines and nodes present in their networks and then cogitating over what they might refer to in the world.

This is, in fact, how this diagram is used by HIV surveillance practitioners in Georgia. The full structure of HIV surveillance in the state is impossible to hold in one's head at one time. The different sources of data that feed into a state HIV surveillance system, and the human and nonhuman actors at play in making the infrastructure function, are too numerous. Hence, the need to create a reference diagram, both to explain HIV surveillance and to aid in the operation of the system itself.

To this end, a copy of this diagram was taped on top of one HIV surveillance interlocutor's desk for the duration of fieldwork, just above her computer screen where she worked with eHARS to manage state surveillance data and do her other work, such as writing epidemiological profiles or generating reports for state planning bodies and the Fulton County Ryan White program.[38] However, in addition to being useful as a tool to aid in comprehension and practice, the diagram of HIV surveillance in Georgia also actualizes a kind of inscrutability that is a hallmark of both new health IT infrastructures (recall the "Health IT Ecosystem" diagram from chapter two) and of programs designed to govern HIV/AIDS through frameworks like the HIV Care Continuum and Data to Care, which link data infrastructures from the domains of surveillance, care, and prevention in new ways. The diagram of HIV surveillance in Georgia served as a kind of roadmap for me in my fieldwork in the HIV world generally. It is a diagram representing some actually-existing realities, and it helps GDPH employees actualize HIV surveillance in practice. It also assists publics in conceptualizing HIV surveillance and specific aspects of the process; for example, audiences to whom HIV surveillance personnel in Georgia give presentations that include the diagram.[39]

From Names-Based Surveillance in 2008 to Continuous ELR Reporting, 2013 onward

My over two years of ethnography among the HIV workforce and HIV community suggests that there is widespread awareness and understanding among this group about the practice of mandatory names-based surveillance for new cases of HIV. Immersion in the discursive milieu of the HIV world made this apparent. People living with HIV and practitioners at all levels know that the names of individuals living with HIV are reported to health departments upon initial diagnosis. This is in part because the need to report new cases is communicated widely and repeatedly to healthcare providers and prevention staff. Anyone who is tasked with administering HIV tests also receives some level of instruction that any new case must be reported to the health department using a paper or electronic Case Report Form. Fully implemented in the United States since 2008, so-called “names-based HIV surveillance” is the bedrock from which all future developments in HIV surveillance have been built.[40]

However, despite widespread knowledge of the HIV Care Continuum as a framework for managing HIV disease, there is far less awareness and understanding among the HIV workforce about the continuous monitoring of patterns of engagement in medical care and levels of HIV virus in the blood of individuals living with HIV by state-based HIV surveillance systems. This is at least in part because widespread workforce education has not been required to successfully implement ELR reporting. Rather, ELR reporting is done in an automated fashion by testing laboratories, rather than by healthcare providers or public health staff directly, and thus does not require workforce education as widespread as the need to report newly-diagnosed cases of HIV.

As discussed previously in the discussion of the HIV Care Continuum, ELR-based reporting of regular HIV bloodwork has moved forward in all HIV Surveillance Systems in the United States since 2013, following the issuance of a "Dear Colleague" letter from CDC to state HIV surveillance offices. Since the launch of the HIV Care Continuum Initiative in 2103, all state HIV surveillance systems have been required to continuously gather and report a range of key data elements on people living with HIV within their state's borders using ELR technologies, although many jurisdictions had been doing this work independently for some years prior.[41] These ELR bloodwork data – with a particular emphasis on viral load and patterns of engagement in medical care – are the data referred to in prior sections, which state HIV surveillance systems receive from every individual sample of HIV-related bloodwork that is drawn in the state, when people living with HIV receive medical care.

From the perspective of surveillance and planning, ELR data are the basis for actualizing sanguine narratives such as the HIV Care Continuum, for determining which individuals are "out of care" and require re-linkage, and for determining how close a jurisdiction is to "Ending AIDS." I refer the reader again to Figure 5.2, which shows the metropolitan Atlanta HIV Care Continuum using 2015 data. Numbers in each bar of the bar graph are generated using ELR data, to determine the number of people who fall into each category – "diagnosed," "linked," "engaged," "retained," "virally suppressed," and "virally suppressed among retained" – in the 20-county area around Atlanta served by the Fulton County Ryan White program. I will present the bar graph data from Figure 5.2 in a different way, to revisit and reconsider the numbers –

both regarding what those numbers mean about the HIV/AIDS epidemic in Atlanta, but also to consider what these data objects are and where these data come from.[42]

- **Diagnosed with HIV**: 100%, of known people living with HIV, not inclusive of undiagnosed cases of HIV
- **Linked**: 74%, the percentage of people newly diagnosed with HIV during 2015 who reported bloodwork within 30 days of their initial diagnosis through ELR reports
- **Engaged**: 61%, the percentage of people living with HIV in the Atlanta metro area who have had at least one laboratory test result reported in the past 12 months
- **Retained**: 46%, the percentage of people living with HIV in the Atlanta metro area who have reported two or more laboratory test results in the past 12 months
- **Virally Suppressed**: 49%, the percentage of people living with HIV in the Atlanta metro area who are virally suppressed, indicating both good health and that they are "undetectable" and thus non-infectious
- **Virally Suppressed Among Retained**: 85%, the percentage of people living with HIV in Atlanta who have been retained in care (two or more lab reports in the past 12 months) and are virally suppressed, indicating both good health and that they are "undetectable" and thus non-infectious

On the one hand, these number show just how powerful and precise HIV surveillance systems are in monitoring local epidemics, and the power of antiretroviral therapies to control HIV virus. On the other hand, they also show the depths of the active AIDS crisis in Atlanta, which reflects national statistics: only around half of people diagnosed with HIV are retained in consistent medical care and virally suppressed. Infrastructures exist to monitor the epidemic, and as I will demonstrate, to link these monitoring infrastructures to ones designed to identify and re-link individuals who are not in care. However, infrastructures adequate to provide the requisite care for people living with HIV to meet domestic 2020 benchmarks currently do not exist in the United States, despite some advocates' insistence.[43]

The most recent federal plan to "End the HIV Epidemic" in the United States, released in early 2019, pushes the goal to 2030 and emphasizes an approach that employs more precise surveillance and re-linkage methods in "hot spots" under the rubric of "Diagnose, Treat, Protect, and Respond," rather than expanded healthcare coverage and social services. The plan has been met with significant skepticism by some HIV/AIDS advocates and practitioners, while others have embraced it.[44] While the strategy's efficacy has yet to be tested, it indicates that the U.S. response to ending HIV will continue to rely on more precise methods of surveillance as its primary aim for the time being, rather than an alternative approach such as the broad-based expansion of healthcare and social safety net infrastructures.

The HIV Care Continuum Initiative and its Far Reach, 2013-Present

The HIV Care Continuum framework was originally proposed by Gardner and colleagues in a 2011 article in *Clinical Infectious Diseases*, which is the official citational starting point for the HIV Care Continuum Initiative and for its further development in the biomedical and public health literatures.[45] It was initially called the "cascade." Since that time, and following directly from this publication, nearly all activity in the management of HV disease globally has reoriented itself around the Care Continuum. In the U.S., this process accelerated following the establishment of the HIV Care Continuum Initiative in 2013 via executive order by the Obama White House and the incorporation of the Care Continuum into PEPFAR grantee requirements and *NHAS 2020*.[46]

PEPFAR requirements are agenda-setting for global HIV priorities. Therefore, in addition to being a framework for governing HIV that has fundamentally reshaped the domestic response to HIV, the HIV Care Continuum is a project that aims to support the United States' global through "health diplomacy."[47] It is what international political communication scholar Robert

Entman calls a "projection of power"[48] in U.S. foreign policy, and a critical mechanism in sustaining the United States' position as the global health governance hegemon and – in the parlance of global public health actors such as the International AIDS Society – the world's primary HIV "donor nation."[49] I underscore this again to note that it is hard to overstate the intensity with which the HIV Care Continuum has become the dominant narrative in nearly every context where HIV disease is managed, at every conceivable scale, and with very far reach. This is as true for individual patients' management of their own HIV and doctors or clinics assessing health outcomes of their patients as it is for entire countries, local jurisdictions, and global public health agencies.[50]

Data to Care, 2014-Present: "Using HIV Surveillance Data to Support the HIV Care Continuum"

While some jurisdictions began linking person-level HIV surveillance data to HIV prevention efforts and infrastructures earlier, as a discourse and a programmatic funding stream supported by HHS, "Data to Care" first appeared in 2014.[51] Data to Care is the bedrock that drives uses of surveillance data for re-linkage. On a website called "Effective Interventions" operated by private contractors and CDC, CDC hosts a "Data to Care Toolkit" and "Data to Care Program Guidance." These documents direct state and local departments of public health about how to use HIV surveillance data to identify individuals who appear not to be retained in HIV-related medical care (and/or who are not virally suppressed), to build "not in care" lists, and then to send these lists to public health prevention programs in order to effectuate re-linkage to care. The document called "Data to Care Program Guidance: Using HIV Surveillance Data to Support the HIV Care Continuum" describes this process in four "Basic Steps for Data to Care":

> STEP 1: **Identify persons out of care or not virally suppressed**
> - Create a presumptive list for follow-up (e.g. not in care(NIC) [*sic*] list or not virally suppressed using:

    - Surveillance data
    - Linked surveillance and provider data

STEP 2: **Refine list by matching with available data sources**

- Examples include (but are not limited to):
    - HIV Partner Services, STD Surveillance, State Medicaid, Department of Motor Vehicle for locating information
    - AIDS Drug assistance program (ADAP), Ryan White Care Database or EMR/clinic data for care status and other info
    - Vital statistics, Social Security Death index for death information

STEP 3: **Conduct follow-up**

- Health Department Model – Health department-initiated linkage and re-engagement outreach (partner services, case management)
- Healthcare Provider Model – Healthcare provider-initiated linkage and re-engagement outreach
- Combination Health Department/Healthcare Provider Model

STEP 4: **Monitor continuum of care**

- Feedback loop to surveillance
- Surveillance data used for analysis
- Data driven planning, monitoring, and evaluation[52]

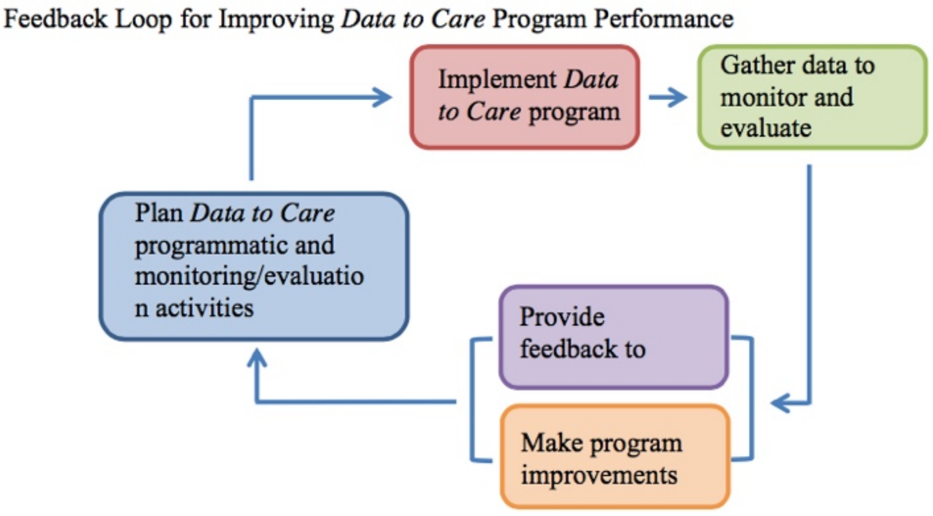
(emphasis in original)

Moving from steps one to four, this guidance describes how health department personnel can build lists of individual people living with HIV who have been identified as out of care or not virally suppressed, using the HIV Care Continuum as a framework and ELR surveillance data as the primary source of information. Then, it instructs health department staff on how to enhance these lists using sources of data such as Ryan White care data, Medicaid EHR data, and even "Department of Motor Vehicle" databases to make individuals easier to locate and re-link. The technical guidance provides health department prevention program-driven and healthcare provider-driven strategies to contact individuals on these lists and re-link them to care. Once care is re-initiated – measured by the receipt of HIV-related bloodwork by the state HIV surveillance office – the "feedback loop to surveillance" is re-initiated.

These four steps are what I call a "sanguine framework" for managing HIV disease, rooted in the hope of successful re-linkage by utilizing new technologies to identify those not receiving services, link them to providers, monitor their progress, and ideally to keep them in care for the remainder of their life. In the next chapter, I describe the State of Georgia's Data to Care program. The state Department of Public Health utilizes what the CDC "Data to Care Program Guidance" document calls a "Combination Health Department/Healthcare Provider Model" to conduct re-linkage outreach to individuals placed on the state's "Out of Care Watchlist" (OWL). The State of Georgia's process essentially mirrors the steps laid out by CDC, with the usual local variability and particularity in style of implementation.

To explore this process in another way, the following diagram from a document called the "Data to Care Toolkit" show how CDC instructs health departments to construct NIC lists, and then to act on these to re-link people to care, thus actualizing the feedback loop between surveillance, public health, and clinical infrastructures. This diagram is simply a visual representation of the four stages outlined above and is another way into understanding what Data to Care is and how it is implemented.

Figure 5.4. The Data to Care "Feedback Loop" from the "Data to Care Toolkit"[53]



Data to Care programs are literal enactments of what Ian Hacking calls the “looping effects of human kind.”[\54] They create new subject-positions and codify these at the level of infrastructure (e.g. “in care” vs. “not in care”).

The documents that describe the creation of these loops show how sanguine frameworks used to govern HIV create a series of closed systems from which people living with HIV cannot opt out. The “feedback loop to surveillance” from public health prevention systems designed to re-link people living with HIV to care is one such closed system. However, as Figure 5.3 shows, HIV surveillance is itself a closed loop in the era of continuous ELR reporting. For the operators of these infrastructures, these are loops of digital labor or what Martin French calls “informatic practice.”[55] The systems that sustain the loops must be kept firmly in place, operational, and constantly becoming better and more precise. The Data to Care Toolkit says: “[conduct] quality assurance activities to improve program operation and efficiency,” and “Implement *Data to Care*…gather data to monitor and evaluate…provide feedback to/make program improvements…Plan *Data to Care* programmatic and monitoring/evaluation activities.”[56] Since 2018, surveillance data do not only include CD4-T cell count and viral load, but also molecular data that facilitate new forms of cluster-tracing, transmission network making, and other more precise surveillance of movements of specific strains of HIV within populations of people living with the virus.[57] As a practice, HIV surveillance has historically only become more precise, exacting, and now increasingly linked to other health data and public health prevention infrastructures.

The ways by which federal policies governing the management of HIV data have developed since the released of the *National HIV/AIDS Strategy* and the accompanying rollout of the HIV Care Continuum Initiative and Data to Care paradigm in HIV prevention demonstrates a concept that I call “infrastructural creep,” which I delineate in the next section. This concept describes how data infrastructures generally, and specifically in HIV, tend to expand to take in more data and to take on more functions than they were originally intended. This is especially true in contemporary U.S. healthcare, as the nationwide interoperable health IT infrastructure expands, making it easier to link datasets and infrastructures to one another that were formerly separate and distinct.[58] The central administration of HIV care, prevention, and surveillance infrastructures by CDC and HRSA has made the process of linkage across domains of practice particularly easy in the provision of HIV services and construction of new programs aimed at ending the epidemic.

III. Infrastructural Creep

Building on the infrastructure studies literature and the notion of “mission creep” – which originated in military discourses but has since itself creeped into other literatures – I describe what I call “infrastructural creep:” the process by which infrastructures slowly expand beyond their initial purview and into other areas. Infrastructural creep captures developments whereby sociotechnical systems morph and encroach into new territories, often with little transparency, meaningful consensus-seeking, oversight by those affected, or even overt decision-making by key parties involved in effectuating the enlargement of a particular infrastructure. The increasingly common practice of linking HIV data infrastructures and organizational operations from the clinical, surveillance, prevention, research, and other domains of HIV practice is an ideal case study to elaborate the concept of infrastructural creep. I present it primarily as a contribution to infrastructure studies and data studies, but also to describe how HIV infrastructures in the U.S. which were formerly separate have become further interwoven at the organizational and technical levels.

From “Organizing for Ontological Change” in HIV/AIDS Research to “Anticipating Ontological Change” in the Administration of HIV/AIDS Programs

Writing about the organizational and informational management practices of HIV/AIDS researchers, David Ribes and Jessica Beth Polk examine how the long-running Multicenter AIDS Cohort Study (MACS) has built processes that they argue constitute a kind of “organizing for ontological change.” For Ribes and Polk, this turn-of-phrase means that MACS practitioners have built the “kernel of an AIDS research infrastructure:” an apparatus that is constituted by workflow processes, physical sample storage procedures, data capture and exchange protocols, and modes of conceptualizing HIV virus that are both shaped by current knowledge about HIV/AIDS and – critically – designed to anticipate changes in basic HIV science that affect how the virus is studied, how medications are developed, what the HIV/AIDS research agenda is, and how the epidemic is managed.[59]

Ribes and Polk borrow the notion of a “kernel” from computer science: the very core of a piece of software onto which additional layers are built as it is changed and developed over the course of time. Software kernels, once developed, generally do not change. Software kernels are vectors through which change takes place and upon which change occurs as programs grow and are further developed by those who maintain and update them. The Windows operating system is an example that will be familiar to most readers: Windows 95 (released in 1995) and Windows 10 (released in 2015) have the same kernel.

Just as new health IT systems and EHR data have expanded the reach of clinical care data to the fields of HIV surveillance and research, new paradigms in the management of HIV that I examine in this chapter show that this logic of “organizing for ontological change” in HIV research also extends to the experience of managing HIV/AIDS in the world as a public health problem. Periodically, some innovation or combination of advances precipitates a revolution in

HIV treatment, prevention, treatment-as-prevention, and/or the general approach to managing the epidemic.[60] The invention of safer sex practices in the early 1980s was arguably one such revolution. It was followed by the introduction of what was then called "Highly Active Antiretroviral Therapy" in 1996 (now simply called "antiretroviral therapy"), which rapidly turned HIV into a "chronic manageable illness" for people able to continuously access medical care. The introduction of names-based HIV surveillance in all jurisdictions in United States by 2008 was arguably another such revolution in the management of HIV. Other periodizations and revolutions could certainly be drawn from the archive of HIV/AIDS.

However, HIV infrastructures built to govern the virus using the HIV Care Continuum since 2013 clearly constitute another such revolution in HIV practice. The sanguine frameworks for governing HIV that have followed from the proliferation of the Care Continuum (90/90/90, "Ending AIDS," et cetera) have been widely adopted with the express purpose of facilitating the construction of programs of management around current biomedical science about Treatment as Prevention (TasP) and existing technologies available to measure and treat HIV at the individual and population levels. This is the just latest in a series of historical evolutions in the governance of HIV, and the history of HIV/AIDS shows that the sociotechnical and biopharmaceutical means to control HIV virus, people living with HIV, and (to quote HIV/AIDS scholar Kane Race) "the problem of HIV" as an individual and public health issue will eventually change again.[61] This will take place in ways that can and cannot be foreseen. As I have discussed, another era is presently dawning as molecular HIV surveillance technologies are being more systematically deployed in states to facilitate new HIV "cluster tracing" methods.[62]

Drawing on nearly four decades of working and living with the problem of HIV, HIV practitioners in public health are used to organizing around ontological change. To wit, the molecular modality of governing HIV is written into the document that facilitated the creation of the HIV Care Continuum and Data to Care model in the United States. The 2013 "Dear Colleague" letter that provided ELR guidance to states says that "[in] addition" to regularly monitoring viral load and CD4-T cell counts, states could begin

> reporting of HIV-1 nucleotide sequences from genotypic resistance testing…to monitor prevalence of antiretroviral drug resistance, and HIV genetic diversity subtypes and transmission patterns.[63]

Before being rolled out, molecular HIV surveillance (MHS) did not undergo a great deal of public scrutiny or review. Other than a "think tank" of experts on this subject convened in 2017 in Chicago by the HIV nonprofit Project Inform and the NIH-funded Third Coast Center for AIDS Research, limited discussion of the issue in HIV/AIDS journals, and two gatherings in Washington, DC made up of practitioners, most meaningful debate about MHS has taken place *post hoc*, after the methods have been rolled out.[64]

Molecular surveillance is grounded in a standard practice used in HIV care, research, and occasionally in public health contexts, and applied as part of standard surveillance operations: the application of genetic tests to individuals' blood to determine the specific strain or strains of HIV virus that they have in their circulatory system. In clinical and research contexts, this sort of testing has a variety of practical functions, such as helping providers prescribe patients the correct antiretroviral medications based on the resistance present in an individual's HIV, or to screen research subjects based on what medications their HIV is likely to resist (many clinical trials, for example, require research subjects with "naïve" virus that has never been treated). In the public health context, molecular testing has been shown to have some value when applied on a small scale. For example, the identification of "clusters" during so-called "outbreaks" of HIV in isolated geographic areas has assisted several public health departments in stopping the spread of particular strains. The most prominent such example was a 2015 event in Indiana during which a community of intravenous drug users shared needles and caused seroconversions within that population.[65] However, other uses of molecular surveillance methods are rapidly emerging and being reported on in academic and journalistic publications, including for conditions other than HIV, such as hepatitis C.[66]

The application of these molecular techniques and public health responses in contexts like these are an example of how infrastructures grow, creep outward, and take on new functions. Specifically, this example shows how the use of surveillance data to identify individuals “not in care” in the “Data to Care” paradigm is transmuting into the use of molecular surveillance data to identify pathways through which specific strains of virus move in a geographic area.

This kind of infrastructural creep in HIV practice has raised alarm bells among advocates. While the value of genetic testing is eminently clear in the clinical context, the value of molecular data to public health practice is far less clear when weighed against concerns related to individual privacy and the criminalization of HIV. The potential misuses of molecular surveillance technologies in contexts such as criminal trials are apparent even to experts who are enthusiastic about molecular surveillance as a public health strategy, and claims about how molecular surveillance can and cannot – or ought or ought not – be used are rife with contradictions and are constantly shifting. For example, at the 2018 International AIDS Conference, a group of experts released a consensus statement on uses of genetic HIV data in criminal cases that echoed the findings of the 2017 Project Inform think tank report. This letter argues that molecular HIV surveillance is a valuable tool for tracing the emergence of clusters and stopping the spread of HIV within transmission networks, but that current technologies cannot determine the directionality of transmission from one specific individual to another. The letter states that

> Recent advances in DNA sequencing and phylogenetics allow some consideration of direction and timing of transmission, but these methods are currently neither precise nor accurate enough to prove who infected whom. This is partly because there may always be unknown and undiagnosed individuals from the transmission network. Consequently, currently phylogenetic analysis cannot eliminate the possibilities that the complainant infected the defendant, that both were infected by a third party, or more complex scenarios of transmission that have resulted in the defendant and complainant having HIV variants that are epidemiologically linked. The fact that having HIV does not protect against a subsequent "super"-infection with a different variant adds complexity. In particular, confidence about the direction of infection is undermined when a defendant and complainant have engaged in numerous sexual acts which may have facilitated multiple transmission events back and forth.[67]

This seems to be a statement that closes the door to the use of phylogenetic HIV data in the context of judicial proceedings or forensic contexts. However, a key section of this same statement concludes with the claim that while "phylogenetic analysis alone cannot prove beyond reasonable doubt that one person infected another…it can be used to exonerate a defendant."[68] Unwittingly, in closing the door to forensic uses of molecular HIV data, this group of medical signatories have also opened new doors that encourage this practice. In the hands of police, prosecutors, public health authorities, and others vested with power who are not educated on the finer points of phylogenetic analysis of HIV data samples, highly technical arguments about directionality of transmission not being discernible using current methods are ripe for misunderstanding and/or misuse – a fact which some U.S. and Canadian advocates have recently noted.[69] Further, phylogenetic testing methods used to identify particular strains of HIV will themselves evolve in time, and, following the empirically demonstrable historical trajectory of HIV surveillance and science toward greater accuracy, are likely to become even more precise in the future. As advocates have pointed out, a future where directionality of transmission from one individual to another can be discerned through genetic testing methods cannot be discounted, and is even likely.[70] Such a future would raise a new round of issues about individuals' privacy and health information than do current methods.

In this context of confusion, complexity, and the adoption of new technologies, states are implementing genetic testing and cluster tracing as part of regular HIV surveillance, public health intervention, and “Data to Care” programs. In materializing molecular HIV surveillance strategies, it is increasingly likely that these tools will be applied more frequently and that their uses will be expanded. This is not a claim rooted in some kind of technological determinism, but a prediction that follows from empirically observable patterns of infrastructural development in the history of HIV and uses of HIV data in the United States.

The history and contemporary evolution of the governance of HIV shows how infrastructures built to manage HIV as an individual and collective problem tend to expand, take on more functions, and operate with greater precision. Since the development of these infrastructures began, they have consistently and regularly creeped outward from their original domains. On this point, the aim of HIV surveillance programs (data from which now also increasingly inform prevention efforts) is no longer just to identify individuals living with HIV, but to discern their patterns of engagement in care and the levels of virus in their blood (as measured using the HIV Care Continuum) and the genetic makeup of the contents of the specific strain(s) of HIV that they carry in their blood. What was once an epidemiological tool (HIV surveillance) intended for monitoring purposes and intentionally sequestered from other sources of data has, over the course of decades, turned into something very different. The course of HIV data and their usage is an apt demonstration of the concept of infrastructural creep, which I believe will be useful for infrastructure studies scholars working in other contexts, and which I finish developing in the following sections of this chapter.

Unseen Infrastructural Development: From “Infrastructuring” to “Infrastructural Creep”

Building on seminal works in infrastructure studies by Geoffrey Bowker and Susan Leigh Star and others, Volkmar Pipek and Voler Wolf describe the process of “infrastructuring,” which they develop as “a more comprehensive term for the creative design activities of professional designers and users” of infrastructures.[71] In the framework of “infrastructuring,” infrastructure is conceptualized not as an object of analysis but as a multi-relational and reflexive network of things-in-process. In a similar vein, David Ribes and Thomas A. Finholt propose “the long now of infrastructure,” which they frame “as an organizing principle for analyzing the work of planning and sustaining infrastructure,” the scope of which goes “beyond…any single project or discipline.”[72] Ribes and Finholt also emphasize “[the] long now” of infrastructure to “[encourage] a consideration of how today’s planning will *effect* tomorrow’s technologies through the practical work of designing, (re)constructing, and then maintaining these systems.”[73]

These and other scholars working in infrastructure studies emphasize that infrastructures are not stable objects of analysis, but are always assemblages of multiple entities, people, and phenomena that are becoming something different: infrastructures are constantly expanding, contracting, and changing their composition to adapt to their contexts and objects. Their classification schemas mutate (as my exploration of the “HIV risk hierarchy” in the first chapter demonstrates), the objects they are designed to manage change in their material or conceptual constitution (as basic knowledge about HIV has changed), the legal frameworks for administering infrastructures changes (as Data to Care has ushered in a new era of “re-linkage” and as the molecular paradigm emerges), software updates alter infrastructures’ functionality, new techniques are applied at different scales, and old ones are abandoned. The constitution of an infrastructure transmutes in a multiplicity of ways during its existence and even day-to-day. Processes of infrastructuring encompass how infrastructures expand, contract, and change, but also how they swallow up, become a part of, or are plugged into other infrastructures as they develop. Bowker and Star note that, in an infrastructure "…each sub-system inherits, increasingly as it scales up, the inertia of the installed base of systems that have come before" and that new infrastructures are "built on an installed base" of previously-constructed ones.[74]

Infrastructuring is on full display in the historical development of HIV surveillance and new uses of HIV surveillance data, wherein surveillance data originally intended exclusively for monitoring the epidemic and planning the general response at the national and jurisdictional levels are now linked to many other clinical and public health prevention infrastructures and are proactively used for re-linkage-to-care efforts. In the "treatment as prevention" era, these developments are framed not only as beneficial to people living with HIV whose health would benefit from treatment, but equally or more so to HIV-negative people who could potentially seroconvert following a sexual encounter with a person living with HIV who is not in treatment. To accomplish the maximal use of HIV data infrastructures to drive up rates of viral suppression, it has not only been necessary for HIV surveillance infrastructures to expand intrinsically. Rather, HIV data infrastructures in the clinical domain and the prevention domain have all had to be restructured to take in more data, to perform more functions than they were originally intended, and to be linked to HIV surveillance data infrastructures in new ways. Clinical electronic health records (EHRs) and laboratory reporting systems have had to assume interoperability functions that they did not have before, or have had to play an increasingly large number of roles as sanguine frameworks for managing HIV disease have advanced. Organizationally speaking, health departments, clinical organizations, and laboratories have had to collaborate, building human and technical means to achieve ends set out for them in HHS policies and programs such as the HIV Care Continuum, Data to Care, and molecular HIV surveillance.

This is infrastructural creep at work. My use of “creep” is informed by the literature on “mission creep” in military studies, a critical term which itself has creeped beyond studies of the military to fields such as the nonprofit sector and higher education.[75] Mission creep has no single definition, but is generally characterized as the expansion of an operation, project, or entity into territories beyond its initial purview or mandate. I propose infrastructural creep following observations of infrastructural creep in the HIV and public health contexts; however, it is also intended to be a general contribution to the fields of infrastructure studies and data studies. Infrastructural creep can happen quickly, like the swift expansion of a military operation into a previously-unauthorized zone, or gradually over time, such as Kudzu vines overtaking a wooded area. The original use of “mission creep” in this way is traceable to former Secretary of Defense Robert Gates’ description of the steady militarization of U.S. foreign policy since 9/11, for example, in CIA uses of drone technologies (the militaristic use of a military technology by a non-military agency).[76]

Infrastructural creep in the development of HIV data infrastructures are not limited to new uses of surveillance data, or even the linking up of surveillance infrastructures to clinical and prevention systems. New EHR technologies and interoperability standards are also facilitating the creation of new classes of health research databases that utilize EHR data for secondary research purposes. A major field site in Atlanta, for example, is the lead entity in the creation of one such “HIV disease registry” that aggregates patient EHR data from multiple sites in the metro area in order to produce research outputs based on patients’ clinical medical records. Websites such as AIDSVu.org – a project housed at Emory University in Atlanta – aggregates surveillance data reported to CDC by states to create interactive maps which are used by a wide variety of stakeholders in planning efforts, generating epidemiological profiles, and conducting basic research. It is unclear what percentage people living with HIV are aware that their health data are being used in this fashion, but my fieldwork data suggest that it is very small. I return to bioethical issues raised by these developments in the conclusion of the next chapter.

Siloed Labor and Infrastructural Creep

Infrastructural creep is often dependent on siloed labor practices. In siloed labor, individuals, teams, divisions of organizations, or even entire communities of practice perform one or more specific, designated functions within the disaggregated sociotechnical assemblages that collectively give an infrastructure form and function. However, laboring in silos, these actors – by design or otherwise – do their work without being afforded the opportunity to see or develop an understanding of the constitutive elements of the whole infrastructure of which they are administering one part. This makes the exact nature of the labor performed by other actors in these networks, or even the function of an individual’s own role beyond the immediate scope of performing a prescribed set of tasks, difficult for actors to see. This is as true for doctors as it is for data entry staff or testing personnel, all of whom play equally critical roles in sustaining the existence of various HIV infrastructures, but many of whom do not know how their labor is contributing to other parts of the HIV data milieus in which they are situated (for example, how keying in an order for an HIV bloodwork test also feeds data into the state’s HIV surveillance system).

In HIV, the existence of siloed labor is attributable to the fact that the HIV sector has not made it a priority to ensure that all actors in the space – including people living with HIV who are not HIV professionals – are informed and educated about the full scope of HIV surveillance and other HIV data infrastructures. Working within slightly-overlapping silos, even high-ranking HIV workers execute tasks that are extremely disconnected from the situated realities that those actions bring into existence: for example, in the manner by which HIV surveillance personnel send data on individuals identified as out of care to public health prevention personnel without much meaningful collaboration beyond the transmission of the list. I explore this specific example in greater detail in the following chapter, in my explanation of the State of Georgia's HIV Data to Care strategy and how surveillance personnel imagine the distribution of the state's Out of Care Watchlist (OWL) versus how it is utilized in practice. I compare surveillance professionals' descriptions of their labor working with the OWL to those of personnel who work with the list during the course of its distribution around the state. Each actor has their own understanding of how the overall infrastructure is built and operated that is informed by their own disciplinary training and the silo or silos in which they work. This leads to people who work in different domains each only possessing a partial understanding of the whole.

Noting that people who work in different domains of HIV practice operate in silos from one another is not an indictment of the HIV workforce. In fact, high degrees of specialization mean that most HIV professionals benefit from what Donna Haraway calls "the privilege of partial perspective" in their work.[77] HIV workers who perform specific functions – from data entry and quality assurance to providing primary care services – understand the problems and potentials of their area of practice intimately, even if they cannot always place their role and function within the broader schematic of HIV work. However, noting the benefits of specialization does not discount the fact that conditions of siloed labor are ideal for fostering infrastructural creep. Further, siloed labor is a function of information control and discretionary educational practices by those who manage HIV infrastructures and provide continuing education to the HIV workforce.

The same characteristics that make HIV infrastructures ideal cases to study for scholars of health IT interested in interoperability are also those which lead to labor within different domains of practice siloed from one another. That is to say, the siloing of labor within domains of HIV work is at least in part attributable to the fact that HIV infrastructures are the product of a kind of top-down bureaucratic control, wherein directives are issued by the White House, CDC, and/or the Health Resources and Services Administration (HRSA) in the form of executive orders, technical guidance, or “Dear Colleague” letters, which are then executed by state and local bureaucrats (who in turn exercise a kind of informational control over those beneath them) with partial oversight from these federal agencies and semi-official private organizations such as the Council of State and Territorial Epidemiologists (CSTE), The National Alliance of State and Territorial AIDS Directors (NASTAD), and the National Coalition of STD Directors (NCSD). This structure ensures a high degree of control over the kinds of information that are imparted to those “lower” on organizational hierarchies by higher-level managers, and of what information is regularly exchanged between domains of practice (for example, how often HIV surveillance personnel and HIV prevention personnel meaningfully interface with one another beyond the transmission of lists from one domain to the other).

Working with members of the HIV workforce, people living with HIV, and HIV advocates in Georgia over the course of two years showed me that, when the full functionality and scope of HIV data infrastructures are revealed to those who administer them, many are given a degree of pause, taken aback, or are evidently surprised to learn that they are playing a role in the operation of infrastructures that (at first blush) seem quite attenuated from the work that they do. This is most clear in discussion and presentations I have given about the state's Out of Care Watchlist (OWL) and Data to Care strategy, which are the subject of the next chapter.

In HIV, infrastructural creep has been hastened by the fact that federal infrastructures are managed by relatively small communities of practice. The expansion of HIV surveillance practices and uses of HIV data has taken place with little transparency or input from people living with HIV. Rather, professionals at public health agencies and biomedical researchers have generally moved forward with changes in the surveillance infrastructure using their expertise, and without meaningfully involving people living with HIV/AIDS. In the United States, the nonprofit group Project Inform has convened two "think tanks" that brought together experts to discuss new uses of HIV surveillance data: a 2012 meeting of experts on what would, two years later, be called "Data to Care," and a 2017 meeting of experts on new "molecular surveillance" practices, each of which resulted in a report.[78] However, beyond these forums and discussions among practitioners and select bioethicists, the U.S. HIV community has moved forward with the expansion of uses of surveillance data and other kinds of HIV data without systematic input from, or efforts to educate and inform, people living with HIV or the full HIV workforce. This is a fieldwork finding that that stems from conversations with practitioners and activists, many of whom – despite being experts in their subject-matter areas – had limited understandings of HIV surveillance policy and new uses of HIV data before I spoke to them.

Even advocates who have historically been critics of HIV data infrastructures' creep into new territories have taken on active role in the expansion of these systems during fourth decade of the HIV epidemic. The following conversation with Jeff Graham, Executive Director of Georgia Equality, shows how Graham and a prominent physician with whom he has worked closely since the early years of the AIDS epidemic went from being two of the final hold-outs against names-based HIV case reporting (on privacy grounds) to becoming leaders in the development of new HIV data infrastructures in Georgia.

> **Jeff Graham, Executive Director of Georgia Equality, former Executive Director of the AIDS Survival Project**: Georgia Equality, I'm pretty sure, supported the position of the HIV community when we fought against names reporting for HIV surveillance data in Georgia...We fought with the state of Georgia... I believe the first time that they had proposed doing names reporting was; ‘92 or ‘93. Probably ‘92; ‘91 or ‘92…then it hit another cycle in ‘99, ‘cause that's when the CDC started to mandate that there had to be reporting of HIV cases. ‘Cause [surveillance] was just [conducted for cases of] AIDS before that. And so, we had another big battle that was like ‘99, 2000. And then, Georgia finally created the surveillance system around HIV in 2004…Everywhere is names reporting, but Georgia was the last state.
>
> **SM**: Oh, really?
>
> **Graham**: Mm-hmm [cheerfully]. Last state to adopt it. Last state to adopt HIV reporting. There were seven states that were doing HIV reporting by some confidential marker system, outside of names, and it was I think 2006 that the CDC finally said, “No, it all has to be names.” But Georgia was last because we fought it – – [laughter] – – frankly, until the world shifted, and suddenly there was no longer a "We." It was a Jeff Graham and [a prominent HV physician in Georgia]. [laughter]
>
> And everybody else was like, “No, we're fine with names.” It's like, “Okay. Well, if everybody is fine with names, we're going to stop fighting it.” [laughter]

Graham’s comments are a key example of how HIV advocates can become agents of infrastructural creep, even if they actively resist it in specific instances. In this case, Graham and his colleague yielded to consensus on the question of names-based reporting in the 2000s. However, several years later in the mid-2010s, they would both serve on the Legal Ethical Workgroup that approved the state’s HIV Health Information Exchange – a key data infrastructure in the state’s Data to Care strategy that is used to distribute the Out of Care Watchlist and to proactively disclose individuals’ HIV-positive and “out of care” status to medical providers using surveillance data. The Georgia HIV HIE Legal Ethical workgroup gave the Department of Public Health the go-ahead to lobby for the passage of a state law in 2014 that allowed the HIV HIE to be constructed by proactively allowing the state department of public health to disclose individuals' HIV status to clinicians, as I explain in greater detail in the next chapter.

The sanguine promise of the HIV Care Continuum and the End of AIDS, which new powerful and precise surveillance infrastructures connected to re-linkage programs say they will deliver, is an evidently seductive framework for governing HIV. This is true, even for those who tend to be skeptical and vigilant about protecting the privacy, confidentiality, and autonomy of people living with HIV. However, as infrastructures creep, consensus around their development can also shift. As knowledge about Data to Care and molecular surveillance initiatives have moved ahead, a cohort of advocates have begun to question both the efficacy of these methods and their implications for the rights of people living with HIV.[79] In this territory, new lines of contestation are actively being drawn.

IV. Conclusion

In *Socialising the Biomedical Turn in HIV Prevention*, Susan Kippax and Niamh Stephenson provide a useful periodization of how the epidemic has been managed from the viewpoint of biomedical governance. The authors note several transmutations that have oscillated between centering demographic groups and centering individual practices: from a model in the very early 1980s that emphasized the social behaviors of particular kinds of people (gay men) who were dying of a set of conditions that would normally be fended off by a healthy immune system, to a strategy that more thoroughly socialized risk by targeting an expanding list of "risk groups" for behavioral change after the HIV test became available in 1985 (this list of "risk groups" would eventually expand into the "HIV risk hierarchy" that I consider in chapter one), and then to a strategy in the 1990s that re-individualized risk through the so-called "test-and-treat" paradigm after effective treatments became available. This final re-individualization of risk in the late 1990s and early 2000s, however, continued to emphasize behavioral modifications aimed at the moment of the sexual (or needle-sharing) encounter to stop viral transmission, and not on treatment as a mode of prevention.[80]

Writing in 2016, just as knowledge about treatment as an efficacious form of prevention was becoming validated to the satisfaction of large institutions such as UNAIDS, NIH, and CDC, Kippax and Stephenson say that

> [f]ollowing the recent advances regarding TasP, the focus has shifted to HIV-positive people who have not tested, not taken up ART or have not adhered to their treatment regimens. The potential for stigma and discrimination is obvious. The most recent group singled out for admonition are those people who have not been recently tested or tested at all and, hence, may be at risk of unwittingly transmitting HIV: the 'undiagnosed' (Holt, 2014b). In a very important sense the old, contested, epidemiological ways of framing HIV have recently expanded to designate new notions of 'risky' individuals: HIV-positive people who are not starting treatment early are 'non-adherers', or those HIV-positive people who are unaware of their HIV status, the 'undiagnosed'[81]

In what follows, I explain how the trend that Kippax and Stephenson have identified has materialized across scales in the management of the HIV/AIDS epidemic. I turn now to the question of the sanguine narratives of care and responsibility that provide the discursive groundwork around which strategies for governing HIV using the Care Continuum framework and biomedical knowledge about HIV treatment as prevention have been constructed.

Undetectable Equals Untransmittable/U = U

The efficacy of TasP had been known for nearly a decade prior to its incorporation into official policy in 2017 and 2018, although the degree to which treatment worked to prevent HIV transmission was uncertain.[82] In fact, in the Executive Order that launched the National HIV Care Continuum Initiative in 2013, the Obama White House highlighted that "a breakthrough research trial supported by the National Institutes of Health showed that initiating HIV treatment when the immune system was relatively healthy reduced HIV transmission by 96 percent."[83] However, a full-throated endorsement of TasP only became official HHS policy during 2017 and 2018, after 100% efficacy was demonstrated in clinical trials conducted in real-world settings. Following a process of consensus-building process led by the Prevention Access Campaign, on September 27th, 2017 (National Gay Men's HIV/AIDS Awareness Day) a "Dear Colleague" letter on the issue was sent by CDC,[84] and on July 22nd, 2018, at a pre-conference of the International AIDS Conference in Amsterdam, Dr. Anthony Fauci of the NIH affirming HHS's full-throated endorsement of "Undetectable Equals Untransmittable" (U=U) messaging.[85] A similar drama played out during debates over the efficacy of PrEP, which was initially reported to be effective at a rate of around 94%, before subsequent real-world trial demonstrated efficacy above 99%.[86]

The dominant media campaign promoting TasP has been U=U. As a discourse, U=U and TasP have been thoroughly transnationalized and are now the cornerstone of HIV care and planning in many jurisdictions. U=U was featured prominently in Atlanta during the final presentation of the *Fulton Country Strategy to End AIDS* at the Center for Civil and Human Rights in July 2017 and TasP has been the organizing framework for all integrated HIV prevention and care planning activities in Georgia since the state began the integrated planning process in 2016. In my interviews at the Georgia Department of Public Health and with local HIV agencies, "care as prevention, prevention as care," was a drumbeat. One person involved in HIV integrated planning at the state department of public health told me:

> The shift has changed just because now we have integrated the planning council where we can't just stick to prevention, we have to also look at the care aspect, because with [the Georgia Planning and Care Council], our driving force is saying that, "prevention is care; and care is prevention."[87]

More recently, the Terrence Higgins Trust, a major LGBTQ rights and health organization in the United Kingdom, has augmented the U=U discourse with its "Can't Pass It On" campaign, the logo for which many people at the 2018 International AIDS Conference in Amsterdam wore literally as badges of pride on their shirts in the form of a sticker distributed by the organization.

Figure 5.5. "Undetectable = Untransmittable" campaign materials from the George House Trust and the Terrence Higgins Trust, organizations based in the United Kingdom

Advocates and scholars have noted that these discourses create new hierarchies of value and can actually re-stigmatize those who are not retained in care because they face structural barriers to accessing care.[88] Most people can become virally suppressed; however, many cannot. While it is biomedically impossible for some people living with HIV to reach viral suppression, undetectability is more commonly out of reach for individuals for other reasons – not because they do not want to become retained in care and virally suppressed, but because adequate systems are not in place that can ensure they remain in care consistently. Notably, the Fulton County Board of Health has declined to adopt U=U messaging for this reason. Too many structural barriers to accessing consistent care exist in Fulton County for it to have meaningful resonance with the population served by the county's public HIV clinic and HIV prevention apparatus. This of course does not apply to individuals who have access to private insurance or who are stable and can remain in consistent medical care while relying on public health programs and support services such as Ryan White. For many people in these categories, U=U has been transformational. This reality makes messages like U=U both uplifting and hope-giving, but also potentially re-stigmatizing or demoralizing for people living with HIV in places where remaining in care can be incredibly difficult – particularly if one does not have private insurance, if one is poor, or is transient. Undetectability, and thus untransmittability, is not an achievable reality for many people living with HIV, and for entire populations. It therefore plays a role in creating new hierarchies within the broader community of people living with HIV that are only just beginning to take shape, let alone be understood in their full complexity.[89]

In U.S. policy, the creation of new hierarchies around U=U has happened most acutely and concretely in the state of North Carolina, which "modernized" its "HIV control measures" in 2018. The state's HIV control measures are set by administrative departments of the state government and govern when people living with HIV are legally required to disclose their positive serostatus to sexual partners. The reforms enacted in 2018 were organized specifically around the question of detectability and viral load in determining when people living with HIV had to disclose their status to sexual partners. The 2018 control measures create a complicated tiered set of conditions in which people living with HIV must disclose their status to sexual partners and use barrier protection versus when they are permitted not to do so.

A technical assistance letter from the HIV and STD Director of the North Carolina Division of Public Health send to local health departments and HIV care providers describes the new control measures thusly (the letters employs the acronym "PLWH," for "people living with HIV," a common practice in public health that I decline to adopt in my own writing):

1) **PLWH who are in HIV care <u>AND</u> adherent to their HIV clinician's treatment plan <u>AND</u> have been virally suppressed for at least 6 months are no longer legally required to use condoms or notify future sexual partners of their HIV status…**

2) **PLWH who do not meet all three (3) of the criteria outlined in #1 must:**
    a. **Notify all future sex partners of their HIV infection, including partners who are HIV positive or on PrEP**

> b. **Use a condom with all sexual encounters, except when:**
>   i. **Their sex partner is also HIV positive, or**
>   ii. **Their sex partner is taking HIV PrEP as prescribed by an attending clinician**[90]

(emphasis in the original)

The letter includes more instructions, both for people living with HIV and healthcare providers, including that "**All PLWH, whether virally suppressed or not, must NOT…a) Share needles, syringes, or other injection drug related equipment"** or donate blood, tissue or organs, unless as part of a research study.[91] Therefore, the state's HIV control measures and changes to parameters around disclosure are not generalizable to all potential routes of transmission, but only sexual routes. They specifically restructure how the state manages the sexualities of people living with HIV on biomedical terms.

The letter also directs attending clinicians to communicate these control measures to people living with HIV. While the merits and drawbacks of such an approach to HIV in the criminal law and public health approaches to the measurement of HIV are a matter of active contestation by the community of advocates and people living with HIV,[92] it is undeniable that they set up new hierarchies and parameters of acceptable sexual behavior for people living by HIV. These control measures are based primarily on metrics that are central to the HIV Care Continuum, the "achievement" of viral suppression, and universal HIV treatment as the primary mode of HIV prevention. The North Carolina control measures enact a sanguine framework for governing HIV and sexuality in policy – one that can be literally enforced by the state, both as a directive to healthcare providers and health departments and as conditions put upon the sex lives of people living with HIV. These control measures also inform the clinical methods used to manage the health of people living with HIV in the state, as physicians are explicitly told to communicate them to patients. To date, there has been no systematic study of the control measures' effects on providers or patients.

In the next chapter, I show how the frameworks and systems I have described as sanguine strategies for managing HIV in federal policy – the HIV Care Continuum and Data to Care – have been implemented in metropolitan Atlanta and the State of Georgia. The empirical realities that correspond to these new federal frameworks for governing HIV in a specific jurisdiction both concretize many of the issues discussed in this chapter related to the management of HIV data infrastructures in a transformed health IT ecosystem, and raise questions for stakeholders in the realm of HIV policy and practice. Specifically, it raises the question of how HIV stakeholders can best collectively move forward to ensure that the infrastructures and frameworks being built to manage HIV data and the HIV/AIDS epidemic both respect the rights and wellbeing of people living with HIV *and* have maximum effect on bringing the virus under control in the context of a serious and ongoing epidemic. Striking a balance between individual autonomy in medical decision-making and public health is always central to ethical considerations in the construction of programs to manage public health problems. However, my analysis in the next chapter aims to empirically demonstrate that new infrastructures that have been built to manage HIV require systematic reconsideration by a wide array of stakeholders, given the rapid pace at which they have developed, the myriad ways in which they have transformed HIV data and uses of these data, and the effects of these new uses on the privacy, wellbeing, and rights of people living with HIV.

References for Chapter 5

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[1] Barack Obama, "Executive Order -- HIV Care Continuum Initiative" (2013), https://obamawhitehouse.archives.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative.

[2] HIV.gov Staff. "What Is the HIV Care Continuum?" HIV.gov, December 30, 2016. https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum.

[3] Ibid.

[4] See, for example: PEPFAR, "QUALITY STRATEGY Phase I: Institutionalization of Countries' Ability to Improve HIV Clinical Programs (Fiscal Year 2014)," Technical Guidance (Washington, D.C: President's Emergency Plan for AIDS Relief, March 2014), https://www.pepfar.gov/documents/organization/224097.pdf, 5-6, 18.

[5] Colleen F. Kelley et al., "Applying a PrEP Continuum of Care for Men Who Have Sex with Men in Atlanta, Georgia," *Clinical Infectious Diseases* 61, no. 10 (November 15, 2015): 1590–97, https://doi.org/10.1093/cid/civ664. In addition to interviewing members of this team for fieldwork, I also attended presentations by researchers on this project to local community groups.

[6] Don Evans and Nanette Dior Benbow, "Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data" (Chicago, IL: Project Inform and Northwestern University, February 2018), https://www.projectinform.org/surveillance2017/

[7] Whether it is possible to use phylogenetic data to determine the transmission of HIV virus from one person to another is a matter of active contestation in the HIV community. CDC and an international cohort of experts on this topic insist that it not possible using currently available methods. However, some scholars and activists claim that the science behind this statement is immaterial in the hands of over-zealous actors. I explore aspects of this controversy in the pages that follow, but it is not a central focus. See, Françoise Barré-Sinoussi et al., "Expert Consensus Statement on the Science of HIV in the Context of Criminal Law," *Journal of the International AIDS Society* 21, no. 7 (July 2018), https://doi.org/10.1002/jia2.25161.

See also, Don Evans and Nanette Dior Benbow, "Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data"; Alexander McClelland, Adrian Guta, and Marilou Gagnon, "The Rise of Molecular HIV Surveillance: Implications on Consent and Criminalization," *Critical Public Health*, February 20, 2019, 1–7, https://doi.org/10.1080/09581596.2019.1582755; Martha Kempner, "New Study Triggers Concerns Over Use of Molecular HIV Surveillance," *The Body Pro: The Complete HIV/AIDS Resource*, March 4, 2019, http://www.thebodypro.com/content/ 81639/concerns-over-use-of-molecular-hiv-surveillance.html; HIV Prevention Policy Project, "Molecular HIV Surveillance: Engaging HIV Community Stakeholders to Examine the Promise and Risks from the New Technology (Conference Program)," June 14, 2018.

[8] For one prominent example of HHS articulating this priority that specifically references HIV as a class of "sensitive" electronic health information over which patients should have the ability to

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control the exchange, see, Office of the National Coordinator for Health Information Technology (ONC), "Federal Health IT Strategic Plan, 2015-2020" (Washington, D.C.: Office of the Secretary, United States Department of Health and Human Services, 2015), https://www.healthit.gov/sites/default/files/9-5-federalhealthitstratplanfinal_0.pdf, 25.

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[10] Fulton County Ryan White Part A Program. "Fiscal Year 2017 Funding Application Narrative." Fulton County, June 2017. http://www.ryanwhiteatl.org/wp-content/uploads/2016/11/Narrative-FY17-Atlanta-EMA-H89HA00007.pdf, 9.

[11] This finding comes from fieldwork data, specifically interviews with the Fulton County Ryan White leadership team.

[12] On individualizing neoliberal logics in contemporary healthcare and HIV discourse, see, Kane Race, *Pleasure Consuming Medicine: The Queer Politics of Drugs* (Durham, NC: Duke University Press, 2009); Barry D. Adam, "Constructing the Neoliberal Sexual Actor: Responsibility and Care of the Self in the Discourse of Barebackers," *Culture, Health & Sexuality* 7, no. 4 (July 2005): 333–46, https://doi.org/10.1080/13691050500100773.

[13] Lauren Gail Berlant, *Cruel Optimism* (Durham: Duke University Press, 2011), 1 and *passim*; "Sanguineous." *Merriam Webster*, n.d. https://www.merriam-webster.com/dictionary/sanguineous.

[14] Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, NJ: Princeton University Press, 2006), 5-8 specifically, on the molecularization of subjectivity, 9-51 generally, and *passim*.

[15] On "methods assemblage," see, John Law, *After Method: Mess in Social Science Research* (London; New York: Routledge, 2004), 13-14.

[16] In referring to "styles of reasoning" in the history of sexuality, I am referring specifically to Arnold Davidson's use of this framework. See, *The Emergence of Sexuality: Historical Epistemology and the Formation of Concepts*. Cambridge, MA: Harvard University Press, 2004, 1-30 and *passim*.

[17] Gayle Rubin, "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality," in *Deviations: A Gayle Rubin Reader* (Durham: Duke University Press, 2011), 152-3.

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[18] Alex Garner, “Being ‘Undetectable’ Today Is a Privilege. It Needs to Be a Right.,” *Hornet*, March 21, 2019, https://hornet.com/stories/undetectable-status-health-care/?fbclid=IwAR2srfQfn_kaRqsxKXvFJPSVsblxy10WPm7JqJzy3G8ThXwog36V305LapY.

[19] Karen C. Lloyd, “Centring ‘Being Undetectable’ as the New Face of HIV: Transforming Subjectivities via the Discursive Practices of HIV Treatment as Prevention,” *BioSocieties* 13, no. 2 (June 2018): 470–93, https://doi.org/10.1057/s41292-017-0080-1.

[20] See, Emerson Rosenthal, “Nine Inch Nails Fans Get a Hand-Burned Art Book: Artist Russell Mills Made ‘Cargo In The Blood’ to Commemorate His Collaboration with Trent Reznor, Creating 2,000 Limited-Edition Art Books, Each One with Its Own Original Artwork,” *VICE*, March 29, 2016, https://www.vice.com/en_us/article/pgq8bg/nine-inch-nails-cargo-in-the-blood-interview; *Cargo In The Blood*, n.d., https://vimeo.com/148964208.

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[22] UNAIDS. “90-90-90: An Ambitious Treatment Target to Help End the AIDS Epidemic.” Geneva, Switzerland: UNAIDS, October 2014. http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf, 1.

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[24] For example, see, Amy Coopes, “Australian Researchers Declare an End to AIDS as a Public Health Issue,” *BMJ*, July 12, 2016, i3895, https://doi.org/10.1136/bmj.i3895.

[25] Luchuo Engelbert Bain, Clovis Nkoke, and Jean Jacques N Noubiap, “UNAIDS 90–90–90 Targets to End the AIDS Epidemic by 2020 Are Not Realistic: Comment on ‘Can the UNAIDS 90–90–90 Target Be Achieved? A Systematic Analysis of National HIV Treatment Cascades,’” *BMJ Global Health* 2, no. 2 (March 2017): e000227, https://doi.org/10.1136/bmjgh-2016-000227; Sarah Boseley, “Hope for ‘End of AIDS’ Is Disappearing, Experts Warn,” *The Guardian*, July 31, 2016; Jeremiah Johnson, “The Usual Suspects: Common Challenges for End the Epidemic Planning and Implementation in Emerging Jurisdictions,” *The Body Pro*, April 16, 2018, http://www.thebodypro.com/content/80953/the-usual-suspects-common-challenges-for-end-the-e.html.

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http://www.aidsmap.com/Europe-close-to-meeting-UNAIDS-90-90-90-target-but-considerable-variability-between-countries/page/3328577/.

[27] This dissertation falls into the second category. For another example, see, Alexis Shotwell, "'Women Don't Get AIDS, They Just Die from It:' Memory, Classification, and the Campaign to Change the Definition of AIDS," in *Against Purity: Living Ethically in Compromised Times* (Minneapolis: University of Minnesota Press, 2016).

[28] While some local departments of public health operate HIV surveillance systems that are independent of their state's HIV surveillance system (one example is Los Angeles County), the vast majority of HIV surveillance systems are operated by states. Herein, I refer to "state departments of public health" which operate HIV surveillance systems as shorthand for the various state, local, and territorial health departments that operate HIV surveillance systems in the country.

[29] Lawrence O. Gostin, John W. Ward, and A. Cornelius Baker, "National HIV Case Reporting for the United States — A Defining Moment in the History of the Epidemic," *New England Journal of Medicine* 337, no. 16 (October 16, 1997): 1162–67, https://doi.org/10.1056/NEJM199710163371611.

[30] The unevenness of the historical development of HIV surveillance practices makes the rollout of new protocols incredibly difficult to track in real-time or historically. This topic is part of a methodological paper that I am in the early stages of drafting, which is focused on the study of HIV data systems using ethnography, health policy analysis, and STS approaches.

See, Gostin et al., "National HIV Case Reporting for the United States"; Allyn K. Nakashima and Patricia L. Fleming, "HIV/AIDS Surveillance in the United States, 1981-2001," *Journal of Acquired Immune Deficiency Syndromes* 32 Suppl 1 (February 2003): S68-85; Lucia Torian et al., "HIV Surveillance -- United States, 1981-2008," *Morbidity and Mortality Weekly Report* 60, no. 21 (June 3, 2011): 689–93; Stacy M. Cohen et al., "The Status of the National HIV Surveillance System, United States, 2013," *Public Health Reports* 129, no. 4 (July 2014): 335–41, https://doi.org/10.1177/003335491412900408; Hoppe, *Punishing Disease*, 71-72.

See, especially and specifically, the "Commentary" that opens the 2011 *HIV Surveillance Report*, which authoritatively confirms that all jurisdictions with cooperative agreements with CDC had implemented names-based reporting by 2008:

> The 2011 HIV Surveillance Report marks the first time estimated numbers and rates of diagnoses of HIV infection have been included from all 50 states, the District of Columbia, and 6 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands). Because states implemented confidential name-based HIV infection reporting at different times, the displayed data on diagnosed HIV infection begin with data from 2008, the first year that all areas had name-based reporting.

Centers for Disease Control and Prevention, "HIV Surveillance Report, 2011" (Centers for Disease Control, February 2013), https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2011-vol-23.pdfevery, 5.

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[32] Don Evans and Nanette Dior Benbow, "Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data"; CDC, "Technical Guidance for HIV Surveillance Programs," 2013.

[33] I attended at least 10 public presentations by GDPH HIV surveillance staff during my two-and-a-half years of fieldwork in Atlanta beginning in August 2016. The final surveillance presentation I attended during this period was given during at a major annual HIV and STD conference put on by GDPH in October 2018. That presentation detailed how new molecular surveillance methods were being rolled out in Georgia. Georgia was one of the final jurisdictions to implement molecular HIV surveillance. The state has historically lagged behind others implementing new surveillance requirements. In 2003, CDC scientists reported that "As of 2001, all but one state (Georgia) and three territories had passed legislation requiring some form of HIV reporting for adults and adolescents using the same methods as for AIDS surveillance." See, Nakashima and Fleming, "HIV/AIDS Surveillance in the United States, 1981-2001," S77.

This also reflects fieldwork data. One prominent Georgia-based HIV advocate told me that Georgia was "the last state" to implement names-based reporting, and implied that this was at least in part because of his lobbying efforts with other state-based advocates.

[34] CDC, "Technical Guidance for HIV Surveillance Programs." I was allowed to review these documents by a surveillance interlocutor.

[35] A general lack of understanding of HIV surveillance practices among non-specialists was a central fieldwork finding.

[36] Alexander R. Galloway, *The Interface Effect* (Cambridge, UK; Malden, MA: Polity, 2012), 80.

[37] Ibid.

[38] I visited this interlocutor at the state government building where GDPH is housed about five times during my two years in Atlanta. Seeing it above her desk was in fact the first time I saw it.

[39] On this double-functionality of diagrams as tools for comprehension and for bringing realities into being, and on diagrammatic thinking as a method of political economy, see, Gilles Deleuze, *Foucault*, trans. Seán Hand (Minneapolis: University of Minnesota Press, 1988), 43-44; Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi (Minneapolis: University of Minnesota Press, 1987), 145-6; See also, this dissertation's

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introduction, particularly around figures 0.1 and 0.2. On my use of "publics," see, Michael Warner, *Publics and Counterpublics* (New York, NY: Zone Books, 2002), 21-124.

[40] Cohen, et al. "The Status of the National HIV Surveillance System"; See also, Hoppe, *Punishing Disease*, 69-73.

[41] Kenneth Castro and Amy Lansky, "'Dear Colleague' Letter Announcing New Guidelines for Electronic Laboratory Reporting Data," Dear Colleague Letter, November 21, 2013, https://www.cdc.gov/hiv/library/dcl/dcl/092717.html.

All states, including Georgia, conducted some form of laboratory reporting related to CD4 T-Cell counts and AIDS cases before 2013. However, following issuance of this letter, all states moved to electronic laboratory reporting that included viral load for all cases.

[42] On the materiality of data, see, Paul N. Edwards, *A Vast Machine: Computer Models, Climate Data, and the Politics of Global Warming*, First paperback edition, Infrastructures Series (Cambridge, Massachusetts London, England: The MIT Press, 2010), 83-5 and *passim*.

[43] For a comparative overview of HIV care quality in the United States and "peer nations," which notes that the United States has the lowest rates of viral suppression among this group, see, Kaiser Family Foundation, "HIV Viral Suppression Rate in U.S. Lowest Among Comparable High-Income Countries" (Kaiser Family Foundation, March 20, 2019), https://www.kff.org/hivaids/slide/hiv-viral-suppression-rate-in-u-s-lowest-among-comparable-high-income-countries/. See also, Jane M. Kelly et al., "Achieving NHAS 90/90/80 Objectives by 2020"; For a transnational perspective, see, Engelbert Bain et al., "UNAIDS 90–90–90 Targets Are Not Realistic."

[44] Department of Health and Human Services, "Ending the HIV Epidemic: A Plan for America," February 7, 2019, https://www.hhs.gov/sites/default/files/ending-the-hiv-epidemic-fact-sheet.pdf; Anthony S. Fauci et al., "Ending the HIV Epidemic: A Plan for the United States," *JAMA* 321, no. 9 (March 5, 2019): 844, https://doi.org/10.1001/jama.2019.1343. See also, Sean Cahill, "Trump's Dubious Promise about Ending HIV," *The Boston Globe*, February 6, 2019, https://www.bostonglobe.com/opinion/2019/02/06/trump-dubious-promise-about-ending-hiv/Lys3X53Y38eaWjO1mtYB4L/story.html. The dynamics of the rollout of the new national "End the Epidemic" strategy within the HIV community will be the subject of future research.

[45] E. M. Gardner et al., "The Spectrum of Engagement in HIV Care and Its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection," *Clinical Infectious Diseases* 52, no. 6 (March 15, 2011): 793–800, https://doi.org/10.1093/cid/ciq243.

[46] Obama, "Executive Order -- HIV Care Continuum"

[47] For an analysis of PEPFAR as a tool of U.S. foreign policy, hegemony, and Empire, see, Ilona Kickbusch, "Global Health Diplomacy: How Foreign Policy Can Influence Health," *BMJ* 342, no. jun10 1 (June 17, 2011): d3154–d3154, https://doi.org/10.1136/bmj.d3154; this technical guidance document provides an example of how the Care Continuum was incorporated into PEPFAR requirement. See, PEPFAR. "QUALITY STRATEGY Phase I: Institutionalization of

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Countries' Ability to Improve HIV Clinical Programs (Fiscal Year 2014)." Technical Guidance. Washington, D.C: President's Emergency Plan for AIDS Relief, March 2014. https://www.pepfar.gov/documents/organization/224097.pdf.

I take my definition of "Empire" from Michael Hardt and Antonio Negri's work:

> We should emphasize that we use "Empire" here not as a metaphor…but rather as a *concept*, which calls primarily for a theoretical approach. The concept of Empire is characterized fundamentally by a lack of boundaries…a regime that effectively encompasses the spatial totality, or really that rules over the entire "civilized" world…an order that effectively suspends history and thereby fixes the existing state of affairs for eternity…the object of its rule is social life in its entirety, and thus Empire presents the paradigmatic form of biopower.

Empire. Cambridge, Mass: Harvard U Press, 2003, xiv-xv.

[48] Robert M. Entman, *Projections of Power: Framing News, Public Opinion, and U.S. Foreign Policy*, Studies in Communication, Media, and Public Opinion (Chicago: University of Chicago Press, 2004).

[49] On the influence of the United States' response to the HIV epidemic on health governance, see generally, Benton, *HIV Exceptionalism*; on the United States' dominant position, see, Jennifer Kates and Adam Wexler, "Donor Government Funding for HIV in Low- and Middle-Income Countries in 2017" (UNAIDS and Kaiser Family Foundation, July 18, 2018), https://www.kff.org/report-section/donor-government-funding-for-hiv-in-low-and-middle-income-countries-in-2017-report/; for other uses of "donor nation" language in reference to the United States and other "high-income" nations in public health discourse, see, International AIDS Society Governing Council. "AIDS Is (Still) Political: Annual Letter 2018." Geneva, Switzerland: International AIDS Society, June 2018. https://www.iasociety.org/Who-we-are/About-the-IAS/Annual-Letter-2018.

[50] Fieldwork at the 2018 International AIDS Conference confirmed this: the 90/90/90 goals and various "Continuum" and "cascade" frameworks dominated almost every aspect of the conference.

[51] Project Inform Staff. "Using Surveillance and Other Data to Improve HIV Care Linkage and Retention." San Francisco, CA: Project Inform, June 7, 2012; Patricia Sweeney et al., "Shifting the Paradigm: Using HIV Surveillance Data as a Foundation for Improving HIV Care and Preventing HIV Infection: Using HIV Surveillance Data to Improve Care and Prevent Infection," *Milbank Quarterly* 91, no. 3 (September 2013): 558–603, https://doi.org/10.1111/milq.12018.

[52] CDC, "Data to Care Program Guidance: Using HIV Surveillance Data to Support the HIV Care Continuum" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), August 2017), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/datatocareprogramguidance.pdf, 3.

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[53] CDC, "Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum (the 'Data to Care Toolkit'" (Atlanta, GA, 2014), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/pdf-of-important-considerations.pdf.

[54] Ian Hacking, "The Looping Effects of Human Kinds," in *Causal Cognition: A Multi-Disciplinary Debate*, ed. Dan Sperber, David Premack, and Ann James Premack (New York, NY: Oxford University Press, 1995), 351–83.

[55] Martin French, "Gaps in the Gaze: Informatic Practice and the Work of Public Health Surveillance," *Surveillance and Society* 12, no. 2 (2014): 226–42.

[56] CDC, "Data to Care Toolkit," 40.

[57] See, for example, Manon Ragonnet-Cronin et al., "HIV Transmission Networks among Transgender Women in Los Angeles County, CA, USA: A Phylogenetic Analysis of Surveillance Data," *The Lancet HIV*, February 2019, https://doi.org/10.1016/S2352-3018(18)30359-X; Don Evans and Nanette Dior Benbow, "Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data"; CDC, "Technical Guidance for HIV Surveillance Systems" (unpublished document).

[58] For an overview of the nationwide interoperable health IT infrastructure, I refer readers to the second chapter of this dissertation. See also, ONC, "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0" (The Office of the National Coordinator for Health Information Technology (ONC), 2015), https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf.

[59] David Ribes and Jessica Beth Polk, "Organizing for Ontological Change: The Kernel of an AIDS Research Infrastructure," *Social Studies of Science* 45, no. 2 (April 1, 2015): 214–41, https://doi.org/10.1177/0306312714558136.

[60] Kippax and Stephenson, *Socialising the Biomedical Turn in HIV Prevention*, 95; I mean "revolution" here in the classic, Kuhnian sense. See, Thomas S. Kuhn, *The Structure of Scientific Revolutions*, Fourth edition (Chicago; London: The University of Chicago Press, 2012), *passim*.

[61] Kane Race, *The Gay Science: Intimate Experiments with the Problem of HIV*, Sexuality, Culture and Health Series (London ; New York: Routledge, Taylor & Francis Group, 2018).

[62] Ragonnet-Cronin et al., "HIV Transmission Networks"; This article – one of the first to clearly demonstrate and visually represent the power and precision of molecular surveillance technologies – generated significant controversy in the HIV community. See, Martha Kempner, "CDC Explains and Defends Molecular Surveillance System," *The Body Pro: The Complete HIV/AIDS Resource*, March 18, 2019, http://www.thebody.com/content/81662/ cdc-explains-defends-molecular-surveillance-system.html?ic=700102; Martha Kempner, "New Study Triggers Concerns Over Use of Molecular HIV Surveillance," *The Body Pro: The Complete HIV/AIDS Resource*, March 4, 2019, http://www.thebodypro.com/content/81639/concerns-over-use-of-molecular-hiv-surveillance.html; HHS, "Ending the HIV Epidemic: A Plan for America."

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[63] McCray and Mermin, “Dear Colleague.”

[64] Evans and Benbow, “Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data.”

[65] CDC’s Advanced Molecular Detection (AMD) Initiative, “AMD in Action: Tracing Connections in an HIV-1 Outbreak in Indiana - AMD Helps Link HIV Genetic Data to Identify Transmission Clusters,” November 2015, https://www.cdc.gov/amd/pdf/factsheets/amd-in-action-tracing-HIV-indiana.pdf; Philip J. Peters et al., “HIV Infection Linked to Injection Use of Oxymorphone in Indiana, 2014–2015,” *New England Journal of Medicine* 375, no. 3 (July 21, 2016): 229–39, https://doi.org/10.1056/NEJMoa1515195; Lisa Rapapport, “Indiana HIV Outbreak among Drug Users May Have Been Avoidable,” *Reuters Health*, October 4, 2018, https://www.reuters.com/article/us-health-hiv-indiana/indiana-hiv-outbreak-among-drug-users-may-have-been-avoidable-idUSKCN1ME2N7.

[66] Sumathi Ramachandran et al., “A Large HCV Transmission Network Enabled a Fast-Growing HIV Outbreak in Rural Indiana, 2015,” *EBioMedicine* 37 (November 2018): 374–81, https://doi.org/10.1016/j.ebiom.2018.10.007; Evan Bush, “Health Officials, Worried about Outbreak, Investigate HIV Cluster in North Seattle,” *The Seattle Times*, August 30, 2018, https://www.seattletimes.com/seattle-news/homeless/health-officials-investigating-cluster-of-hiv-infections-in-north-seattle/.

[67] Sinoussi et al. “Expert Consensus Statement on the Science of HIV in the Context of Criminal Law.”

[68] Ibid.

[69] See, Kempner, “New Study Triggers Concerns”; Kempner, “CDC Explains and Defends Molecular Surveillance System.”

The misuse of phylogenetic data in criminal proceedings and public health work, and a potential future where methods would be deemed appropriate to use to discern directionality of transmission between individuals are active concerns among many interlocutors. See also, Alexander McClelland, Adrian Guta, and Marilou Gagnon, “The Rise of Molecular HIV Surveillance: Implications on Consent and Criminalization,” *Critical Public Health*, February 20, 2019, 1–7, https://doi.org/10.1080/09581596.2019.1582755.

[70] Ibid.

[71] Volkmar Pipek and Volker Wulf, “Infrastructuring: Toward an Integrated Perspective on the Design and Use of Information Technology” 10, no. 5 (May 2009): 447–73.

[72] David Ribes and Thomas A. Finholt, “The Long Now of Technology Infrastructure: Articulating Tensions in Development” 10, no. 5 (May 2009): 446–7.

[73] Ibid.

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[74] Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, MA: MIT Press, 2000), 33.

[75] Leslie Gonzales, “Responding to Mission Creep: Faculty Members as Cosmopolitan Agents,” *Higher Education* 64, no. 64 (2012): 337–53.

[76] Gordon Adams and Shoon Kathleen Murray, eds., *Mission Creep: The Militarization of US Foreign Policy?* (Washington, DC: Georgetown University Press, 2014).

[77] Donna Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective,” in *Simians, Cyborgs, and Women: The Reinvention of Nature* (New York: Routledge, 1991), 183–202.

[78] Project Inform Staff, “Using Surveillance and Other Data”; Don Evans and Nanette Dior Benbow, “Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data.”

[79] See especially: Kempner, “New Study Triggers Concerns.”

[80] Kippax, Susan, and Niamh Stephenson. *Socialising the Biomedical Turn in HIV Prevention*. London, UK; New York, NY: Anthem Press, 2016, 95.

[81] Ibid.

[82] A genealogy of grassroots and official knowledge about TasP would be a huge contribution to the HIV/AIDS studies literature; however, see, Barbara Hasse et al., “Frequency and Determinants of Unprotected Sex among HIV-Infected Persons: The Swiss HIV Cohort Study,” *Clinical Infectious Diseases* 51, no. 11 (December 2010): 1314–22, https://doi.org/10.1086/656809; Myron S. Cohen, “HIV Treatment as Prevention and ‘The Swiss Statement’: In for a Dime, in for a Dollar?,” *Clinical Infectious Diseases* 51, no. 11 (December 2010): 1323–24, https://doi.org/10.1086/656810.

[83] Obama, “Executive Order – HIV Care Continuum.”

[84] Prevention Access Campaign. “Risk of Sexual Transmission of HIV From a Person Living with HIV Who Has an Undetectable Viral Load: Messaging Primer and Consensus Statement,” July 21, 2016. https://www.preventionaccess.org/consensus; McCray, Eugene, and Jonathan Mermin. Dear Colleague Letter. “‘Dear Colleague’ Letter Announcing CDC’s Position That ‘People Who Take ART Daily as Prescribed and Achieve and Maintain an Undetectable Viral Load Have Effectively No Risk of Sexually Transmitting the Virus to an HIV-Negative Partner.’” Dear Colleague Letter, September 27, 2017. https://www.cdc.gov/hiv/library/dcl/dcl/092717.html.

[85] Anthony S. Fauci, “U=U: Science and Policy” (July 22, 2018), https://www.youtube.com/watch?v=ewxa8UW6h_0.

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[86] This over-simplified historical narrative of progression of confidence in PrEP (as measured by percentage) is present in the most recently-released U.S. clinical guidelines for PrEP. See, Centers for Disease Control and Prevention: US Public Health Service, "Preexposure Prophylaxis for the Prevention of HIV Infection in the United States - 2017 Update - A Clinical Practice Guideline" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), March 2018), especially 19, 53.

The knowledge-base about the progression of knowledge about PrEP efficacy would benefit from more rigorous analysis by social scientists who study biomedicine and health. Additionally, the reasons why biomedical HIV prevention strategies seem to require a much higher level of efficacy than barrier protection methods in order to secure the endorsement of major actors in public health is an area where HIV scholars ought to dedicate additional attention. For an exploration of this topic, see, Kane Race, "Reluctant Objects: Sexual Pleasure as a Problem for Biomedical HIV Prevention," *GLQ: A Journal of Lesbian and Gay Studies* 22, no. 1 (2016): 1–31, https://doi.org/10.1215/10642684-3315217.

[87] Interview with a Georgia integrated HIV planning professional on June 6th 2017.

[88] Lloyd, "Centring 'being undetectable.'"

[89] Ibid.; This finding also emerges from fieldwork.

[90] Victoria Mobley and Evelyn Foust, "Modernization of North Carolina's HIV Control Measures" (March 28, 2018), https://www.sog.unc.edu/sites/www.sog.unc.edu/files/course_materials/Mobley%20PPT-NC%20Legal%20Conference_HIV%20control%20measure%20changes%204_5_18.pdf; Victoria Mobley, "Modernization of North Carolina's HIV Control Measures," March 13, 2018, https://www.mecknc.gov/HealthDepartment/CDControl/ForProviders/Health%20Advisory%20Documents/Updated%20NC%20HIV%20Control%20Measures.pdf; State of North Carolina, "CONTROL MEASURES – HIV," 10A NCAC 41A .0202 § (2018), http://reports.oah.state.nc.us/ncac/title%2010a%20-%20health%20and%20human%20services/chapter%2041%20-%20epidemiology%20health/subchapter%20a/10a%20ncac%2041a%20.0202.html.

[91] Ibid.

[92] This approach notably does not reflect the "Consensus Statement on HIV 'Treatment as Prevention' in Criminal Law Reform" issued by the Center for HIV Policy and Law, a major U.S. group that works on research and policy issues related to HIV criminalization, disclosure, and other issues. That consensus statement's opening sentence says,

> "THE UNDERSIGNED AGREE that reliance on viral load or compliance with medical treatment as a basis to reform HIV criminal laws poses dangerous consequences for those who lack access to care. It also contradicts everyone's basic right to make health care decisions, including whether and when to get treatment, without running afoul of the criminal law."

Center for HIV Law and Policy, “Consensus Statement on HIV ‘Treatment as Prevention’ in Criminal Law Reform (2017)” (The Center for HIV Law and Policy, July 13, 2017), https://www.hivtaspcrimlaw.org/the-consensus-statement.

Chapter 6. "Data to Care" in Georgia: How New Uses of HIV Data for Public Health are Remaking the Governance of HIV and Reshaping Sexuality for People Living with HIV

I. Introduction

In this chapter, I describe how the federal HIV "Data to Care" initiative promoted by CDC has been implemented in the state of Georgia by the Georgia Department of Public Health (GDPH), in tandem with safety net clinics in metropolitan Atlanta and local health departments around the state. In the last chapter, I described Data to Care as a key federal strategy in the management of HIV. Along with the HIV Care Continuum and "End of AIDS" discourses, Data to Care is what I term a *sanguine* framework for the governance of HIV: an assemblage of practices rooted in measuring the molecular content of the blood of individual people living with HIV on a continuous basis (sanguine as in "sanguineous" or related to blood) in pursuit of sustained viral suppression at the individual level and the "End of AIDS" or even "zero new infections" at the jurisdictional or population level ("sanguine" as in naively optimistic).

Data to Care programs aim to "re-link" individual people living with HIV who have been identified as "out of care" in state HIV surveillance systems to medical providers. The primary source of state HIV surveillance data in Data to Care infrastructures are clinical electronic laboratory reports (ELR) that are sent via automated feeds by testing laboratories to state HIV surveillance systems every time a person living with HIV receives bloodwork. Current standards of care recommend linkage-to-care within 30 days for new cases of HIV, universal antiretroviral therapy (ART) for people living with HIV, with blood draws at least twice per year.[1] Using the HIV Care Continuum as a framework, state HIV surveillance systems use ELR data to determine how quickly newly diagnosed people are "linked to care," to discern the intervals at which people living with HIV engage in care (and whether they become "retained in care" by reporting bloodwork at least twice per year), to identify when individuals are not in care at all (or have "dropped out of care"), and to record when people in this lattermost group have been "re-linked." Since 2008, all HIV surveillance in the United States has been names-based, meaning that all individual cases of HIV are associated with an individual's name in state HIV surveillance systems, thus allowing for longitudinal tracking over time.[2]

To implement its Data to Care strategy, the GDPH HIV surveillance office maintains an infrastructure called the "Out of Care Watchlist" (OWL). The OWL is represented by GDPH with the image of a wise and watchful little owl, who sits perched in the "O" of the "Out of Care Watchlist Notification Portal" logo.

Figure 6.1. Screenshot of the Georgia Out of Care Watchlist Logo Produced by GDPH

The OWL is an enhanced spreadsheet – a Microsoft Excel file culled from core HIV surveillance data – made up of people living with HIV in Georgia who have not reported bloodwork to the state HIV surveillance system in the last 15-to-24 months. No recently-reported HIV-related bloodwork is the key indicator that an individual is not engaged in HIV-related medical care, from the perspective of HIV surveillance. OWL entries contain all the demographic data and contact information about individuals that is gathered using HIV Case Report Forms that are filled out and sent to GDPH within seven days of an initial positive diagnosis, as well as data about the diagnosing entity and last known healthcare provider. Individual entries also contain other information that is regularly added and updated through ELR feeds and other sources of HIV data that are incorporated into the surveillance dataset. All HIV surveillance data are held in a piece of software called the Enhanced HIV/AIDS Reporting System (eHARS), a browser-based program provided to state departments of public health by CDC to use in HIV surveillance work. Enhancements to eHARS core surveillance data include periodic matches of the state HIV surveillance database against CAREWare databases maintained by the GDPH Ryan White program and the Fulton County Ryan White program, as well as against data from large healthcare organizations that provide HIV-related medical care or conduct HIV clinical trials.

However, once an individual is placed on the OWL after a 15-month period of not reporting bloodwork to GDPH (the indicator that they are “out of care”), their entry on the OWL spreadsheet is further enhanced by HIV surveillance personnel using additional sources of data. These include private “people search” databases to which the state HIV surveillance office maintains subscriptions and other sources of publicly available information. This work is done utilizing “Data to Care” guidance produced by CDC.[3] The OWL – again, short for “Out of Care Watchlist” – is the foundation for all Data to Care activities in Georgia. Using federal Data to Care guidelines, the OWL stages a specific way of managing both HIV and sexual risk at the individual level: one aimed at linking people living with HIV to care, getting them retained in care, and driving their viral loads toward suppression, thus making them non-infectious or “untransmittable” and active contributors to the collective project of “Ending AIDS.” The OWL effectuates sanguine methods for managing HIV that are rooted in driving the epidemic to “zero” through the constant monitoring of the viral content of individuals' blood (a literally sanguineous logic) and the utilization of health IT systems and clinical and public health interventions to achieve the goal of "Ending the Epidemic" (an endpoint predestined to fail, in its sanguine naiveté).

The OWL is distributed via two modalities: the first is called "passive" and the second is called "active." The first, "passive" mode of distribution happens through an IT infrastructure called the Georgia HIV Health Information Exchange (HIV HIE), which was established in 2014.[4] The HIV HIE is maintained by the state HIV surveillance office. It links the electronic health record (EHR) systems of three metro Atlanta safety net healthcare providers to the OWL spreadsheet. When an individual on the OWL registers for services at one of these sites for any reason (whether or not their visit that day is related to their HIV disease), an alert is sent in real time to one or more designated clinicians at that site notifying them that an individual living with HIV who has been identified as "out of care" is at the clinic. This activates "re-linkage" protocols at the clinic, which vary widely at each of the three sites whose EHR systems are linked to the HIV HIE. Distribution of the OWL via the HIV HIE is called a "passive" re-linkage strategy because it requires the individual on the OWL to self-present for services at a healthcare facility, rather than for health department personnel to conduct proactive outreach to them. However, importantly, the person on the OWL presenting for services at one of the clinical sites connected to the HIV HIE does not need to be there seeking HIV-related medical care. They could be at the facility for any reason – for an ankle injury, for example. This means that individuals on the OWL who present to one of these healthcare organizations for reasons unrelated to their HIV are approached during the clinical workflow about their "out of care" status. It also means that every individual who registers for services at one of these three sites (whether or not they are living with HIV) has their EHR data matched against the OWL during the intake process in order to see if a match is generated. Distribution of the OWL to clinics using the HIV HIE infrastructure raises a range of bioethical questions that I explore herein, following a thorough explanation of how healthcare personnel work with the system.

The second, “active,” way that the OWL is distributed in Georgia is through the HIV, STD, Tuberculosis (TB), Hepatitis C (HCV), and public health prevention apparatus operated by GDPH and local health departments. This area of activity also involves the application of linkage-to-care programs that are designed to link people who are newly diagnosed with HIV to medical providers to “re-linkage” activities designed to target individuals on the OWL and connect them with healthcare providers and supportive services. The OWL is transmitted to prevention personnel and linkage specialists in the Atlanta metro area and other parts of the state through an infrastructure called the State Electronic Notifiable Diseases Surveillance System (SENDSS), a piece of software built and maintained by GDPH. SENDSS is used by various classes of prevention personnel for case management, partner follow-up services (or “contact tracing”), managing linkage-to-care activities, and since 2018, conducting “re-linkage to care” for people on the Out of Care Watchlist. This is this called “active” re-linkage because it involves health department and GDPH re-linkage staff using the OWL to proactively locate people on the list and re-link them to medical care.[5]

These passive and active re-linkage programs provide the groundwork for particular kinds of biomedical sexualities and sexual realities to emerge. The structure of these realities is determined by ELR data gathered and held by the state HIV surveillance office, and then by how these data are utilized and distributed in an interwoven array of clinical and public health infrastructures that are all designed to re-link people to care so that they become virally suppressed and non-infectious. Perhaps most notably, Data to Care involves linking data infrastructures that are maintained by disparate actors who hold their data in different systems and which are regulated by different areas of the law: for example, data held by the state HIV surveillance office, clinical organizations, and local health departments. The linkage of these systems became possible in new ways and at larger scales and faster velocities following the development of the nationwide interoperable health IT infrastructure and rollout of the *National HIV/AIDS Strategy* and federal initiatives like Data to Care.[6]

Both the active and passive re-linkage strategies utilized to distribute the OWL raise issues related to patient privacy, autonomy, informed consent, secondary utilizations of patients' health information, patient access to and control over their health data, and the regulation of formerly-distinct classes of electronic health information in a transformed health IT ecosystem. Herein, I explore how some of those critical issues manifest in practice in Georgia. I describe how Data to Care programs exist in tension with current and emergent regulatory frameworks in health IT, and how these programs raise pressing concerns about the rights of patients in the course of their implementation in a specific place. I undertake this analysis through a deep contextualization of Data to Care in Georgia. I scrutinize the use of Data to Care infrastructures like the OWL and the HIV HIE along with laws governing the disclosure of HIV data in the state, which give broad leeway to public health departments and healthcare providers to disclose patients' HIV status to others. I study and explicate the methods used to proactively reach out to people on the OWL using public health infrastructures (active re-linkage) and to respond to OWL alerts sent through the HIV HIE in clinical settings (passive re-linkage). I also undertake a close analysis of the operational documents and consent forms of the specific, federally-recommended, gold standard re-linkage program that is used in Georgia to bring people back into care, called the "Anti-Retroviral Treatment and Access to Services" (ARTAS) intervention.

Before conducting this analysis, I offer an account of how baseline HIV surveillance is conducted in the state, and of how the OWL is constructed using base surveillance data and other sources of information. I then draw upon ethnographic and state-level health policy research and infrastructural analysis data to describe how Data to Care is implemented in the state in both its active and passive modalities.

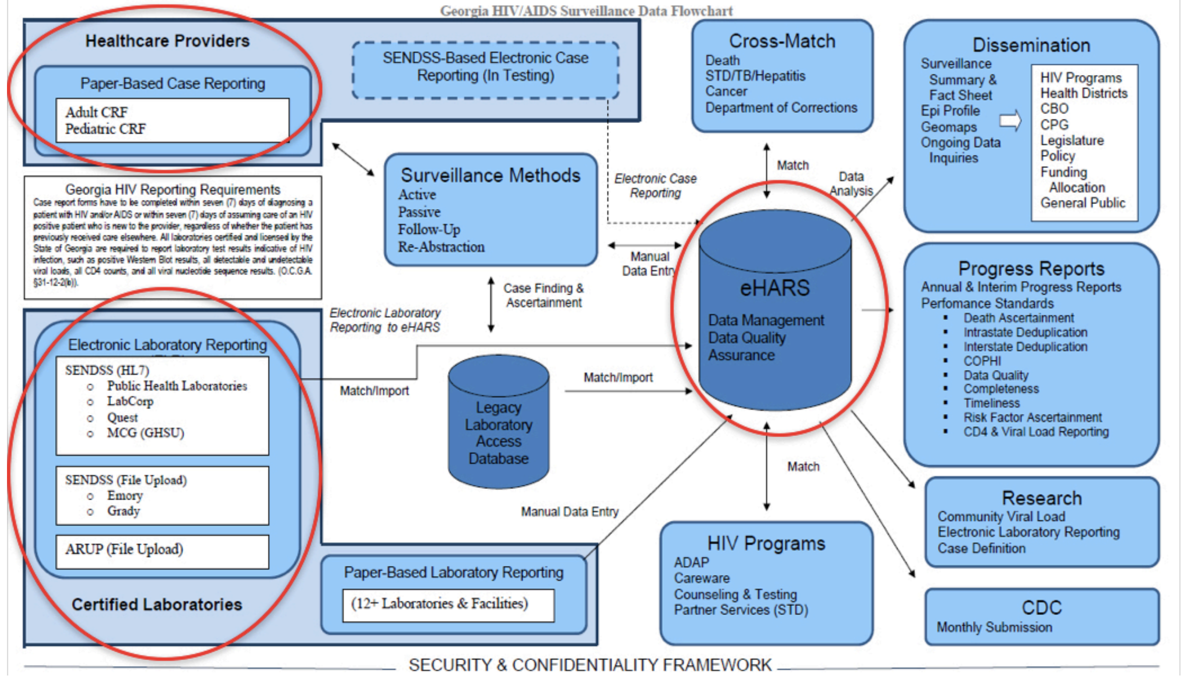
In the conclusion, I draw on my analyses of the HIV Care Continuum and Data to Care as a federal policy paradigm and Data to Care as it has been implemented in Georgia to describe how new infrastructures and strategies for the management of HIV in the United States are creating new hierarchies of sexual value for people living with HIV. This includes new forms of *de facto* criminalization of people who are not able to remain in HIV-related medical care, who are disproportionately poor, unhoused, rural, queer, trans, and/or people of color. I draw on the emerging primary and secondary literatures on the effects of Pre-Exposure Prophylaxis (PrEP) and Treatment as Prevention (TasP) on people living with HIV to show that engagement and retention in HIV-related medical care – along with sustained viral suppression – have become new ways of governing people living with HIV and of allowing people living with HIV to enact of new forms of "good" and "bad" citizenship, biomedical personhood, and sexual subjectivity. I show that, as a sanguine strategy for managing HIV, Data to Care is actively reshaping the constitution of the sexual system for people living with HIV. I present a detailed analysis of a final diagram: "The New Sex Hierarchy for People Living with HIV," which I discuss as a kind of organizational axis in the modern sexual system for people living with HIV.

I conclude with an overview of some of the ethical challenges that emerge for stakeholders from the findings of this chapter and the previous one, on Data to Care and other sanguine frameworks for managing HIV as an individual and public health problem such as the HIV Care Continuum and End of AIDS discourses. Drawing on Science and Technology Studies (STS), bioethics, health informatics, canonical documents from the People Living with HIV/AIDS movement, and the stated policy priorities of the U.S. Department of Health and Human Services (HHS), I focus on articulating how to build the foundation for a multi-stakeholder research agenda oriented toward reforming how HIV is managed. I suggest a pluralist policy research agenda that center the rights, needs, and autonomy of people living with HIV in the overlapping contexts of a "person-centered healthcare system," an active national AIDS crisis, and accelerating nationwide interoperability.[7]

Core HIV Surveillance in Georgia

Here, I again present the diagram of Georgia's HIV Surveillance System. I first discussed this diagram in the previous chapter, framing it as an entry point to understanding how HIV surveillance is structured in the United States, and particularly how ELR data are used to generate HIV Care Continuum data in HIV surveillance systems operated by state departments of public health, and then how HIV Care Continuum data stage Data to Care interventions by identifying individuals who are "out of care." With that context, this chapter analyzes how HIV surveillance is structured in Georgia with greater specificity. While the fundamentals of HIV surveillance are the same from jurisdiction-to-jurisdiction in the United States – such as requirements for names-based reporting of new cases of HIV and of electronic laboratory data of regular bloodwork for existing cases of HIV – the specific elements of each state's surveillance apparatus vary widely. Their structure is shaped by the local ecology of clinical, research, and public health actors in the state and by the history of HIV surveillance infrastructures in that jurisdiction.

Figure 6.2. Visualization of the Georgia State HIV Surveillance System Produced by GDPH



Case report forms have to be completed within seven (7) days of diagnosing a patient with HIV and/or AIDS or within seven (7) days of assuming care of an HIV positive patient who is new to the provider, regardless of whether the patient has previously received care elsewhere. All laboratories certified and licensed by the State of Georgia are required to report laboratory test results indicative of HIV infection, such as positive Western Blot results, all detectable and undetectable viral loads, all CD4 counts, and all viral nucleotide sequence results. (O.C.G.A. §31-12-2(b)).

The red circles on the left of the diagram below encompass major sources of surveillance data: Case Report Forms filed upon initial diagnosis and ELR data sent to GDPH by labs whenever people living with HIV receive bloodwork, ideally twice or more per year. The red circle in the middle surrounds eHARS, the "Enhanced HIV/AIDS Reporting System" software given to state surveillance programs by CDC to manage HIV surveillance data. In the "Cross-Match" bubble on the upper-right side of the graphic, the categories "Death," "STD/TB/Hepatitis," "Cancer," and "Department of Corrections" appear, noting databases that are regularly cross-referenced with HIV surveillance data. Similarly, in the "HIV Programs" bubble on the bottom-right side of the graphic, the categories "ADAP (for "AIDS Drug Assistance Program), "Careware (for CAREWare)" and "Partner Services (STD)" appear. These are all different sources of data that are regularly "matched" against the state HIV surveillance database (held in eHARS), as the “match” label by the dual-arrowed lines indicates. These “matches” between datasets in different parts of the state public health apparatus allow for the updating of critical information in the HIV surveillance dataset. Matching processes facilitate, for example, the population of missing data fields in individual entries and the overall enhancement of individual entries in the state’s build of eHARS. Unlike automated reporting into eHARS through ELR feeds, these matches are not automated, but are conducted periodically by surveillance personnel in cooperation with staff from other state departments or local branches of the state’s public health system. A successful matching process requires an HIV surveillance staff person to receive the updated database from the source – for example, from the Fulton County Ryan White CAREWare database manager Greg Nowitzki – and then to match the file against HIV surveillance data in eHARS. Following matching processes where mismatches in specific entries are identified, the specific fields in individual people’s eHARS entries are updated to reflect the most accurate and up-to-date data identified during the match. The state HIV surveillance office also receives inputs from CDC, mainly to identify individuals who have been identified as having moved out of state following a report of HIV-related bloodwork to that jurisdiction’s HIV surveillance system.[8]

eHARS is also used by surveillance personnel to generate a wide variety of outputs. Outputs are listed in the “Dissemination,” “Progress Reports,” “Research,” and “CDC” bubbles on the far right-hand side of the surveillance system diagram in Figure 6.2. Like inputs into the surveillance system, regular surveillance data outputs by the GDPH HIV surveillance office range from manual processes such as assembling a specific data set for a public presentation or report to a government entity or community group, to more automated and ongoing feeds established between infrastructures, such as monthly submissions of state HIV surveillance data to CDC. Key outputs include annual surveillance reports and fact sheets published by GDPH ("core surveillance" activities), publicly-available HIV Care Continuum data made available on the GDPH website that are updated annually, public presentations by surveillance staff, epidemiological profiles that are requested by local jurisdictions such as the Fulton County Ryan White office or statewide entities such as the Georgia Prevention and Care Council, and the establishment of data-sharing relationships with entities such as AIDSVu. AIDSVu.org – along with its companion website HIVContinuum.org – is an Emory University-based collaborative project supported by CDC. AIDSVu collects aggregated, de-identified HIV Case Report Form and Care Continuum data from several jurisdictions in the United States and presents data visually in an interactive map environment using Geographic Information System (GIS) software. AIDSVu.org and HIVContinuum.org are tools designed to be utilized by anyone seeking to learn more about HIV/AIDS in their region, from school-age and university students, to public health workers and community-based organization staff seeking to self-educate or to identify information to include in grant applications.[9]

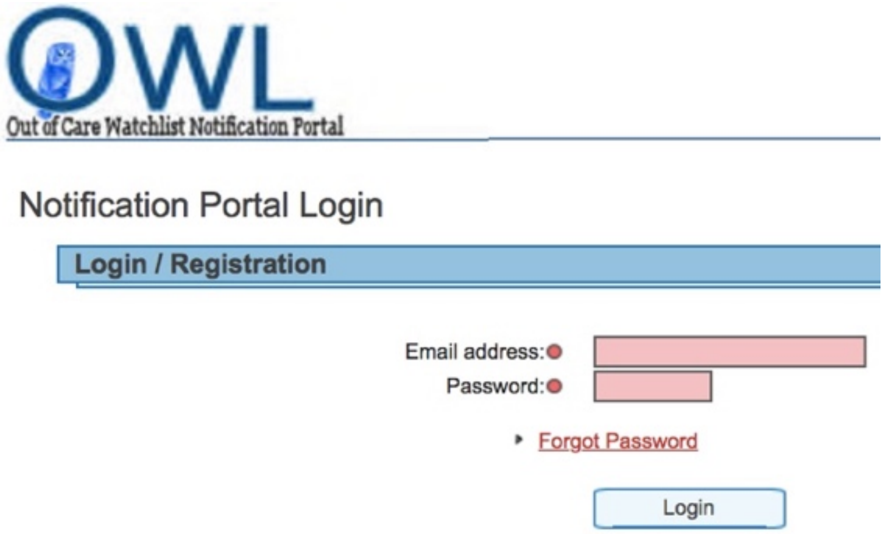
One of the most critical, regularly-updated outputs of the HIV surveillance office is the Out of Care Watchlist, or "the OWL." As discussed above, the OWL forms the basis of the state's Data to Care strategy. I now describe how the OWL is built by HIV surveillance personnel at GDPH, who pull data from eHARS on individuals who have not reported bloodwork in the last 15-to-24 months into the OWL Microsoft Excel spreadsheet. I then describe how this dataset of "out of care" people living with HIV in Georgia is enhanced with other data using "people search" tools, and is then distributed around the state via its "passive" and "active" modalities: through the HIV HIE linked to three clinical sites' medical record system and via the state's public health prevention apparatus.

II. The Basis for Data to Care in Georgia: The Georgia Out of Care Watchlist (OWL)

Georgia’s HIV Data to Care strategy is made possible by an infrastructure called the Georgia Out of Care Watchlist (OWL or “the OWL”). The OWL is an enhanced database of people living with HIV in Georgia who have not reported HIV-related bloodwork through Electronic Laboratory Reports (ELR) ordered by clinicians and sent to the state HIV surveillance office by testing labs in the last 15-to-24 months. Following the narrative of the HIV Care Continuum, the lack of ELR reports for an individual is an indicator that a person living with HIV is not retained or engaged in HIV-related medical care. The OWL cuts off at 24 months because, per an HIV epidemiologist at the Georgia Department of Public Health (GDPH), anyone beyond that mark is “going to be really hard to find,” given the lack of up-to-date contact information and the high likelihood that the individual has moved.

The OWL is a Microsoft Excel spreadsheet culled from core surveillance data that is held in the state’s build of the Enhanced HIV/AIDS Reporting System (eHARS). Again, eHARS is HIV surveillance software provided by CDC to state-based HIV surveillance systems. The OWL is built using the Data to Care framework promoted by CDC and described in the previous chapter. A screenshot of the OWL notification portal is included in Figure 6.3, below.

Figure 6.3. Screenshot of the Georgia HIV Out of Care Watchlist (OWL) Notification Portal



While individuals are listed as “out of care” in the state’s HIV Care Continuum data reports at the 12-month mark, they are only placed on the OWL after 15 months of not reporting bloodwork the HIV surveillance office. This is because, per GDPH HIV epidemiologists, many people living with very well controlled HIV may only see their provider once a year (versus the recommend two-plus times per year). Those individuals may miss annual appointments by one or two months, and should therefore not be placed on the OWL. Placing them on the OWL would not only generate an erroneous entry, but would also involve wasted labor on the part of HIV surveillance staff who are charged with enhancing individual OWL entries with additional data not included in baseline eHARS data.

To make contacting people easier, when building the OWL, HIV surveillance staff augment baseline surveillance data included in individuals’ eHARS entry with people search tools such as LexisNexis, a database called CLEAR maintained by ThompsonReuters, publicly available datasets, and other sources of information. Dr. Gregory Huntington, an epidemiologist who plays a key role in operating the GDPH HIV surveillance system and oversees the OWL, explained that the surveillance office has little to do with the distribution of the list. Rather, the surveillance office focuses on keeping the OWL regularly updated and on sending it out for use through the HIV Health Information Exchange (HIV HIE) and the state's public health prevention apparatus. Other than the transmission of the list back and forth, HIV surveillance and prevention personnel operate in relative silos from one another. Dr. Huntington explained this process in an interview:

> **SM**: How does surveillance staff, other than constructing the out of care list and giving it to [the re-linkage] team, work to actualize the linkage program or to...
>
> **Dr. Gregory Huntington, GDPH Epidemiologist**: We don't.
>
> **SM**: You don't?
>
> **Huntington**: Our role is to give them the list and their role is to find the people on the list. That's pretty putting it simply [chuckle]…what we *do* do is, after we have taken – created – the list, we use people search tools to update the address.

These enhancements are intended to makes people on the OWL easier to locate and contact when the list is given to prevention personnel who actively work to reach people who have been identified as out-of-care and placed on the OWL after 15 months of not reporting ELR data. Prevention personnel manage OWL data in an infrastructure called the State Electronic Notifiable Disease Surveillance System (SENDSS), where case managers, dedicated linkage and re-linkage staff, and others attribute "dispositions" to individuals after outreach attempts (e.g. "could not reach," "re-linked to care," "deceased," "moved," et cetera). The surveillance office also receives updated OWL spreadsheets from the HIV prevention personnel at regular intervals. The surveillance staff then update individual entries in eHARS using data from the updated OWL spreadsheet. Per Dr. Huntington:

> **Huntington:** The [OWL] spreadsheet is the start. It gets imported into SENDSS, a disposition gets attributed through SENDSS, and then that information has to then get imported back into eHARS. [Another epidemiologist] might have shown you – there's a

> tab for Data to Care in eHARS that's new, where we enter people who had some kind of outreach effort, and then what the disposition was.

Dr. Huntington is describing what CDC calls the “feedback loop to surveillance” that Data to Care efforts stage.[10]

Before turning to a consideration of how the OWL is distributed, I explore what it means for an individual person living with HIV to be “out of care” in Georgia. As with other data ontology management strategies explored in this dissertation, whether a person living with HIV is “out of care” is more a matter of perspective by the human and non-human actors involved in making the determination than it is a given in a particular state-of-affairs. This is because multiple definitions of “out of care” often co-exist in a single HIV infrastructural assemblage.

Being “Out of Care” Versus Being on the OWL

Definitions of what it means to be “out of care” among those who work in HIV in Georgia, and specifically people who work on aspects of the state’s re-linkage program, range from between six and 36 months. A nurse case manager named Cassie Schlesinger, who manages all OWL alerts sent through the Georgia HIV HIE at Immaculate Heart Healing Center, one of the HIV HIE performance sites, told me that she does not understand what the OWL is or how it is constituted, only how to act on alerts that are sent to her. However, Schlesinger assumed that the OWL was made up of a list of people living with HIV who had not received medical care for six months, because that is how Immaculate Heart defines a client as “out of care” for their internal quality management purposes. A six-month “out of care” metric follows from the current standard of care for people living with HIV in the clinical domain, which calls for blood testing at least every six months. This clinical guideline is often paired with the best practice that antiretroviral medications only be prescribed at six month intervals at most. Nurse Schlesinger spoke to me about the process of acting on OWL alerts. In doing so, she also informed me of how she conceptualized "out of care," and expressed her general confusion and amusement about how the OWL and HIV HIE infrastructures are constituted.

> **Nurse Cassie Schlesinger, Ryan White Case Manager at Immaculate Heart Healing Center:** There are times when you do things and you don't understand how it all works, but you still do it…
>
> I'm like "OK, so somewhere, there's some master list of clients who have, you know, not been seen – I'm guessing in six months, because that's what we consider 'out of care,'" and – [pause] – yeah. And then it's connected to all of these providers' offices where, if that person's name – ? [exaggerated shrugging motion]
>
> It's a mystery! [smile]

Nurse Schlesinger also told me that she is aware of strategies that clients employ to strategically transfer a six-month prescription of antiretroviral medications from one pharmacy to another, and then (during the course of the transfer), manage to pick up a 12-month supply in one day: six months from each pharmacy. Per Schlesinger, some clients do this because they do not like to go to the doctor or are transient. Such clients (possessing a full year of medications) may not return to the clinic for another year. These individuals would be marked as "out of care" at Immaculate heart at the six-month mark, "out of care" in the HIV Care Continuum in the State of Georgia HIV Surveillance System at the 12-month mark, but perhaps never placed on the OWL (in the case that they returned during before the 15-month mark to receive bloodwork and care). In any case: at Immaculate Heart, no clinical visit at the six month marks a patient as "out of care" in their clinical record. The nurse case manager applies this standard, a clinical conceptualization of "out of care," to the OWL. However, a person is only included on the OWL after 15 months of inactivity from the surveillance perspective, with no ELR data being sent to the state surveillance office.

However, as mentioned, in HIV Care Continuum data maintained by the state surveillance office, an individual is listed as "out of care" once they have passed the 12-month mark of no lab report data. Therefore, an individual can simultaneously be listed as “out of care” in the core surveillance data used to generate HIV Care Continuum reports, but not yet on the Out of Care Watchlist. This effectively makes them “out of care” in one part of the surveillance infrastructure, but not yet “out of care” for long enough be on the official list which flags them as out of care and in need of re-linkage interventions. Other definitions of “out of care” exist in the research literature and from clinic-to-clinic. Further complicating matters, an individual living with HIV can be seeing a doctor and receiving medical care, but not be receiving HIV-related bloodwork, or even be receiving HIV-related bloodwork and antiretroviral medications but mis-matching with their record in the state HIV surveillance system (owing, for example, to a change of name). Such an individual would be listed as “out of care” (and potentially placed on the OWL), and thus be “out of care” from surveillance and prevention perspectives, when they are, in fact, seeing a doctor or even retained in HIV care and having bloodwork done.[11]

Like the management of different classes of HIV risk hierarchy and sexual orientation data that I document in earlier chapters of this dissertation, one’s status as “out of care” is more a matter of perspective than an absolute truth or even static definition. Being “in” or “out” of HIV-related medical care is a managed reality that involves the patient themselves and the various healthcare infrastructures of which they are a part. This can be an entangled set of circumstances that makes someone appear as “out of care” from one or more vantages (or in one or more infrastructures), but still “engaged in care” from others.

III. “Passive” Re-Linkage: Distribution of The Georgia Out of Care Watchlist (OWL) through the Georgia HIV Health Information Exchange (HIV HIE)

Georgia’s first effort to implement Data to Care using the Out of Care Watchlist (OWL) was the establishment of the Georgia HIV Health Information Exchange (HIV HIE), also occasionally called the “Georgia Public Health Information Exchange” (GA PHIE). The HIV HIE links the OWL to the electronic health record (EHR) systems of three safety net clinics in the Atlanta metropolitan Area, with intentions to expand to future clinics in the future.[12] The Georgia HIV HIE is modeled on a statewide HIV HIE used in Louisiana, which was highlighted as a case study in the 2012 Project Inform report on Data to Care discussed as a case in the previous chapter. Thus, the HIV HIE is considered an “evidence-based” re-linkage intervention for people living with HIV identified as out of care, and has been shown to increase rates of linkage and retention when implemented.[13]

The HIV HIE and HIV Law in Georgia: Historical Accumulation, Infrastructural Creep

An HIV HIE Legal Ethical Workgroup was established to review the secondary literature on the Louisiana HIV HIE and to consider other issues during the planning and rollout process. The work group convened in advance of the project’s launch. This group was made up of prominent LGBTQ and HIV/AIDS advocates and practitioners in the state, as well as lawyers, ethicists, and GDPH employees.[14] The group and the HIV HIE implementation team determined that establishing the HIV HIE required the Georgia General Assembly (the state legislature) to pass a special law carving out an exception to when HIV data could be disclosed to providers by the health department over an electronic exchange network. In 2014, then- GDPH employee and future GDPH Commissioner Dr. J. Patrick O’Neal testified in favor of this law - Senate Bill 342 – in committee. It passed without much debate, fanfare, or opposition in both houses of the Assembly (147-16 in the House, and 50-1 in the Senate, not counting non-votes or absentee legislators).[15]

Such minor legislative amendments to state laws at the advice of administrative departments in the executive branch of state governments (such as departments of public health) and/or private sector actors are normal and vital to the functionality of state governments. However, additionally, the passage of this law as part of facilitating the state's HIV Data to Care strategy shows, concretely, one way that a phenomenon I call "infrastructural creep" in the previous chapter takes place in the realm of HIV practice. In Georgia, actualizing the federal push to create new infrastructures at the state level that link HIV surveillance data infrastructures to clinical EHRs through exchange networks – a key element of Data to Care – did not only require the technical know-how to do so, with an accompanying ethical review before and during implementation. Establishing the HIV HIE also required a new legal framework – and not just a legal argument or justification within the existing law, but an actual new law – that would facilitate the disclosure of information by the department of health to clinical providers over this exchange network and their EHR systems. Infrastructural creep happens because of many actions in different areas of practices. Forces at play include the expansion of technical capacities and funding for projects – the HIV HIE project was funded by the Health Resources and Services Administration (HRSA), for example – to legal and ethical reviews, and the passage of new state laws.

In the case of HIV, state laws governing HIV data, the management of HIV disease, the reporting and disclosure of HIV status or test results to individuals and/or between different actors in the healthcare system (and the conditions for informed consent regarding specific kinds of disclosure or exchange), and laws that criminalize actual or potential HIV transmission are the result of many amendments and changes that have taken place of the course of nearly four decades, since AIDS first became a known public health issue in the early 1980s. Some of the changes to HIV law are related to the creation of public health infrastructures (such as making HIV a mandatory reportable condition and enacting names-based reporting) while others (such as criminalization statutes or laws defining "AIDS transmitting crimes," which in Georgia include potential transmission via saliva, which does not transmit HIV but was once thought to) are the effect of HIV-related panics and/or outdated understandings of HIV transmission risk that found their way into the law, but were not updated when HIV science changed. Some HIV laws were certainly enacted with little understanding of the existing science in the first place.

At least in Georgia, the effect of this accumulation of laws specific to HIV over time has been to create an entangled mess of statutes that are often contradictory and confusing, even to those whose job it is to interpret and enact them. This process of accumulation over time in HIV law is not dissimilar to the kind of taxonomic accumulation that I document in chapter one, regarding the genealogy of the HIV risk hierarchy, which has often produced effects that make little logical sense when viewed outside of historical developments in the management and governance of HIV. As HIV/AIDS panics took place and generated responses from the media and policymakers, as knowledge about mode of transmission and other relevant areas in the management of HIV changed, and as certain laws were enacted at the advice or guidance of federal agencies regarding mandatory HIV reporting or other policies, states responded by enacting laws and building increasingly convoluted legal codes specifically addressing HIV/AIDS. The addition of a law about HIV disclosure over an electronic exchange network in 2014 is just one episode in the legal history of HIV/AIDS in Georgia.

Consider briefly the history of laws criminalizing HIV transmission, which have been the subject of sustained critique by U.S. HIV/AIDS advocates and scholars in recent years, particularly as consensus has grown about the efficacy of treatment as prevention (TasP). The first major wave of state HIV criminalization laws were an effect of the Ryan White CARE Act of 1990. As HIV/AIDS scholar Dini Harsono and colleagues write, "as one of its conditions for receiving federal funds, the Ryan White Care Act required all U.S. states to certify that they had a legal mechanism to prosecute HIV-infected individuals who knowingly exposed others to HIV…HIV exposure statutes were one such mechanism."[16] Some states, like Georgia, already had HIV criminalization statutes in place in 1990. Georgia's law was enacted in 1988, predating the 1990 federal demonstration requirement by two years.[17] However, it was the 1990 federal requirement that pushed more states to enact statutes specific to HIV. In Georgia, laws governing the disclosure of information related to HIV status exist in several parts of the Georgia Code. The primary sections are called "Confidential nature of AIDS Information," "Disclosure of AIDS Confidential Information," "HIV tests – who may perform test," and "HIV tests – report of positive results; notification; counseling; violations; exception for insurance coverage; exposure of health care provider." The HIV criminalization provision of Georgia's code is titled "Reckless conduct causing harm to or endangering the bodily safety of another; conduct by HIV infected persons; assault by HIV infected persons or hepatitis infected persons." Hepatitis was added to the statute in 2003.[18] This follows trends in the criminalization of specific sickness in U.S. law, processes that often beginning with the criminalization of HIV and which have been explained by sociologist of health and illness Trevor Hoppe in his work on the subject. Advocates in the Georgia HIV Justice Coalition have been working to reform the state's HIV criminalization law since 2013, which I took part in as a member of the coalition during fieldwork.[19]

The need to add a special provision to the "Disclosure of AIDS Confidential Information" section of the Georgia Code to facilitate the operation of the HIV HIE is a key example of historical accumulation in HIV law that requires further study. Such research would ideally use a combination of genealogical methods and strategies from legal history that would facilitate the mapping of key tendencies in this area, comparative analysis across states, and the differentiation of the various forces that are at work in the labyrinthine state codes (determined by legislative and administrative law) that shape the governance of HIV. This work would be done with the recognition that current laws have only taken their present form as the result of uneven processes of historical accumulation that exist in tension and relation to HIV science, public attitudes, and the management of HIV by public health institutions. These investigations are particularly important in the current historical moment, given that many efforts to reform state HIV laws, with an emphasis on HIV in the criminal law, are currently underway in many U.S. states. For example, advocates come together annually now, for the "HIV is Not a Crime" conference, to share strategies, success stories, and failures in their state-based efforts. I take up the question of problems and potential reforms related to Georgia's HIV laws in the conclusion of this chapter, as part of a broader discussion of informed consent, privacy, and confidentiality in the HIV Data to Care paradigm.

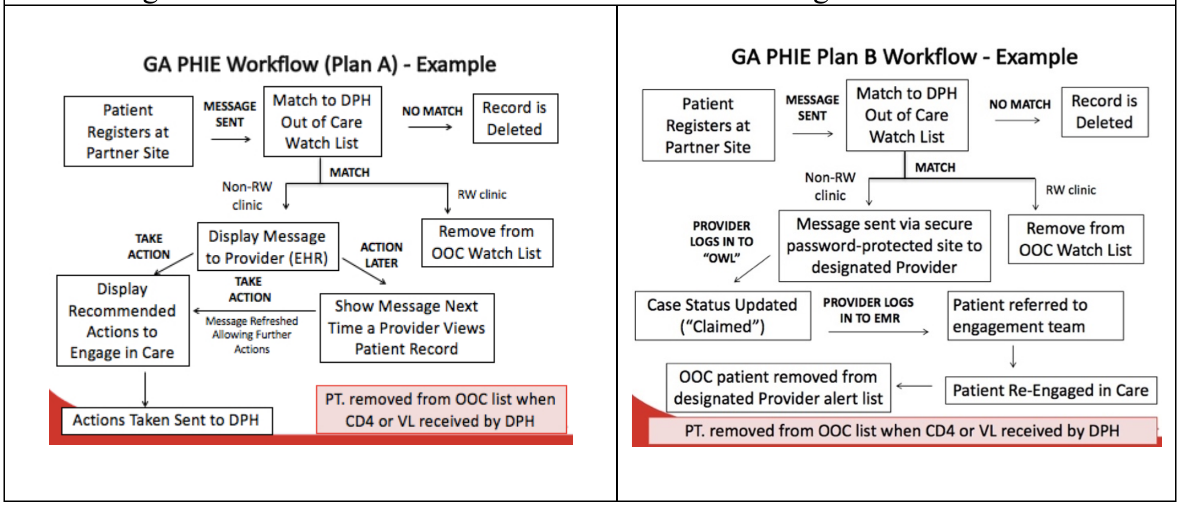
How it Works: The Two HIV HIE Workflows

The HIV HIE was originally intended to be a mechanism to send alerts that would appear directly on EHR screens in real time during clinical encounters whenever an individual on the OWL appeared for services at one of three clinical sites in the Atlanta metro area. This is how the Louisiana HIV HIE was set up, which was the model for the Georgia HIV HIE. The three initial performance sites in metro Atlanta were (1) a health department's clinic, (2) Immaculate Heart Healing Center – a Federally Qualified Health Center (FQHC) that focuses predominantly on people who experience housing instability and maintains a large Ryan White clinic, and (3) the Emergency Room of a major public hospital system. However, even after the special law was passed in 2014, in order for Georgia's HIV HIE to be implemented, two different workflows had to be established in order to help ensure that improper disclosures of HIV status did not occur over the network. The "Plan A" workflow would send alerts directly to EHR screens. The "Plan B" workflow would operate through email alerts sent to designated individuals at the clinics; these alerts would prompt them to log in to the OWL Notification Portal, "claim" the alert, and then execute the clinical workflow to re-link the individual to care.

Both "Plan A" and "Plan B" workflows had to be built because of issues related to which classes of healthcare professionals qualified as "clinicians" under Georgia law for the purposes of automatically disclosing an individual's HIV-positive serostatus. Linkage case managers, "Disease Intervention Specialists," and "Communicable Disease Specialists" who normally handle linkage and re-linkage in the public health system did not count as "clinicians." However, nurses, mid-level providers such as Physician Assistance and Nurse Practitioners, and doctors did. The workflows were built to accommodate these legal requirements.

Figure 6.4, below, contains graphical representations of the two workflows used to act on Out of Care Watchlist alerts that are sent through the HIV HIE (called the GA PHIE in the diagram, for "Georgia Public Health Information Exchange," the project's secondary name). "Plan A" shows alerts being sent directly from the HIV HIE to a clinical organization's EHR interface as a visual alert on the screen following a match with a new patient to the OWL. "Plan B" shows an alert being sent via email to a designated clinician after a successful match between a new patient and the OWL; again, in Plan B, the designated clinician is then tasked with manually "claiming" and then "pushing" alerts to a dedicated "engagement team" using a browser-based "OWL Notification Portal." In this workflow, the OWL is called "OOC list" for "out of care list."[20]

Figure 6.4. Workflow A and Workflow B for the Georgia HIV HIE Alerts



To repeat, the workflow presented in Plan A involves an alert appearing directly on the EHR screen. This is still the system in place at the county public health department. However, when I was conducting interviews about the HIV HIE, the data feed had been down for some time, so alerts were not actually being sent (to the frustration of GDPH HIV surveillance staff). I never had the chance to actually observe Plan A in practice. My empirical analysis is therefore limited to how Plan B was effectuated at the two clinical HIV HIE performance sites: Immaculate Heart Healing Center and the public hospital's ER.

Both workflows are designed to send alerts in real time whenever a person on the OWL presents at one of the sites, whether or not the reason for their visit that day is related to their HIV. Once a person presents for services and is registered in the EHR system at one of the three sites, their name and date of birth is matched against the OWL. In health IT, this is a process called either "patient-matching" or "identity-proofing."[21] If a match is generated against the OWL, an alert is sent from GDPH to the clinical organization. This means that every time any person registers to receive services at one of the HIV HIE demonstration sites (whether HIV-positive or HIV-negative), their first name, last name, date of birth, and potentially other data are matched against the OWL to attempt to generate a match.

Plan B had to be established for the public hospital's ER and the health center's process to accommodate the specific workflows, linkage interventions, and clinical protocols in place there. The relevant teams at the sites and GDPH determined that if Plan A had been implemented at these sites, legally improper disclosures to "non-clinicians" could have taken place. In sum, Plan B had to be implemented at these sites because the public hospital's ER intake process – and the various intake processes at the community health center's different clinics and mobile units – potentially involved interaction with Paramedics, Medical Assistants, and other intake personnel who were not qualified "clinicians" per Georgia law. Those individuals were ineligible to receive automated disclosures of patients' HIV-positive serostatus from the health department.

At both Plan B sites, designated providers receive email alerts notifying them that a patient on the OWL has arrived seeking services at their organization. At the hospital, the designees are Infectious Disease physicians who were invested in the success of the HIV HIE project; these individuals are referred to as "clinical champions" in a PowerPoint presentation on the HIV HIE produced by the GDPH HIV surveillance team. At Immaculate Heart Healing Center in mid-2018, the HIV HIE OWL alert designee was the Cassie Schlesinger, the organization's Ryan White nurse case manager quoted above.

Every time an alert is sent at one of these sites, the designee receiving the alert must log into the OWL Notification Portal and "claim" specific alerts. This "claiming" notifies the GDPH HIV surveillance system that an individual on the OWL has presented at a clinic for services and that the clinical team is aware that the patient is at the site. After "claiming" specific alerts, clinicians designated to receive them then "push" the alerts to the personnel who are charged with re-linking people to care at that organization. In the Plan B workflow shown in the figure above, the team that alerts are "pushed" to by designees is called the "engagement team." At

Immaculate Heart Healing Center, this "pushing" is usually Nurse Schlesinger making a phone call or physically walking to the area of the clinic where the patient is being seen. At the public hospital ER, the "pushing" of alerts takes the form of emails, text messages, and/or EHR messages sent by the clinicians who receive and claim OWL alerts to an engagement team made up of dedicated HIV linkage case managers.

Plan B in Action at Immaculate Heart Healing Center

Cassie Schlesinger, the Ryan White Nurse Case Manager at Immaculate Heart Healing Center who was designated to receive HIE alerts at that site when I was conducting ethnography in 2018, describes the process of acting on OWL alerts sent to the HIV HIE thusly:

> **Nurse Cassie Schlesinger, HIV HIE designee at Immaculate Heart:** You get this email, you open it up, you go in, you "claim" it. So, that's the big thing – you [deepens voice] *claim the person*. And then, once you claim them, I'm sort of responsible for following up.

Per Schlesinger, "nine times out of 10," the individual for whom an alert is generated is presenting at the Ryan White clinic to re-link themselves to HIV-related medical care. In these cases, Schlesinger notes this in the individual's OWL entry through the OWL Notification Portal. This "closes" this specific alert and indicates to the HIV surveillance office that the alert has been claimed. However, it does not remove the associated individual from the OWL. Per both Plan A and Plan B workflows represented in Figure 6.4 – in the red box at the bottom – the "Pt. [patient is] removed from [the] OOC [out of care list] when CD4 or VL [viral load Electronic Laboratory Reporting data are] received by DPH." This does not take place until an individual has received HIV-related bloodwork. In other words, an individual will only be removed from the OWL when they have successfully been "re-linked" to care in the HIV Care Continuum framework, which occurs when evidence of re-engagement in care is sent to the state

Department of Public Health through electronic laboratory reporting data that are ordered by clinicians and collected during a specific instance of HIV care.

At Immaculate Heart Healing Center, in the cases where an individual is not presenting to re-link themselves to HIV-related medical care, Nurse Schlesinger first claims the alert in the OWL Notification Portal. She then sends a message using Immaculate Heart's EHR to the specific physician or mid-level provider in the clinic where the person on the OWL has presented for services – for example, directly to the dentist in the dental clinic, or to the doctor on duty in the primary care clinic. Sometimes, Schlesinger will attempt to make a phone call or to physically walk to the area of the clinic where the encounter is happening, to inform the clinician that they are seeing a patient on the OWL. She then informs the provider of the alert, and suggests that they should (A) bring up HIV care with the patient, and (B) attempt to refer that patient to Immaculate Heart's Ryan White clinic for treatment.

Nurse Schlesinger described the process thusly, in a 2018 conversation in the main building of Immaculate Heart:

> **SM**: How do the alerts from the HIV HIE, from people who are on this Out of Care Watchlist…actually come through?...If someone presents here, let's say…[for] a foot infection and they are coming here to hopefully get some relief for that, and they come up on the Out of Care Watchlist, what is the process by which…you get notified that "hey we have a patient here who is on the Out of Care Watchlist?"
>
> **Cassie Schlesinger, Ryan White Nurse Case Manager and HIV HIE Alert Designee at Immaculate Heart Healing Center:** …So what happens is I actually get an email that comes from the State, and then, from that, it is telling me I have an alert. I go in to, um, into an off-site – – I don't know how to explain it.
>
> I have to log into the site, for OWL. And, from there, I will see a person's name and date of birth…and it will also show me the clinic [where they are presenting for services].
>
> So, I have had occasions where an OWL alert has come up for one of our mobile units…or some other location. So, then, I go into the client's chart [in the EHR], confirm that this is a client being seen, where are they being seen (are they in dental?), who is seeing them.

> Nine times out of ten, they are actually here to get back into [HIV-related] care: they are actually here to see our [Ryan White] Intake Specialist, which makes it easy-peasy for me, 'cause then all I have to do is put a note in their chart that I received this "out of care" alert, and that the client is actually here to re-establish care, it's all good.
>
> Now, say there are here to see primary…they have an infection or something. Depending on how timely I have gotten that message – and I am seeing clients in the clinic, so it's [dependent on] how often I look at my email. If I see the message and the client is here, then I will approach that provider, and let them know that this client is coming up as an HIV-positive client who is not in care…[22]

The narrative walkthrough that Nurse Schlesinger provides captures the entire process of acting on OWL alerts at Immaculate Heart. It is one organization's version of the "Plan B" workflow represented in Figure 6.4. Notably, even though (as a Registered Nurse), Cassie is a "clinician" qualified to receive OWL alerts per Georgia law, and works in a Ryan White clinic, she does not consider *herself* a "provider." She says that she would never disclose someone's HIV status to them following an OWL alert. Rather, she sees her role as to notify "providers," whose role is in turn to inform the patient. She would only interact with the patient if they chose to re-engage in HIV-related medical care at Immaculate Heart, following an intra-organization referral to the Ryan White clinic there, and after the patient (or "client") had been seen in the clinic.

Plan B in Action at a Major Public Hospital's ER

The process is somewhat reversed at the ER of the major public hospital, where an "engagement team" made up of non-clinician HIV (re)linkage case managers has been established with funding from a major pharmaceutical company to work with new and existing HIV patients who require re-linkage. This team of non-clinician social workers (working in a clinical context) reports and links new cases of HIV identified at the hospital, and also re-links people living with HIV to medical care. Cases are identified during the ER's intake process through the OWL and in other ways, such as "routine opt-out" HIV tests that are administered to all patients who pass through the ER, and patient self-disclosure.

The ER's HIV HIE workflow still follows the "Plan B" route in Figure 6.4. No alerts automatically pop up on EHR screens. However, at the hospital system, two doctors receive email notifications from the OWL when a patient on the list initially registers. One of these physicians then "claims" the alert in the OWL Notification Portal, and pushes notifications to the team of medical social workers (the "engagement team") either through text message to one of their phones or by email. As one of the social workers told me, "either they text us or email us, but in some way, they sort of push out the notification that they got to the social workers on the team and that's usually by email or text." Whereas at the low-volume site at Immaculate Heart, the designee informs the clinicians about OWL notifications, at the high-volume ER site, the clinicians claim alerts and then push that information to non-clinical HIV linkage and case management specialists.

Avery Sanderson, one of the social workers on the engagement team, described the process of receiving and acting on alerts thusly, reflecting on both technical and organizational challenges related to the HIV HIE workflow. Acting on alerts in real-time is difficult, particularly given that the engagement team works from "nine to five, Monday through Friday," and most visits to the ER happen at night.

> **Avery Sanderson, HIV linkage social worker at an HIV HIE-linked public hospital:** There are a couple of reasons that maybe, if there's an HIE [alert], we haven't heard. So, I think one of the biggest reasons, is that a lot of those alerts come during "off/peak hours." The Emergency Room is busiest during the evening. So, a lot of the time alerts that we miss are honestly just because they're sort of not during [the engagement team's] peak hours. And so, in that way, sometimes [HIV HIE designee] Dr. Abramovich [pushes through an HIE alert] at eight o'clock [at night]...So, that's something that happens.
>
> And then it's also just sometimes – it's a lag time that could come from the Department of Public Health in and of itself. They send us the alert. So, it's a newer system that's had to

> get some kinks out. But that can create an issue where we didn't get an alert. Also, a lot of the smaller HIV providers may not report their data to DPH. So, we've had scenarios where patients have gone, “Oh, I'm going to Dr. So-and-So, a small private clinic.” And so DPH wouldn't have gotten those updated labs. So, they are actually HIV positive and often times in care, but got an alert because the state hasn't got any information from them other than that initial positive test. So, it's a lot of variance in sort of why that alert might not trigger an HIV positive note at our Emergency Room.

In cases where Avery can receive and act on an alert during her shift, how she proceeds depends largely on why the patient is at the hospital that day.

If the patient is in the waiting room for a minor issue, she might go to the ER and pull the patient out of the normal workflow to begin the re-linkage conversation as part of that patient’s visit to the hospital. If they are there for something more serious, she will use the hospital’s EHR system to monitor the various clinics and areas of the hospital that the patient is being moved through. In other cases, such as when the individual is homeless or has experienced trauma, Avery gives them time to settle in, following their path through the various clinics they might move through in the EHR before engaging the providers working with the patient, and then the patient individually about their HIV and “out of care” status. If a patient is admitted overnight, she may wait an additional day before reaching out to them. However, at whatever time she or another member of the engagement team – along with the other members of a patient’s care team – determines to be an appropriate juncture, she or another team member will go to that part of the hospital and will engage the patient as part of the larger team.

Avery’s statement above also shows how the HIV surveillance infrastructure is imperfect. She notes that OWL notifications are sent through the HIV HIE for people who are already engaged in HIV-related medical care. During fieldwork, interlocutors also told me about several cases of people who were engaged in care being proactively contacted by health department staff in the OWL’s “active” mode of distribution, which I describe in the next section. Avery’s quotation above also shows the silo-ing effect that working in a specific domain of HIV practice has on how personnel conceptualize the infrastructures they work with. Even though her work in the clinical domain is connected to the state's HIV surveillance infrastructure, she does not entirely understand how the HIV surveillance system is operated. Avery speaks of "smaller HIV providers" who do "not report their data to DPH." However, it is testing laboratories – not providers – who send bloodwork results to GDPH to generate HIV Care Continuum data and for the department of health to determine who is in and out of care. She – like other HIV professionals discussed herein – thus possesses a specific, siloed, and partial perspective of the infrastructure she plays a role in operating.

I asked Avery about privacy concerns in responding to HIE alerts and generally around HIV disclosure and initiating (re-)linkage attempts, particularly in instances where a patient might have family members present in the hospital with them. She showed great concern for her patients in this regard, noting that she often employs creative strategies to ensure that their privacy and wishes are respected.

> **Avery, HIV linkage case manager and HIV HIE engagement team member at a major public hospital**: I have had some HIV disclosures where maybe I pulled the patient back and mom was waiting in the waiting room, and the patient is just sort of – "Mom is gonna ask what's going on," when she comes back out. My own practice actually is to sort of walk through the patient – talk to the patient. Sort of: "how do we want to address this?" "So obviously if someone's coming in this room right now, you're gonna be really upset." "Are we at the stage where we want to share with them that information?"
>
> And a patient may say, "Yes." And from that point, I would sort of let the patient have that conversation, which has happened before – patients have wanted to disclose to parents or family members. Or a patient may say, "No. I'm not ready to have this conversation right now, I maybe want to tell her when I get in [care], later."

I asked Avery a follow-up question regarding her thoughts on the ethics of re-linkage strategies that employ HIV surveillance data in clinical or public health prevention contexts to re-link individuals to HIV-related medical care – programs such as the OWL, the HIV HIE, and "active" re-linkage by health departments. I focused particularly on how she personally balanced the issue of medical providers and public health institutions putting pressure on people living with HIV to become retained in medical care with the rights of patients to determine whether starting treatment at a given time is the right medical decision for them, along with the reality of barriers to accessing care.

This had come up earlier in our conversation, and was also a concern expressed to me by other interlocutors in Atlanta. Several interlocutors even told me that they felt that the rapid 30-day linkage-to-care goal set by the *National HIV/AIDS Strategy: Updated to 2020* reflected a lack of understanding of how newly-diagnosed individuals experience their diagnosis, and low regard for the cognitive, life-pattern building, and habit-forming preparation that is required to begin antiretroviral therapy, which is intended to be a lifelong commitment to taking medication on a daily basis. Avery responded thusly:

> **Avery:** My concerns from the beginning sort of remain the same. I believe that a patient who doesn't want to be in care, has the right to not be in care. If the patient's sort of given all the information and has decided that they don't want to take medication, a patient has a right to determine that. And I've always been concerned about how exchanging health information impacts those patients, and what autonomy they have in a system that sort of says that "the only reason that they aren't in care is 'cause they just don't know how." *That's not true*. We're not operating with the same facts here. So, I have concerns, ethically, about our patient's right to sort of self-determine, and also about sharing of information.
>
> [The hospital] shares information with the health department, the health department shares it back with [the hospital]. I think as a consumer of health care, how *I* would feel about that – if it was my psychiatrist's desire to share information with other people, or my gynecologist. It's uncomfortable to sort of speak through these things. And especially when you layer on top that I don't think the broader ethical considerations are always at the forefront of these conversations. It's just, "Let's get everybody into care," without any true understanding that it's not always just housing or transportation that is the reason someone's not going to the doctor.

I replied, drawing on other conversations I had had with interlocutors:

> **SM**: Right. And someone could be like, “Hey look, I know I can't take a pill every single day right now. I can’t even make it – I can’t even hold a job down right now. How am I supposed to keep my – take my meds every day?”
>
> **Avery**: Yes, exactly. And it's going to be these more vulnerable populations that are more apt to those things. Some of the honest conversations my patients had – I had a guy (and a couple) the other week. And they’re like: “I'm trying – I am ready to get on medication, but you know, I'm behind on child support, and I just started this job, and they've taken the money, da-da-da.” And I'm still like, to be completely honest, HIV was the least of his issues in his life.
>
> And I don't know how you get that across to other people – that it wasn't that he didn't care about his health, or that he didn't take it seriously. It's that humans can only do so much at one time, and our populations that were already vulnerable oftentimes *before they were infected with HIV*. And if we aren't sensitive to the fact that people are trying to live lives and also live those lives with HIV, I just – – Yeah. I have lots of feelings, but I don't know that we're all sharing those feelings.

Noting her extreme thoughtfulness about these issues, and building on what she had said, I asked a follow-up question, inquiring to Avery about a topic we had discussed regarding the potential for public health interventions such as the OWL and the HIV HIE to potentially run afoul of the right to privacy, confidentiality, and personal autonomy in medical decision-making for people living with HIV.

Avery had earlier discussed concerns about her “Hispanic clients who might be undocumented,” and the potential for “some random person like this shows up knocking at the door saying they're someone from a government office” to create an environment of fear for that patient. Avery said that it could potentially even be (or at least appear to the patient as) “dangerous, if I'm undocumented and random government officials are sort of popping up, asking me about my health information.” She acknowledged the very real pressures that people living with HIV face to become engaged in medical care in the era of universal treatment and treatment as prevention (TasP), even if they are currently healthy or have a high CD4-T cell count. As discussed previously in the chapter, universal treatment recommendations were only issued in 2015, replacing earlier ones that recommended antiretroviral therapy when an individual's CD4 T cell count dropped below a certain threshold (500 copies/ml of blood, and before that, 800 copies).

Avery went on to discuss how potential dangers are exacerbated for clients whose life circumstances do not allow them to easily remain in continuous medical care or to take antiretrovirals every day. This is a reality for many people in the United States and a basic requirement for successful, long-term antiretroviral therapy. She also discussed ongoing issues with providers who do not effectively communicate the meaning of an HIV diagnosis with their patients.

> **Avery, HIV linkage case manager at a major public hospital in Atlanta:** I've had a patient (this was a while ago), but he was a young, black, gay man, and – whether the provider had sort of meant it this way, or he heard it – but he had left his first appointment with his infectious disease provider.
>
> The comment [the provider] made was something along the fact that, "Your demographic is driving these numbers and getting you in care –" He took it *personal* as though *he and who he was, was responsible for this epidemic*, "–and you live in Atlanta." You sort of see everywhere it is – it's almost sort of a scare tactic. And [the patient] had internalized what [the provider] had said and he was going to go back, but wasn't sure what he thought about it. And I don't know how – our not understanding about the lives that our patients live – *just our thoughtlessness*, how that impacts our patients' willingness to stay engaged in care.
>
> Something as simple as – well, I have trans clients whose pronouns aren't listed inside of [the hospital's EHR]. And that's information now that I only have, and I need to go and put all caps letters, inside of a note, I guess. I don't know, is the answer. But it – *for sure*, these systems do *continually*, *regularly* re-traumatize our patients.
>
> Especially a community that's seeing it-selves, almost sort of like as the mascot that was driving this epidemic. The posters you see in town, they target one specific population! And I'm very concerned about how they are hearing that message and internalizing it, and following up for care, you know? There's this inevitability of *this* [a black gay man or trans woman] being *that* [HIV/AIDS].
>
> I think that something about this disease has gone through before, and I would hate to see that we're getting into this thing again, where this is a fatalness that "everyone who looks like me eventually ends up here, so there's nothing for me to be safe or cognizant about."

> Lots of my patients who I'm diagnosing already have friends –. It's not that this generation doesn't know what HIV is, that might be different than earlier ones. They are familiar. But there's some other disconnect there, where just the support and respect that you would hold, I don't think that they see. And I do have concerns about how that's internalized here, specifically in Atlanta among young gay black men.[23]

Avery works in the "passive," clinical, HIV (re-)linkage space, which means she is charged with acting on OWL alerts sent through the HIV HIE and reactive HIV test results as part of her work as an HIV linkage case manager at the large public hospital. However, our conversation about the ethics and risks of re-linkage programs included considerations of both clinical/"passive" re-linkage and "active" re-linkage strategies employed by departments of public health.

In the "active" re-linkage paradigm, individuals identified as "out of care" using state surveillance data are proactively identified and contacted by health department staff, in order to re-link them to care and (in the narrative of the HIV Care Continuum) help them become retained in care, virally suppressed, and therefore noninfectious to others and on the road to good health. I now turn to a consideration of Georgia's active re-linkage strategy, wherein the OWL is linked to the state's public health prevention apparatus used to manage STDs, tuberculosis, reporting and linking new cases of HIV, and to conduct contact tracing activities.

IV. "Active" Re-Linkage in Georgia: Distribution of the OWL through Public Health Prevention Infrastructures via the State Electronic Notifiable Surveillance System (SENDSS)

Georgia's "active" re-linkage strategy involves distribution of the Out of Care Watchlist (OWL) through the state's HIV and STD prevention, HIV linkage-to-care, and contact tracing apparatuses. This infrastructure includes employees from the state department of public health (GDPH) and also personnel at local health departments around the state who receive training, instructions, and directives from GDPH.[24] These prevention infrastructures make up some of the core functionality of public health institutions in the United States, and are largely driven by partner follow-up services created in the mid-20th century to manage and stop the transmission of syphilis and other STDs by contacting sexual partners of people who had been diagnosed and providing them with treatment that would eliminate the infection. Along with other STDs and reportable communicable and infectious diseases such as Tuberculosis (TB), HIV is included among a range of "mandatory reportable conditions" that providers and testing laboratories are required to report to health departments, and to which prevention departments are charged with monitoring and responding.

A critical part of these infrastructures involves the linkage of newly-reported cases of HIV to medical providers, and, in the Data to Care paradigm, the re-linkage of people living with HIV who have been placed on the OWL to medical providers. In this "active" modality, the OWL is distributed through the prevention software that is used to conduct all HIV and STD prevention activities in the state, including partner follow-up activities and case management. The infrastructure is called The State Electronic Notifiable Diseases Surveillance System (SENDSS). Figure 6.5 below shows the SENDSS logo, with the node-and-line network graphic symbolizing how – during the course of their work – Communicable Disease Specialists (CDSs), Disease Intervention Specialists (DISs), and linkage/re-linkage personnel trace the networks of sexual contacts and/or other engagements (e.g. an attempted contact) for any given individual in the system.

Figure 6.5. The State Electronic Notifiable Disease Surveillance System (SENDSS) Logo

Unlike CAREWare (considered at length in chapter four), which is only accessible via Virtual Private Network (VPN) and exists as a “walled garden,” SENDSS is browser-based. It serves many purposes in the state’s public health infrastructure, and (as discussed above) was built primarily with the aim of assisting case managers and health department personnel in contacting partners of people who may have been exposed to an STD by a sexual partner.

There are a wide range of ethical issues regarding informed consent, patient privacy, and confidentiality related to these programs as they have been used for STD follow-up services. However, when the logics of these systems are extended to HIV, which (unlike other STDs) cannot be cured, but only managed, and is furthermore one of the most highly stigmatized of all medical conditions, existing ethical issues are amplified and new ones arise. As sociologist Trevor Hoppe writes of contract tracing in *Punishing Disease: HIV and the Criminalization of Sickness*:

> Developed in the early twentieth century for managing syphilis outbreaks, contact tracing involves asking diagnosed individuals to reveal the names of their sexual partners so that they may be tested and treated, if necessary. The practice is best suited to diseases that are curable and highly contagious – two things that HIV is not. Despite questions over its effectiveness (not to mention its potential threat to privacy), the practice was widely implemented in HIV testing clinics around the country.[25]

As Hoppe notes, the use of public health infrastructures designed to manage infectious and communicable diseases that can be eliminated entirely from the body to manage HIV (a condition that can only be managed through lifelong therapies) raises questions about how well-suited these infrastructures are to governing and managing long-term chronic conditions like HIV in the first place. Nonetheless, the process of doing so for new cases of HIV is widespread best practice in the management of HIV/AIDS in the United States, especially for partner follow-up services for newly-reported cases of HIV. Further, now, in many jurisdictions (like Georgia), Data to Care is also practiced. This is a key example of what I call "infrastructural creep" in action.

The addition of HIV-related linkage and re-linkage services is still a relatively young phenomenon in the history of HIV and public health. Later in this section, I analyze the "Anti-Retroviral Treatment and Access to Services" (ARTAS) (re)-linkage intervention for people living with HIV. ARTAS is the main program used to link people who have been newly-diagnosed with HIV to care and other social services, and is also used to re-link those on the OWL to care through the active Data to Care re-linkage strategy administered through the state's public health prevention infrastructure.

Infrastructural Misalignments Between Newly-Integrated Domains

In the last chapter, I presented "infrastructural creep" as a framework for describing how health IT capacities enabled by standards and the nascent "nationwide interoperable health IT ecosystem" are a key facilitator of infrastructures expanding beyond their original purpose to take on other, additional functions. As I discuss there and elsewhere in this dissertation, the realm of HIV practice has been at the cutting edge of fostering interoperability and data integration between its various domains when compared to other areas of the healthcare system – although this integration process has been highly uneven, and has moved forward with serious problems and shortcomings in achieving programmed visions of automation and interoperability.

Greater automated interoperability between domains or practice areas in the HIV world when compared to the healthcare system in general is attributable to the fact that programs built to manage HIV in the United States are centrally-administered by offices within HHS – primarily CDC (which oversees surveillance and prevention) and the Health Services and Resources Administration (HRSA, which oversees the Ryan White program). This centralized federal administration takes place with coordination and consultation from outside, pseudo-state actors like the Council of State and Territorial Epidemiologists (CSTE) in the domain of surveillance, the National Association of State and Territorial AIDS Directors (NASTAD) in the domain of prevention, and the HIV Medicine Association and the Communities Advocating for Emergency AIDS Relief (CAEAR) Coalition in the domain of care. The integration of "out of care" lists culled from HIV surveillance data – which are themselves generated through electronic laboratory tests ordered by providers working in the clinical domain – to prevention re-linkage infrastructures like SENDSS and the HIV HIE, is a key example of how interoperability and integration between different domains of practice takes place at a very wide scale in HIV. This integration – while not at all uniform – occurs in policy and both at the technical and organizational levels.

However, each actor in this increasingly-integrated set of networks speaks from their own situated vantage and works in at least somewhat of a silo. This is true in the same way that a health worker only being responsible for one aspect of an infrastructure's operation (for example, acting on HIV HIE alerts in the clinical context, as Nurse Schlesinger does at Immaculate Heart) can lead to a kind of myopia and inability to see or sense the whole assemblage. This, in turn, tends to cause infrastructural creep. Actors laboring within silos also create substantive misalignments within and across infrastructures about what they believe other actors in the network actually do in their area(s) of practice, and thus affect how the network itself is both conceptualized and constituted. This process is on acute display in the active re-linkage arm of Georgia's Data to Care Strategy. Susanna Garcia, an epidemiologist with a PhD in statistics who operates aspects of Georgia's HIV surveillance infrastructure, told me that:

> **Dr. Susanna Garcia**: SENDSS is a data system homegrown in Georgia that the districts use, for example, to follow up on cases to do partner services. So now there's a new tab

> linkage to care where they get assigned their regular linkage to care work, which is newly diagnosed people, and they get assigned these out of care people…[the Out of Care Watch List (OWL)] gets imported into SENDSS, a disposition gets attributed through SENDSS, and then that information has to then get imported back into the Enhanced HIV/AIDS Reporting System (eHARS)…
>
> **SM**: What the disposition was? Is that like: "they want to re-engage in care," or they-
>
> **Dr. Garcia**: – or they did re-engage in care, or they didn't want to re-engage in care, or we found out they were deceased, or we found out they were in Michigan, or we couldn't find them.

While Dr. Garcia is one of the most informed actors in the entire HIV sector in Atlanta, and ably describes how the OWL is sent to the prevention staff charged with re-linkage, the way the OWL (which she and her team are charged with building and sending to the prevention office) is incorporated into SENDSS in practice is slightly different. While there were plans for a new linkage tab when we spoke, it had not actually been built into the SENDSS interface yet, although the OWL was in fact being transmitted to prevention staff through the SENDSS infrastructure. This is a non-substantive issue, from Dr. Garcia's perspective in the surveillance office, which is chiefly concerned with whether the list is successfully transmitted to prevention personnel in Excel format, and then that those data (with additions about attempted follow-ups and "dispositions") are sent back to the surveillance office at regular intervals and entered into eHARS.

However, this example shows how infrastructures can be technically and organizationally aligned, but conceptually misaligned in the sense that people in one part of the infrastructure (even those who possess a high level of knowledge and skills – in this case, Dr. Garcia in surveillance) might not understand precisely how another part of the infrastructure they work with functions and exists in practice. Dr. Garcia thought there was a special linkage tab when there was not. However, the OWL was being sent over from the surveillance office to prevention, personnel the re-linkage work was being done, and the data were being transmitted back to eHARS so that targeted individuals' "disposition" could be marked. There was, however, no corresponding special "linkage" tab in the SENDSS system. A linkage manager informed me that there were plans in the works to make one, but that it had not yet been rolled out.

Cutting in the opposite direction, Pat Gillette, a statewide linkage manager who oversees aspects of Georgia's HIV linkage and re-linkage activities – including the incorporation of the OWL into HIV prevention and linkage work– described the addition of the OWL into SENDSS for "active" re-linkage as a "scaling down" of the HIV Health Information Exchange (HIV HIE), which is used to distribute the OWL to metro Atlanta safety net healthcare organizations. She understood the movement to "active" re-linkage through SENDSS to be a move away from "passive" HIV HIE-based re-linkage, which requires patients to self-present for services to be flagged and targeted for re-linkage at the three clinical sites in Fulton County. Gillette said:

> **Pat Gillette, statewide HIV linkage manager:** 'Cause you have the technical data side, but that's only one component. Without the people actually going and finding these people, it's not gonna happen. So, we've kind of scaled down the HIE concept and what we did is we're starting off with the idea of an Out of Care Watchlist. If we can find people who have recently fallen out of care based on a certain timeframe, provide this list to our specific districts and then allow them to try to go out and find these people to get them into care.

In fact, the incorporation of the OWL into SENDSS and the state's HIV linkage-to-care program for the purposes of re-linkage to care to enable health departments to "go out and finding these people and get them into care," was a *scaling up* of GDPH's overall re-linkage and Data to Care strategy by adding an "active" re-linkage program to an existing "passive" one. However, because Gillette did not work in the care domain and therefore never worked with the HIV HIE directly, and because she only worked with the HIV surveillance office for the purposes of receiving the OWL, she had a limited understanding of the HIV HIE, and in fact conflates it with the OWL. Pat was under the impression that the program she was running (the active re-linkage program) would be replacing or taking the place of, rather than supplementing, the existing "passive" re-linkage program.

Infrastructures into Interventions: The "Anti-Retroviral Treatment and Access to Services" (ARTAS) Program in Georgia

The "Anti-Retroviral Treatment and Access to Services" (ARTAS) intervention is the gold standard linkage and re-linkage program in HIV care and prevention. Its efficacy as a linkage and retention intervention has been tested in a randomized control trial.[26] At base, it is a framework for case management that is specifically designed to (re)link people diagnosed with HIV (or placed on an out of care list) to (re-)engage in HIV-related medical care, and to help them to remain (or be "retained") in HIV-related medical care in the long-term. ARTAS is promoted on the CDC "Effective Interventions" webpage where the Data to Care materials discussed in the last chapter are housed and disseminated. ARTAS is the main intervention used by health department staff in Georgia for individuals who are determined by practitioners to require additional assistance in engaging and being retained in medical care. Only a portion of individuals contacted by health department staff for linkage or re-linkage-to-care will be determined to require ARTAS; it is offered in many jurisdictions for those who ask for or evidently need additional assistance.

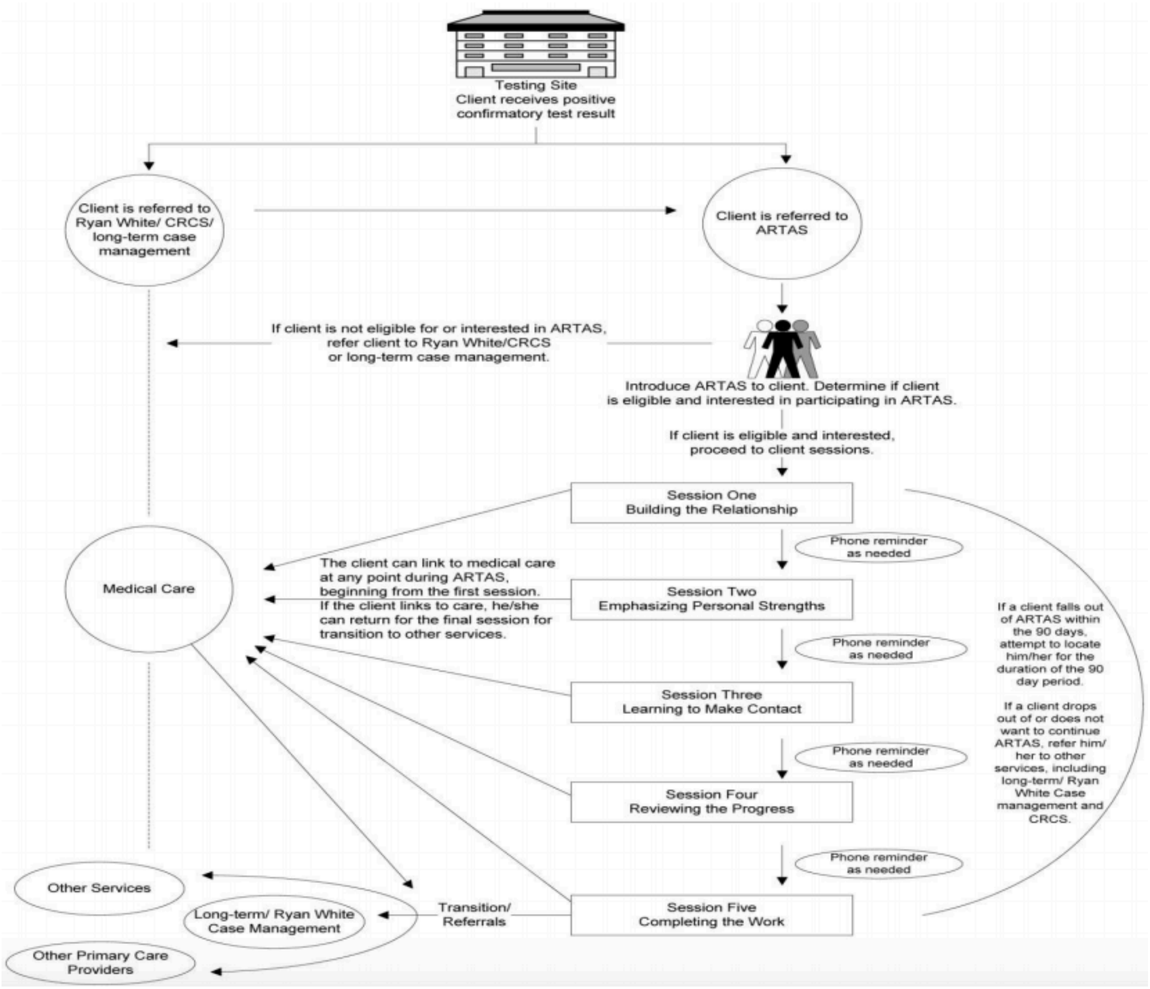
Before a determination can be made about whether ARTAS will be required for a specific individual, or if normal case management and re-linkage efforts will suffice, individuals must be proactively contacted by health department staff. Health department personnel can attempt to contact people who are listed as new cases of HIV, or who are people living with HIV on the OWL, through three methods: (1) a letter sent to the individual's home marked "confidential," (2) a phone call with the option to leave a message requesting a call back to discuss "confidential" information, or (3) an unannounced home visit by a health department staff person.[27] Because these outreach activities fall under laws regulating public health prevention, they do not require informed consent.[28] They are often hardly subtle in their execution and raise serious concerns about patient privacy – an issue I return to in the conclusion of this chapter. Case managers use these outreach tools to contact individuals who are newly diagnosed or on the OWL, and then determine whether they can be easily linked to care or require linkage to the ARTAS intervention.

Figure 6.6, below, shows the ARTAS workflow, as excerpted from GDPH ARTAS trainings and operations materials. The diagram begins at the top with a "confirmatory test result," operating on the premise on which ARTAS was initially designed: that the intervention will be for the linkage of a person newly diagnosed with HIV to medical care. However, in the Data to Care paradigm and "active re-linkage" strategy pursued by GDPH and other health departments, the starting point could also be an individual on the OWL being targeted for re-linkage. In either case, the case manager would begin the re-linkage process by interacting with an entry in the SENDSS infrastructure and then conducting outreach to the individual they have been assigned.

Just like the closed "Data to Care" loop discussed in the last chapter, and the closed loop staged by electronic laboratory reporting (ELR) in HIV surveillance, the ARTAS intervention is itself a closed loop. I return to the implications of this in the conclusion of this chapter, when I address informed consent at greater length. However, put simply: there is no situation in the diagram below where a client can fully exit the loop of referrals set up by ARTAS. Following the lines from start to finish as they move across the diagram through different stages of the intervention, they all end in receiving "medical care," "other services," or "long term/Ryan

White Case Management.” Further, if an individual “falls out of ARTAS” (per the text on the lower right-hand side of the diagram), they can still be contacted by health department staff.

Figure 6.6. Illustration of the ARTAS (Re-)Linkage-to-Care and Case Management Program



The core elements of ARTAS are the five sessions with the case manager, which are represented in the five square boxes. These are aimed at getting the person living with HIV to become comfortable engaging with medical care, educating them about what HIV is, and giving them tools to self-advocate to medical providers. While the ARTAS client can choose to link to care at any point during the intervention, it is geared toward graduation after the fifth session, when referrals to medical care or case management are made. At any point during the ARTAS intervention, the individual can drop out (although health department personnel are directed to "attempt to locate him/her for the duration of the 90 day period"), or discontinue voluntarily. Either way, if the ARTAS client does one of these things, they will still likely be followed up with later by health department staff. I return to the ethical issues posed by this state-of-affairs in the conclusion of this chapter – particularly regarding patient privacy, confidentiality, informed consent, and individual autonomy in medical decision-making. However, suffice to say that there is no way for people living with HIV to meaningfully opt-out of being contacted by public health agencies in Georgia, whether they are engaged in care or not. Even for those who choose to opt-out of ARTAS interventions or voice their wishes not to be contacted by public health, there is no guarantee that they will not be contacted in the future.

The only way that people living with HIV can exit the re-linkage loop is to engage in medical care, which will be determined by the state department of public health when ELR data begin to be collected on a regularly basis through the HIV surveillance system, thus moving the individual from the "out of care" to "linked to care," then "engaged in care," and then "retained in care" after two instances of bloodwork in a 12-month period. Linking the closed loop of HIV surveillance to additional closed loops of public health intervention creates a kind of closed infrastructural ecosystem from which there is no method of opting out for people living with HIV in the United States. This work is done without individuals' informed consent and with the primary aim of bringing people into medical care so that they can "achieve" viral suppression, thus making them non-infectious: good actors in the healthcare system and contributors to the sanguine project of "Ending AIDS."

While these are noble goals – and while many have certainly been assisted by the Data to Care paradigm and interventions such as ARTAS – there is much less data on the potential negative effects of these interventions on communities and individual people living with HIV/AIDS. Further, there are many lingering questions about the value of approaches to re-linkage and to "Ending AIDS" that are undertaken without the informed consent or knowledge of people living with HIV, as my conversation with Avery and discourses critical of these frameworks in public health reveal.[29]

In the next, penultimate section, I turn to how programs such as those I have described in this and the last chapter are involved in the creation of new hierarchies of sexual and personal value for people living with HIV. I argue that these programs are thus reshaping sexuality for people living with HIV: reorienting the parameters around which state and health controls are exerted on the sexualities and selves of people living with HIV.[30] I then turn back to pressing ethical issues that attend new re-linkage interventions and attempts to proactively trace and reach out to people living with HIV by linking clinical, surveillance, and prevention infrastructures to one another.

V. The New Sex Hierarchy for People Living with HIV: How New HIV Data Infrastructures are Reshaping Sexuality for People Living with HIV

"The weight of the earth is about things in captivity:
animals and people and all that surrounds us."
-David Wojnarowicz (d. 1992), tape-recorded journal entry, November 1988[31]

In what follows, I aim to open new pathways into understanding a four-decade-long drama – one with no End in sight: the drama of HIV/AIDS and its management.[32] During specific periods in the history of AIDS, knowledge about HIV, sexual risk, and the effect of HIV/AIDS on sexual minorities come into friction with one another and can be said to induce broader transformations in the modern sexual system. One could even say that "[in] such periods, the domain of erotic life is, in effect, renegotiated," for people living with and disproportionately affected by HIV/AIDS.[33]

These renegotiations involve the intense and multi-directional transfer of information, bodies, and raw stuff: exchanges between researchers, grassroots activists, institutionalized advocates, public health institutions, clinicians, legal experts, pharmaceutical companies, and people and communities who live with HIV every day. These renegotiations affect people who "live with HIV" in their bodies and those who "live with HIV" as part of their sexual reality – conceptualized as the entire milieu that shapes their sexual decisions and life. Exactly how discourses, approaches, or priorities aimed at controlling, preventing, or governing HIV/AIDS and its transmission migrate from one group or institution to another – from grassroots energy to clinical trial, from researcher's inkling to advocate's ear at a conference, and back again – is often not easy to discern.[34]

Even so, the history of AIDS is peppered with such periods of intense change and knowledge-transfers: dramatic shifts that affect the constitution of biomedical sexualities and sexual realities in the long, menacing, and tentacular shadow cast by the human immunodeficiency virus and responses to it.[35] Douglas Crimp writes of such changes in the official governance of sexuality as the result of developments in the history of AIDS in his 1987 essay "How to Have Promiscuity in an Epidemic." This piece was written a different moment in time, when "male homosexual" (an identity category) was still included in CDC's official HIV risk hierarchy, but when behavioral modes of HIV transmission and methods for effective prevention were widely known among both grassroots activists and epidemiologists:

> The debate about condoms, and safe sex education generally, is one of the most alarming in the history of the AIDS epidemic thus far, because it will certainly result in many more thousands of deaths that could be avoided. It demonstrates how practices devised at the

> grass-roots level to meet the needs of people at risk can be demeaned, distorted, and ultimately destroyed when those practices are coopted by state power.[36]

Crimp writes about how transformations in sexuality rooted in new safer sex practices that sprang from grassroots knowledge were coopted and re-deployed by actors hostile to people living with HIV and gay and bisexual men. He goes on to discuss how public acts of mourning in displays of the NAMES Memorial Quilt Project (the AIDS quilt), and the promotion of safer sex educational materials were used against people living with HIV by social conservatives both in and out of government. “Bottom-up” efforts to educate people at risk of becoming HIV positive about how to protect themselves were framed by elected officials, media actors, clergy, and other powerful actors as perverse attempts to convince “the culture at large to affirm and support the legitimacy of the gay life-style,” per one right-wing activist cited by Crimp[37]

Crimp’s grim prediction in 1987 would prove correct, as laws barring safer sex education in states, “no promotion of homosexuality” policies in schools, and abstinence-only sex education would continue to be enacted and be centerpiece policies encouraged by the religious right in the United States. AIDS, homosexuals, and “sodomy” would remain the primary discursive scapegoats for several decades. However, this did, at some point, seem to wane or give way, as lesbians and gays increasingly became part of civil society discourses and were given a central seat at the table in federal health policy – owing, most recently, in no small part to the proactive efforts of the Obama administration to ensure that this happened.

To this point, the situation is rather different in the contemporary moment, when compared to 1987, 1997, or 2007: there is now a *National HIV/AIDS Strategy of the United States* that was released in 2010 and updated in 2015 by a Democratic administration. This plan has recently been now enhanced by a strategy called *Ending the HIV Epidemic: A Plan for America* released in 2019 by a Republican administration. Support for HIV/AIDS programs is into at least its second or third decade of being a bipartisan public health issue, if bipartisanship is to be measured by votes in Congress or support from the executive branch.

This is the milieu in which recent transformations in the management of HIV/AIDS are also showing themselves to be effectuating transmutations in the modern sexual system – transformations that are particularly pronounced for people living with HIV/AIDS, who I have shown in the last two chapters to be acutely surveilled and targeted by public health interventions with the explicit purpose of bringing them into care, retaining them in care, and helping them become virally suppressed so they are both healthy and (often as the primary concern) non-infectious to others. Biomedical advances in treatment as prevention (TasP), paired with technological advances in HIV surveillance have played a major role in this reorientation of sexual risk and sexuality itself, as it materializes as an actionable object of knowledge by biomedical actors and public health institutions.

In "Thinking Sex," Gayle Rubin posits the existence of a "sex hierarchy" that defines the parameters around which sexuality has been governed and structured by biomedical, legal frameworks, social movements, and other forces that have structured and order sexuality since the late 19th Century. She writes that

> Individuals whose behavior stands high in this hierarchy are rewarded with certified mental health, respectability, legality, social and physical mobility, institutional support, and material benefits. As sexual behaviors or occupations fall lower on the scale, the individuals who practice them are subjected to a presumption of mental illness, disreputability, criminality, restricted social and physical mobility, loss of institutional support, and economic sanctions.[38]

HIV/AIDS, in the course of its nearly four decades of existence as a known public health crisis and individual disease-state, and reactions to HIV/AIDS by society's major institutions have played key roles in reorienting not only how biomedical actors, branches of the state, and social movements (right, left, and otherwise) manage and respond to sexual risk, but also – and largely as an effect of these reactions – how sexuality is organized as a system of power that orders and organizes society, groups, and individual conduct.

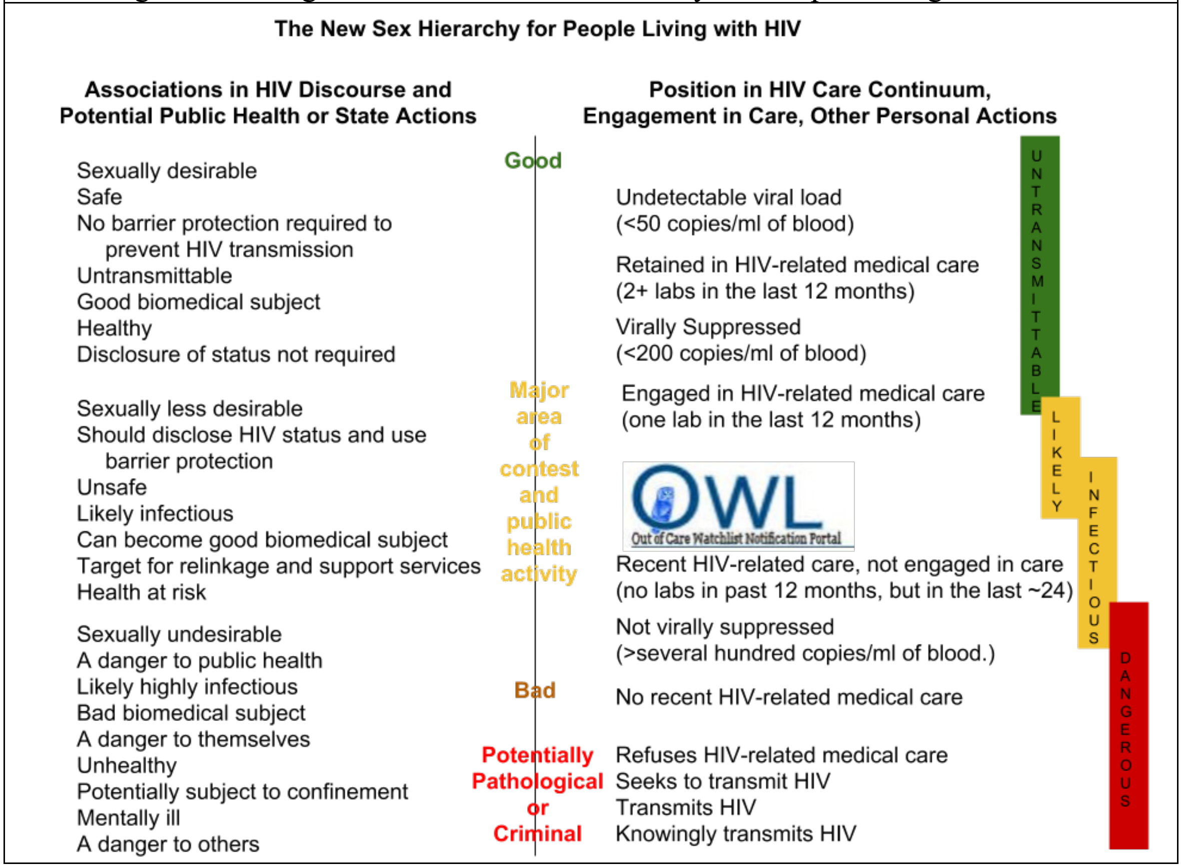
In recent years, sexual identities and subject-positions have even emerged around the real or imagined transmission of HIV virus.[39] As the politics of AIDS and biomedical knowledge about HIV/AIDS changes, so, too, do the virus's effects on sexual health education, biomedical knowledge about sexual risk, and ultimately on sexuality itself. These developments have resulted in what I call a new sex hierarchy for people living with HIV: a sex hierarchy that is determined not *primarily* by good or bad sexual behaviors or identities (although it is in part by this), but chiefly by the molecular and viral content of the blood of individual people living with HIV, their patterns of engagement in medical care, and corresponding actions undertaken by individual people living with HIV and medical institutions.

In the last chapter, I described the HIV Care Continuum and federal Data to Care initiatives as a kind of sanguine method of governing HIV rooted in the naively utopian (or "sanguine") promise of reaching "zero new infections" or the "End of AIDS." This end is to be achieved through the collective and ongoing actions of institutions charged with managing the epidemic – and ultimately of individual people living with HIV – to suppress HIV virus at the population- and person-level using new surveillance technologies, prevention infrastructures, and biomedical advances in HIV treatment and prevention. In this framework, the "End of the Epidemic" can only be pursued and determined by using Electronic Laboratory Reporting (ELR) data that measure the levels of virus in the blood of individual populations: the HIV Care Continuum, Data to Care, and related programs are also therefore literally sanguineous, as in "of or relating to blood." Sanguine strategies for managing HIV that rely on the false promise of "Ending AIDS" and techno-utopian discourses in health IT (programmed visions of perfect interoperability which posit that health data infrastructures can deliver promised outcomes that far exceed their capacities) enact especially cruel optimisms for those targeted by them.[40] The cruelness of these frameworks are especially true in resource-poor places such as metropolitan Atlanta and the state of Georgia: places where the majority of people living with HIV are not virally suppressed, where many people living with HIV do not have regular or easy access to healthcare, where people living with HIV are singled out in the criminal law, and where other problems related to the wellbeing of people living with HIV and their treatment by the public health system simultaneously present a hopefully vision of the future and concrete "obstacles to [their] thriving."[41]

In this chapter, I have worked to demonstrate how the sanguine strategies for governing HIV that are staged by federal HIV/AIDS initiatives and the "End of AIDS" discourse are enacted in practice in Georgia's Data to Care strategy. In the conclusion, I turn to ethical issues in the administration of these programs. However, here, I consider how the state's Data to Care strategy, understood in the discursive context of discourses promoting "Zero New Infections" and the "End of AIDS" are changing the constitution of sexuality for people living with HIV. I frame sexuality here primarily as a mode of ordering society. I am not speaking about individual sexual subjectivities, identities, or "orientations" as much as I am referring to *sexuality the system*: the ontological groundwork from which sexual realities are worked into existence by a multiplicity of actors, institutions, and others through habituated everyday practices.[42]

In Figure 6.7, below, I present a diagram that visualizes "the new sex hierarchy for people living with HIV," as I conceptualize it and as I have observed it take material and discursive shape in my research. This hierarchy is enacted and sustained in the United States primarily through the sanguine frameworks staged by the HIV Care Continuum, Data to Care, and related programs. However, it also comes into existence because of other forces that shape both the history of sexuality and the history of AIDS, which continue to have force in the present. These include non-biomedical HIV prevention methods such as condom use, ethical issues pertaining to HIV disclosure or non-disclosure that are shaped by sex education programs and laws, and HIV criminalization. Together, these forces constitute a hierarchy for people living with HIV that not only govern HIV/AIDS as clinical object and public health issue, but which also reshape and give form to the biomedical sexualities that people living with HIV are assumed to possess, affect the constitution of the modern sexual system, and thus lay the groundwork for new subject-positions.

Figure 6.7. Diagram of the New Sex Hierarchy for People Living with HIV



This diagram is primarily intended to be read first vertically, and then from side-to-side, providing a set of visual coordinates that re-present the topics explored in this chapter and the previous chapter into a single visualization. Beginning at the top, good/desirable sexual subject positions are defined by individuals' low viral loads, untransmittability ("Undetectable = Untransmittable/U=U"), and regular engagement in medical care. The middle section constitutes the "major area of contest" and public health activity (such as "re-linkage" efforts or placement on an Out of Care Watchlist) that people living with HIV are caught up within when they "fall out of care."[43] These are indicators, to the public health system, of their "likely infectiousness." Beneath this are the "Bad" and "Potentially pathological or criminal" zones, where people cross the line into territory that makes them not only non-compliant biomedical subjects, but framed as potentially malevolent actors requiring extreme measures such as arrest, prosecution, and/or other forms of control.

The diagram attempts to capture a particular moment in time, at the intersection of the histories of HIV/AIDS and sexuality, with close attention to the many forces and discourses at work in placing an individual living with HIV in one or another zones using the dominant logics in biomedicine and public health that have largely been taken up by the HIV/AIDS movement. These sanguine framings are designed to coax people living with HIV upward into the "Good" (undetectable and untransmittable) zone, and the HIV/AIDS epidemic itself toward the "End" or "Zero."

Viewed one way, making viral undetectability and TasP the primary goals in the management of HIV/AIDS by using frameworks like the HIV Care Continuum and programs like Data to Care is a kind of institutionalized (or, in Crimp's more framing, "state cooptation") of a practice once called "serosorting."[44] Serosorting is a term that first appeared in the public health literature in the 1990s, referring to practices that gay men had begun employing to engage in sex without condoms while still engaging in practices that would reduce the risk of transmission of HIV to HIV-negative partners. Serosorting has taken different forms, ranging from HIV-positive men only having sex with other HIV-positive men to the early adoption of “treatment as prevention” before it was called this in official policy, where the HIV positive partner was “undetectable,” thus placing the HIV-negative partner at lesser (what would, in 2016 or so, come to be acknowledged as essentially zero) risk of seroconversion. From the vantage of 2019, what was once a set of innovative grassroots safer-sex practice created by gay men is now the central orienting element of HIV governance strategies in the United States: undetectability, untransmittability, TasP. Immensely powerful orienting frameworks and material infrastructures have been built to achieve these ends, to drive individuals into care in the service of public health and to “End HIV.”

However, as the diagram in Figure 6.7 shows, it would be reductive to say that the new sex hierarchy for people living with HIV is reducible to the adoption of TasP by major public health institutions, clinicians, and the broader HIV movement. The new hierarchy is not only held up by this, but by the sum of all the forces that might enable someone to remain in care for years, cause them to fall out of care, or give reason for a state or health actor to act upon them. What is, on the one hand, a reorganization of sexual risk and knowledge about HIV in the service of “Ending the Epidemic” is also a framework that is likely to primarily reproduce or even exacerbate existing inequalities among people living with HIV/AIDS for whom barriers to accessing continuous healthcare are non-trivial – such as access to housing, food, water, and basic healthcare. It is a kind of *de facto* criminalization of the poor, immiserated, or people who are otherwise marginalized and unable to see a doctor regularly.

Despite the best intentions of Infectious Disease doctors, these issues – often discussed as the “social determinants of health” – cannot be solved by the construction of more powerful surveillance, prevention, and re-linkage tools (or even the expansion of existing prevention and care programs).[45] Eliminating these negative "determinants" will require much greater investment in the affected populations and the construction of a more robust healthcare system and social services sector. However, as I have shown in my discussion of the HIV Care Continuum and Data to Care in the United States and the State of Georgia, the direction of the HIV movement is presently toward greater and more precise surveillance.

Time will be the judge of how this most recent development in the history of HIV/AIDS will re-shape the modern sexual system and sexual hierarchies particular to people living with and affected by HIV. However, there can be little doubt that this reshaping will occur and continue to move forward. As the AIDS crisis continues, and its territories transform and its subjects are made targets of increasingly precise and powerful surveillance and interventions, the stakes could not be higher.

VI. Conclusion: Unresolved Ethical Issues in the Integration of HIV Data Infrastructures and Next Steps for HIV Data Reform

In this conclusion, I consider some of the unresolved ethical implications raised by the federal and state programs analyzed in the preceding two chapters. These include issues of informed consent, patient access and control over their health data, and regulatory misalignments in a transformed health information ecology. I end by presenting the beginnings of a potential foundation of a framework for a reform-oriented, multi-stakeholder research agenda for making changes to the governance of HIV/AIDS that are center the rights of people living with HV/AIDS. This framework for action-oriented inquiry would provide opportunities for informed consent and meaningful education about current practices to the HIV workforce and people living with HIV, and it would respect the individual autonomy of people living with HIV in making their personal medical decisions with providers as well as in giving people living with HIV control over use and the exchange of their health data. In proposing this reform-oriented research and policy agenda, I bridge across movements and intellectual traditions, drawing on the stated commitments of HHS, the People Living with HIV/AIDS movement, and the health IT and health informatics profession's patient data bill of rights.

Data to Care, Informed Consent, and "Patient Access and Control Over their Electronic Health Information"

There are specters haunting HIV surveillance and HIV Data to Care interventions in the United States. On the one hand, there is the specter of informed consent, which is required in clinical and research contexts, but not for data held by departments of public health. On the other hand, there is the specter of greater informational liquidity and interoperability between different health IT infrastructures where HIV data are managed. Due to processes of infrastructural creep that I have documented here, public health HIV data infrastructures use clinical data as the basis for public health surveillance, interventions, and research. These clinical data – clinical at point of collection – require informed consent, but do not once those data are transmitted for secondary re-use in surveillance and prevention infrastructures via electronic laboratory reporting (ELR) and other infrastructures.

This raises some basic questions: in an era where data ordered by clinicians, and which primarily serve a clinical purpose, move automatically from clinical contexts where informed consent is required to public health contexts where informed consent is not, should informed consent not also be required for the use of those clinical data for public health surveillance and prevention purposes? How can it be that data which required informed consent at point of collection be transformed into data that can be freely used in ways that patients did not consent to by health departments, in the domains of surveillance and prevention, simply because the data are transmitted from a clinical to a public health infrastructure? How do data that require informed consent to be collected and used in a clinical context for provision of care, not require informed consent for many other secondary uses, just because the data are moved into in different hands? How did such a situation – which presents clear paradoxes in the realm of data ontology management – even come about?

As I have described in this and the previous chapter, the U.S. approach to HIV surveillance is one of the most distinctive elements of the national response. Since the 2000s, person-level HIV surveillance data associated with individuals' first and last names have informed nearly every aspect of the domestic governance of HIV. "HIV surveillance data" held by health departments and "HIV care data" have historically been very separate classes of data that are regulated by different parts of U.S. federal and state laws.

Practitioners still generally work under the premise that HIV surveillance data, clinical data held in medical records, and prevention data still exist separately in reality: in different infrastructures, in different parts of the health apparatus. However, as I have demonstrated, this is no longer the case, speaking from technical, infrastructural, and organizational standpoints. It is only true from the predominant regulatory perspective, which sustains neat divisions between how different classes of HIV data are overseen that increasingly do not reflect the actual IT systems and infrastructures that are used to administer HV care, prevention, and surveillance programs. The regulation of these data has lagged behind the accelerating creep of different infrastructures and data classes into one another.

However, as I have described, HIV care data – clinical data requiring informed consent to be collected and utilized in clinical contexts primarily for clinical purposes – are now also HIV surveillance data. Further, in the Data to Care paradigm, surveillance data are also HIV prevention data. The primary basis for most HIV surveillance data as of 2014 has not been Case Report Forms for newly diagnosed individuals (and reports of progression of individual cases of HIV to AIDS). In the new paradigm driven by the sanguine frameworks of the HIV Care Continuum, the main source of HIV surveillance data are Electronic Laboratory Reports (ELR) sent to HIV surveillance systems after test results are ordered by clinicians for primarily clinical uses.

Further, in the Data to Care paradigm, surveillance data are also prevention data. This is an effect of developments in U.S. health IT, the proliferation of HIV Care Continuum models since 2013, and new standards of HIV care recommending universal antiretroviral therapy and clinical visits twice or more per year for people living with HIV. ELR data generated during provision of care become public health data not subject to informed consent when the data change hands; the data themselves remain the same, but the context transforms the conditions of their use and the terms of their exchange. Why do the conditions of the data's use change when they are simply transposed into a different infrastructure? This logic does not hold water.

To reiterate, when clinical infrastructures become further linked to public health surveillance and prevention infrastructures, the regulations in place governing the use of data in previously-distinct systems no longer reflect the systems and data as they exist and are used in the world. The effect of developments in HIV public health work that have linked data infrastructures from separate domains (care/surveillance/prevention) in the United States, without an accompanying effort to change the way that patient consent is sought regarding uses and re-uses of their data (identifiable in each infrastructure by name, age, and date of birth at least), has been to maintain regulatory distinctions between different classes of HIV data that do not exist as such in HIV practice. Formerly very separate classes of HIV data are increasingly de-differentiated from each other in the day-to-day labor of HIV work.

This collapsing of formerly-distinct classes of data into one another through the integration of clinical, prevention, and public health data infrastructures in HIV is reflective of broader trends in the development of the nationwide interoperable health IT infrastructure. An examination of this transformed landscape regarding uses of HIV data in the new health IT ecology and accompanying regulatory lag lays bare the need for reforms in this area that can not only adapt to the new health data ecosystem, but which can also ensure patients' "access to and control over" their electronic health information – a stated priority of HHS.[46]

Patient access and control over their health data is a stated priority of HHS in documents such as the *Federal Health IT Strategic Plan, 2015-2020* and rulemaking processes led by the Office of the National Coordinator for Health Information Technology (ONC) following passage of bills such as the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) and the 21st Century Cures Act of 2016. For example, the *Federal Health IT Strategic Plan, 2015-2020* clearly states that HIV is a protected class of sensitive electronic health information which patients should have the "ability to control the exchange of…in an electronic environment":

> The federal government is committed to stimulating the development and use of policy, standards, and technology to advance individuals' rights to securely access, amend, and make choices for the disclosure of their electronic health information.
>
> The federal government supports these developments to achieve two ends. First, **the government should facilitate patients' ability to control the exchange of specific health information that many consider to be "sensitive" (which includes information related to substance use disorder treatment, reproductive health, mental health, domestic abuse, or HIV), in an electronic environment**. For example, using technology to document applicable permissions to access, use or disclose health information saves time and resources, and can build trust and confidence in the system

> overall. Second, such developments should support the availability of health information about individuals when and where they need it for treatment.[47]
>
> (emphasis mine)

This same commitment to patient access and control over their electronic health information is reflected in rule-making processes led by ONC regarding the creation of new interoperability and health IT certification frameworks. Further, ONC – the coordinating entity charged with regulation health data infrastructures has made "electronic health information" (EHI) a capacious and emergent regulatory category that does not only include clinical data or data in certified health IT, but many other classes of EHI.[48] This lack of differentiation between different data classes on ONC's part reflects the fact that the development of the nationwide interoperable health IT infrastructure has been built specifically with the aim of collapsing distinctions between different classes of health data and linking public health, clinical, research, and other sources of electronic health information to one another in order to foster information liquidity in the healthcare system, the provision of value-based care, and the cultivation of a "person-centered," "learning healthcare system" that places individual patients in control of their health information.[49]

ARTAS: What Not Requiring Informed Consent in Data to Care Means in Practice

Consider, again, the "Anti-Retroviral Treatment and Access to Services" (ARTAS) intervention. If you are an individual living with HIV who is not retained in regular HIV-related medical care, it is currently not possible to meaningfully evade being targeted for the ARTAS intervention. The Georgia ARTAS informed consent form contains the following paragraph:

> The Health Department tries to contact all people with HIV to make sure they know about their diagnosis, know where to get medical care, and help any partners get tested. This is required by law and would happen whether or not you are enrolled with this provider. So, if you are diagnosed with HIV or an STD, the Health Department may still contact you even if you choose not to participate.[50]

Several paragraphs down, however, the following sentence appears:

> Your participation is voluntary. You may choose to withdraw at any time. **Your decision not to participate will in no way impact the services you may be getting now or may get in the future** from any of the ARTAS Intervention partners/agencies/organizations.[51]
>
> (emphasis mine)

The claim that "participation is voluntary" in the specific ARTAS intervention an individual is participating in at that time may be true. However, it is not true when extended to the entire re-linkage enterprise, from which there is no opting out. This is, of course, because "the Health Department may still contact you even if you choose not to participate," because neither health department outreach nor HIV surveillance activities are subject to informed consent requirements (despite their main source of data being laboratory test results ordered by clinicians, for clinical purposes, which requires informed consent in that context).

Further, if an individual is contacted at a later date (at least in Georgia), the likely goal will be to get that induvial to re-engage in an ARTAS intervention. Even if a person living with HIV chooses not to participate in ARTAS or "drops out" of the program, it is not possible to totally avoid ARTAS in the long-term until they are "retained in care" from the vantage of the state HIV surveillance system. This is because of the closed feedback loops of surveillance and Data to Care. The introduction of informed consent into this milieu would provide individuals living with HIV – in care or otherwise – with the ability to opt out or to withhold their consent to participate. The need to provide these opportunities is standard procedure in the overwhelming majority of health contexts and digital services. It should also be so in the realm of HIV, so that the rights of people living with HIV are respected and given the same consideration as people who are not living with HIV.

The sincere alternative would be for HHS to acknowledge clearly that people living with HIV do not possess the same rights that other patients do: that people living with HIV are second-class citizens or what has been called a "viral underclass," and that health data infrastructures are built to manage them as individuals and a group around this orienting principle or maxim.[52] This would constitute the official recognition of what is already the case in practice, and would help to clarify the stakes.

Data to Care and HIV Criminalization: Toward Expanded Understandings of HIV Criminalization that Includes Everyday Administrative Violence

Recently, "carceral studies" and critiques of everyday "administrative violence" have emerged as a distinct field of inquiry that exists in critical dialogue with the prison abolition movement and other movements aimed at eliminating inequalities in society through the radical refashioning of the social order and the unmaking of systems such as white supremacy and heteronormativity.[53] As carceral studies scholars Michelle Brown and Judah Schept write in a recent article:

> New abolitionists and critical carceral studies scholars show little interest in a public sociology or criminology dedicated to questions of abolition's political tenability in policy discussions. Rather, their work emanates from experiences, practices, and movement-generated theories grounded in survivability: the urgent pursuit of liberation from the threat of captivity, torture, and social death, from generational histories in the continuous shadow of conquest, settler colonialism, slavery, Jim Crow, and the carceral state.[54]

Most work on HIV criminalization has focused on the threat of imprisonment due to HIV criminalization laws, practices of community policing by public health officials, or uses of public health infrastructures as mechanisms of control usually relegated to police.[55] However, the current assemblage of sociotechnical, jurisprudential, and sometimes literal enclosures to which people living with HIV are subjected require a broadened understanding of HIV criminalization.

This is because these systems themselves constitute a kind of *de facto* criminalization – what Trevor Hoppe calls the conversion of disease from “sickness” into “badness” – and are critical elements of a larger set of mechanisms that are used to effectuate a variety of forms of digital and other sorts of confinement, shaping of life patterns, and controlling of movements.

Such a broadened understanding of the notion of criminalization in regard to the treatment and autonomy of people living with HIV would consider overly-aggressive linkage efforts or attempts to hold people who have dropped out of care in a clinic or another context to be unacceptable. It would emphasize freedom of will, autonomy, and the need for vastly expanded and improved HIV care and prevention education and supportive services. People living with HIV should have the freedom to refuse engagement with a program for whatever reason, to engage in medical care on their own terms, and to decline to participate in programs in such a fashion that actually allows them to exit those programs. As part of this, people living with HIV should have the right to refuse to participate in HIV surveillance and any other intervention: participation should be discretionary, and interventions should be designed to support people living with HIV. The burden of articulating their value to people living with HIV (to solicit their participation) should be on the public health institutions that manage the programs, and should be done non-coercively. This will require new models for governing HIV that cast aside the old ones. Innovative models of health data management are emergent that could offer models for doing this work.[56]

The distribution of out of care lists to health district staff also increases the possibility of coordination between public health authorities, police, and criminal prosecutors, particularly in the event that an individual on an out of care lists resists to re-linkage or is determined to have had sexual contact with HIV-negative people. Currently, Georgia has a particularly draconian

HIV criminalization statute that makes it illegal for an HIV-positive person to have any kind of sex without disclosing their status. The Williams Institute at The University of California – Los Angeles Law School released a report on HIV criminalization in Georgia in January 2018, one of the main findings of which was that arrests using the state's HIV criminalization law are far more common in rural areas than they are in metro Atlanta. In some small counties, up to 10% of people living with HIV had experienced a logged arrest related to their HIV status, and fully 1.3% of people living with HIV in rural Georgia had experienced some kind of arrest based on their status.[57] These are only data about logged arrests where the arresting officer opted to fill out all of the required paperwork in the state database and to reference the HIV criminalization statute (in other words, almost certainly an under-count of total HIV-related arrests). The report does not capture casual encounters with, or harassment by police, nor does it capture casual contact with health department personnel that are experienced as harassing or invasive. The discourse on HIV criminalization should be expanded from primarily being concerned with prosecutions and arrests of people living with HIV by police to also include the everyday or *de facto* criminalization of HIV by logics in healthcare that disproportionately and proactively target people living with HIV on the "low" or "bad" end of the spectrum of engagement in medical care.

From sociologist Trevor Hoppe's work on HIV criminalization in Michigan and other states, and work by HIV decriminalization activists, it is known that public health staff in other states have actively coordinated with local law enforcement to refer people for investigation and prosecution when a suspected transmission or instance of non-disclosure of HIV-positive status has occurred. This is not a theoretical problem, but an active threat to people living with HIV. During fieldwork, I attended a statewide planning meetings where a health district staff person called for the criminal prosecution of pregnant women living with HIV who are not engaged in care. It was further reported to me by multiple interlocutors that several Communicable Disease Specialists who work in county health departments in the Atlanta metro area are supportive of existing HIV criminalization laws. When I asked about the possibility of criminal prosecution occurring as the result of OWL distribution, a leader in HIV surveillance at GDPH said they had not thought of this issue, were unaware that coordination between law enforcement and public health was a documented phenomenon, and cited Michigan's approach as a model that Georgia looked to for execution of its Data to Care strategy.[58]

Systemic discrimination against LGBTQ people and people living with HIV is endemic in many of Georgia's health districts (rural and otherwise). One GDPH official who I have worked with extensively, and whose primary job is to coordinate programs related to the health of sexual and gender minorities in the state, told me that they are regularly met with giggles or open moralism when they travel around the state to interact with health district staff to educate them about HIV prevention and other issues in sexual and gender minority health. "It's disgusting," they once said to me, shaking their head. Rural Georgia is also made up of very tight-knit communities where nearly everybody knows each other or is only one degree of remove from nearly everyone in their town. In these contexts, it is likely that people on the OWL will be assigned to be re-linked to care by people in their immediate social networks.

Against backdrops of potential harassment, pervasive stigma, the threat of contact with police and criminal prosecution, and the potential impossibility of successfully remaining in care due to lack of public health infrastructure in a state where many counties do not even have a single HIV provider, the distribution of lists of people living with HIV who are out of care – who are perceived as more likely to be infectious, sexually dangerous, or otherwise deviant, and who are also more likely to come from the most vulnerable segments of the population – is as distressing a development as it is a positive one.

Next Steps for HIV Data Reform: Toward a Reform-Oriented, Person-Centered, Multi-Stakeholder Research Agenda

In the preceding sections, I have described how the proliferation of new health IT systems and standards, advances in HIV care that focus on treatment as prevention as the central strategy in controlling the epidemic, and frameworks for managing HIV such as the "HIV Care Continuum" and "Data to Care" have collectively transformed how HIV/AIDS is governed in the United States. In the conclusion, I focused on how the collapse of formerly-distinct classes of HIV data and HIV data management infrastructures into one another – particularly via the technical and organizational linkage of clinical, surveillance, and prevention infrastructures that are managed by state and local health departments following federal technical guidelines – raise serious questions about informed consent, patient privacy, and patient access and control over their electronic health information. In presenting the information as I did, I aimed to highlight tensions in both policy and practice at the federal, state, and local level, and some of the potential ramifications for patients generally and for people living with and affected by HIV/AIDS. In sum, the current regulations that exist to govern the exchange and use of HIV data are increasingly out of alignment with current best practices and relevant infrastructures as they exist in states and localities.

In this final section, I describe some potential next steps for the community of HIV/AIDS stakeholders in light of these findings, with the aim of bringing utilizations of HIV data generated by and transmitted between clinical, prevention, research, and surveillance infrastructures into closer alignment with HHS policies that prioritize patient access to and control over their health information. My approach is not only informed by HHS priorities regarding the regulation of electronic health information, but also by the longstanding commitment of the People Living with HIV/AIDS movement and of the health informatics profession that patients have the right to know, access, and control how data about them are collected and transmitted in different health contexts and IT infrastructures.[59]

An interdisciplinary and broad-based consensus about patient access and control over health information exists in the health IT and HIV/AIDS movements. However, it has yet to be articulated as such, or formulated into an actionable program for policy reform or collaborative research.

In the domain of health IT, documents such as the *Federal Health IT Strategic Plan, 2015-2020* and related publications by ONC emphasize patient access and control over their health data as a central priority. In the domain of HIV/AIDS advocacy, publications such as the 1983 Denver Principles by the People with AIDS Coalition describing the rights of people living with HIV to "full explanations of all medical procedures and risks…to make informed decisions about their lives" and to "privacy, to confidentiality of medical records" and critical advocacy by groups such as the Positive Women's Network-USA lay the groundwork for sustained advocacy around people living with HIV having rights to be informed about uses of their data and even to control instances of exchange.[60] Uniting these threads of health IT governance and advocacy by and for people living with HIV in the realm of HIV data, the American Health Information Management Association (AHIMA) – a key professional organization for health informatics professionals – has published the "Consumer Health Information Bill of Rights: A Model for Protecting Health Information Principles." That document says that patients should have the right to:

1. Look at your health information and/or get a paper or electronic copy of it
2. Accurate and complete health information

3. Ask for changes to your health information
4. Know how your health information is used or shared and who has received it
5. Ask for limitations on the use and release of your health information
6. Expect your health information is private and secure
7. Be informed about privacy and security breaches of your health information
8. File a complaint or report a violation regarding your health information[61]

Taken together, a shared concern for patient consent, access, and control over health information collection and exchange can be discerned: a program of inquiry and action which cuts across many different constituencies in the public health system, health policy community, and overall health IT ecology.

I propose that these shared interdisciplinary principles be the starting point for a reform-oriented research agenda regarding how HIV data – and potentially other sensitive health data – ought to be collected, exchanged, and utilized at the intersection of clinical service provision, public health surveillance, and prevention. This research agenda should result from sustained dialogue and engagement by policymakers, patients, patient advocates, researchers, practitioners, bioethicists, health IT professionals, and others. It should focus on bringing out what in bioethics are called the Ethical, Legal, and Social Implications (ELSI) of the full range of new, widespread, and accelerating practices linking clinical, surveillance, research, and prevention data infrastructures in HIV and related domains of practice. It should not merely assess the landscape, but should also focus on generating concrete proposals to bring federal and state policy into alignment with current practice, and on recommending new best practices which center the needs and rights of people living with HIV regarding informed consent, access to their electronic health information, and control over its exchange.

Creating such a research agenda – one oriented toward driving reforms in healthcare policy, practice, and implementation – will take the investment of time and resources by key stakeholder groups. It should be the focus of future research agendas and sustained engagement by civil society institutions across the healthcare system. Some of these, such as the CDC, ONC, the National Institutes of Health, and Institute of Medicine, have figured centrally in this dissertation. Others – such as advocacy organizations focused on patients' rights, groups dedicated to advancing the interests of people living with HIV/AIDS, and bioethics institutes housed at universities – have not. However, in the years ahead, as the nationwide interoperable health IT ecosystem continues to expand and as new tools to bring about the "End of AIDS" and "Zero New Infections" are further honed and utilized to identify and re-link individual people living with HIV to services with greater and greater precision, all stakeholders stand to benefit through greater collaboration. As these conversations move ahead, I aim to advance the cause of greater patient access and control over their health data, and healthcare workforce education pertaining to the ethical exchange and use of HIV data, and to utilizing the capacities of new health information technologies to give individuals greater abilities not only to access, but also to control the exchange and utilization of their electronic health information. Through this work, I hope to contribute to the development of health information ecologies that both empower individuals and put infrastructures to use for the maximum benefit of individual and collective wellbeing – particularly for people living with and affected by HIV.

References for Chapter 6

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[1] On 30-day linkage-to-care for new cases of HIV in the United States, and the twice-annual bloodwork recommendations, see, Centers for Disease Control and Prevention, "Understanding the HIV Care Continuum" (Atlanta, GA, June 2018), https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf; See also, World Health Organization, "Guideline on When to Start Antiretroviral Therapy and on Pre-Exposure Prophylaxis for HIV," September 2015, http://apps.who.int/iris/bitstream/handle/10665/ 255884/9789241550062-eng.pdf?sequence=1.

[2] Stacy M. Cohen et al., "The Status of the National HIV Surveillance System, United States, 2013," *Public Health Reports* 129, no. 4 (July 2014): 335–41, https://doi.org/10.1177/003335491412900408; Centers for Disease Control and Prevention, "HIV Surveillance Report, 2011" (Centers for Disease Control, February 2013), https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2011-vol-23.pdf, 5.

[3] See the discussion in the previous chapter, and see also, CDC, "Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum (the 'Data to Care Toolkit'" (Atlanta, GA, 2014), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/pdf-of-important-considerations.pdf; CDC, "Data to Care Program Guidance: Using HIV Surveillance Data to Support the HIV Care Continuum" (Atlanta, GA: Centers for Disease Control and Prevention (CDC), August 2017), https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/datatocareprogramguidance.pdf; interviews with GDPH staff.

[4] This infrastructure is sometimes called the "Georgia Public Health Information Exchange," indicating its potential use for other public health purposes. However, I refer to it as the HIV HIE, because this is what it is most commonly called.

[5] Interviews with GDPH surveillance and prevention personnel.

[6] For a discussion of the nationwide interoperable health IT infrastructure, see chapter two of this dissertation. For treatments of clinical data that use metaphors of scale and speed in the manner I do here, see, Steven C. Tiell et al., "Informed Consent and Data in Motion: Preventing Unintended Consequences through Stronger Data Ethics" (Accenture Labs, 2016), https://www.accenture.com/t20180705T112407Z__w__/us-en/_acnmedia/PDF-30/Accenture-Informed-Consent-Data-Motion.pdf; Christine L. Borgman, *Big Data, Little Data, No Data: Scholarship In the Networked World* (Cambridge, MA: The MIT Press, 2015); Cornelius Puschmann and Jean Burgess, "Metaphors of Big Data," *International Journal of Communication* 8 (2014): 1690–1709.

[7] ONC, "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0" (The Office of the National Coordinator for Health Information Technology (ONC), 2015), https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf, *passim*.

[8] Interviews with GDPH surveillance personnel in 2017 and 2018.

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[9] AIDSVu, "About AIDSVu: Making HIV-Related Data Widely Available, Easily Accessible & Locally Relevant to Inform Public Health Decision Making," 2019, https://aidsvu.org/about/.

[10] CDC, "Data to Care Program Guidance," 3.

[11] For an exploration of this issue in a very different geographic context and HIV epidemic, see, Julia C. Dombrowski et al., "'Out of Care' HIV Case Investigations: A Collaborative Analysis Across 6 States in the Northwest US," *Journal of Acquired Immune Deficiency Syndromes (1999)* 74 Suppl 2 (February 1, 2017): S81–87, https://doi.org/10.1097/QAI.0000000000001237. These authors concluded that "[m]ost persons living with HIV in the Northwest US who appear to be out of care based on laboratory surveillance are not truly out of care," owing to "missing laboratory reports because they have moved out of state and established medical care elsewhere or are in-state but did not have laboratory results captured in the surveillance system," S81-2.

[12] Here I draw from conversations with interlocutors. I also draw from a PowerPoint presentation and and a conference presentation by GDPH interlocutors, which I do not cite in order to conceal the identities of interlocutors who do not wish to be identified.

[13] GDPH personnel framed the HIV HIE as an evidence-based intervention in interviews. On the webpage dedicated to explaining the HIV HIE website (which has since been taken down) GDPH staff also cite these articles to support the evidence-base for the HIE as a public health intervention: J. Herwehe et al., "Implementation of an Innovative, Integrated Electronic Medical Record (EMR) and Public Health Information Exchange for HIV/AIDS," *Journal of the American Medical Informatics Association* 19, no. 3 (May 1, 2012): 448–52, https://doi.org/10.1136/amiajnl-2011-000412.

For the case study of the Louisiana project in the Project Inform "Think Tank" report, see, Project Inform Staff, "Using Surveillance and Other Data to Improve HIV Care Linkage and Retention" (San Francisco, CA: Project Inform, June 7, 2012) https://www.projectinform.org/pdf/surveillance_0313.pdf, 8-10.

[14] These data come from the public-facing Georgia HIV HIE webpage, which was closed in or around December 2018.

[15] Georgia General Assembly, "2013-2014 Regular Session - SB 342 Evidence; Disclosure of a Person's HIV Status to Certain Health Care Providers" (Atlanta, GA, March 2014), http://www.legis.ga.gov/legislation/en-US/display/20132014/SB/342; Georgia General Assembly Senate Health and Human Services Committee, "Minutes of the Senate Health and Human Services Committee , 2013-2014 Regular Session" (Atlanta, GA: Georgia General Assembly, 2014), http://www.senate.ga.gov/committees/Documents/2014Minutes76.pdf, 25; Dean Burke, "Senate Bill (SB) 342: A Bill to Be Entitled An Act To Amend Code Section 24-12-21 of the Official Code of Georgia Annotated, Relating to Disclosure of AIDS Confidential Information, so as to Provide for Disclosure of a Person's HIV Status to Certain Health Care Providers; to Provide for Related Matters; to Repeal Conflicting Laws; and for Other Purposes.," Pub. L. No. SB432, Georgia Code (2014), http://www.legis.ga.gov/Legislation/20132014/141750.pdf.

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[16] Dini Harsono et al., "Criminalization of HIV Exposure: A Review of Empirical Studies in the United States," *AIDS and Behavior* 21, no. 1 (January 2017): 27–50, https://doi.org/10.1007/s10461-016-1540-5.

[17] Amira Hasenbush, "HIV Criminalization in Georgia: Penal Implications for People Living with HIV/AIDS" (Los Angeles, CA: Williams Institute, January 2018), https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-Georgia-Jan-2018-1.pdf.

[18] I utilized a publicly-available LexisNexis database of a searchable version of the Georgia Code, along with limited legislative history, to determine this. This is the reference edition of the Georgia Code to which the website of the Georgia Secretary of State refers members of the public. See, State of Georgia, "Official Georgia Code Annotated" (LexisNexis), https://advance.lexis.com/container?config=00JAAzZDgzNzU2ZC05MDA0LTRmMDItYjkzMS0xOGY3MjE3OWNlODIKAFBvZENhdGFsb2fcIFfJnJ2IC8XZi1AYM4Ne&crid=fd5bf2e0-e346-44a6-a11b-0de8a834af83&prid=8e7794f5-ff01-4228-bcc8-c6f9ad76a2a3.

[19] On the expansion of HIV criminalization to other diseases, see, Trevor Hoppe, *Punishing Disease: HIV and the Criminalization of Sickness* (Oakland, California: University of California Press, 2018), 10-17. For a brief overview of efforts to reform HIV criminal laws in Georgia since 2013, see, Georgia HIV Justice Coalition, "Georgia HIV Justice Coalition: About," https://thegeorgiacoalition.wordpress.com/.

[20] This figure and some of the contextual data for this subsection comes from a PowerPoint presentation about the HIV HIE process that was shared with me by interlocutors at GDPH during fieldwork.

[21] For a general overview of patient-matching, identity-proofing, and "Patient Identity Management" best practices and challenges in health IT, and how it fits into the broader federal Health IT strategy, see, Allison B McCoy et al., "Matching Identifiers in Electronic Health Records: Implications for Duplicate Records and Patient Safety," *BMJ Quality & Safety* 22, no. 3 (March 2013): 219–24, https://doi.org/10.1136/bmjqs-2012-001419; Claudia Williams et al., "From The Office Of The National Coordinator: The Strategy For Advancing The Exchange Of Health Information," *Health Affairs* 31, no. 3 (March 2012): 527–36, https://doi.org/10.1377/hlthaff.2011.1314; Rita Torkzadeh, "Advancing a Nationwide Patient Matching Strategy," *Journal of AHIMA* 89, no. 7 (August 2018): 30–35.

[22] Interview conducted with the Nurse Case Manger on-site on April 27th, 2018.

[23] Interview with the case manager who acts on HIV HIE alerts sent through the public hospital system's EHR conducted by phone on May 29th, 2018.

[24] In Georgia, county-level health departments are called "Boards of Health," although I will continue to refer to "local health departments." Further, the structure of the public health system in Georgia is made up of nested political subdivisions: 18 "public health districts" that govern

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boards of health that are operated by counties. There are 159 counties in Georgia, but many counties combine services. While I did fieldwork with the state Department of Public Health, which has jurisdiction over health districts and local health departments outside of metropolitan Atlanta, my fieldwork was limited to the Atlanta metro area.

[25] Hoppe, *Punishing Disease*, 71.

[26] Thomas P. Giordano, "Strategies for Linkage to and Engagement With Care: Focus on Intervention," *Topics in Antiviral Medicine* 26, no. 2 (June 2018): 62–65; Lytt I. Gardner et al., "Psychological and Behavioral Correlates of Entering Care for HIV Infection: The Antiretroviral Treatment Access Study (ARTAS)," *AIDS Patient Care and STDs* 21, no. 6 (June 2007): 418–25, https://doi.org/10.1089/apc.2006.0115; Lytt I. Gardner et al., "Enhanced Personal Contact with HIV Patients Improves Retention in Primary Care: A Randomized Trial in 6 US HIV Clinics," *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America* 59, no. 5 (September 1, 2014): 725–34, https://doi.org/10.1093/cid/ciu357.

[27] Interview with a GDPH linkage manager.

[28] Participation in the ARTAS intervention itself does require informed consent. However, as I describe in sections below, health department staff can continue to contact individuals who choose not to participate in ARTAS or other re-linkage interventions.

[29] See, for example, Nora Kenworthy, Matthew Thomann, and Richard Parker, "Critical Perspectives on the 'End of AIDS,'" *Global Public Health* 13, no. 8 (August 3, 2018): 957–59, https://doi.org/10.1080/17441692.2018.1464589.

The study of the actual practice of re-linkage programs on individuals targeted by them pose serious methodological and ethical challenges for social scientists who want to study them. For example, how would a social scientist ethically follow a Communicable Disease Specialist employed by a local health department through the pathways of outreach (which can involve home visits to individuals), and then measure the ripple effects of these contacts on the social networks of those contacted? How can the material effects of a notification letter sent through the mail be traced? From the perspective of a social scientist or ethnographer, how can any of this empirical work be done while respecting the rights of the human subjects? It is difficult to imagine that any Institutional Review Board (IRB) or other research ethics review body would approve such a study, since most such studies require the informed consent of participants (which health department outreach does not). The inscrutability of (re-)linkage programs are central reasons that they ought to be systematically examined, studied, and ideally reformed with the input of a diverse range of stakeholders. I return to this topic in this chapter's conclusion.

[30] This is not, per se, a new argument. See especially, Karen C. Lloyd, "Centring 'Being Undetectable' as the New Face of HIV: Transforming Subjectivities via the Discursive Practices of HIV Treatment as Prevention," *BioSocieties* 13, no. 2 (June 2018): 470–93, https://doi.org/10.1057/s41292-017-0080-1; Susan Kippax and Niamh Stephenson, *Socialising the Biomedical Turn in HIV Prevention* (London, UK ; New York, NY: Anthem Press, an imprint of Wimbledon Publishing Company, 2016).

However, it is a new argument in that I am centering infrastructures that have been built to manage and create these new parameters for sexual subjectivity, and I believe I am the first to lay it out in the systematic fashion that I do in the next section.

[31] David Wojnarowicz et al., *Weight of the Earth: The Tape Journals of David Wojnarowicz* (South Pasadena, California: Semiotext(e), 2018).

[32] I capitalize "End" here to reflect the curious practice of nearly always capitalizing the "End of AIDS" when it is spelled out. See for example: Fulton County Task Force on HIV/AIDS, "Phase III Progress Report: Building the Strategy to End AIDS in Fulton County" (Fulton County, GA: Fulton County, July 31, 2017).

On there being no end in sight, see, Jane M. Kelly et al., "Achieving NHAS 90/90/80 Objectives by 2020: An Interactive Tool Modeling Local HIV Prevalence Projections," ed. Rasheed Ahmad, *PLOS ONE* 11, no. 7 (July 26, 2016):, https://doi.org/10.1371/journal.pone.0156888; Luchuo Engelbert Bain, Clovis Nkoke, and Jean Jacques N Noubiap, "UNAIDS 90–90–90 Targets to End the AIDS Epidemic by 2020 Are Not Realistic: Comment on 'Can the UNAIDS 90–90–90 Target Be Achieved? A Systematic Analysis of National HIV Treatment Cascades,'" *BMJ Global Health* 2, no. 2 (March 2017): e000227, https://doi.org/10.1136/bmjgh-2016-000227; HIV Epidemiology Section, Georgia Department of Public Health, "Georgia HIV Care Continuum Update: Persons Living with HIV, 2016, and Persons Diagnosed with HIV, 2015" (2018), https://dph.georgia.gov/hiv-care-continuum.

[33] Gayle Rubin, "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality," in *Deviations: A Gayle Rubin Reader* (Durham: Duke University Press, 2011), 138.

[34] See, Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley, CA: University of California Press, 1996); Alexis Shotwell, "'Women Don't Get AIDS, They Just Die from It:' Memory, Classification, and the Campaign to Change the Definition of AIDS," in *Against Purity: Living Ethically in Compromised Times* (Minneapolis: University of Minnesota Press, 2016).

[35] I borrow the metaphor of tentacles and the notion of "tentacular thinking" from Donna Haraway, who writes that "[t]entacularity is about life lived along lines – and such a wealth of lines – not at points, not in spheres. 'The inhabitants of the world, creatures of all kinds, human and non-human, are wayfarers"; generations are like 'a series of interlaced trails.'" *Staying with the Trouble: Making Kin in the Chthulucene,* (Durham: Duke University Press, 2016), 31-2.

[36] Douglas Crimp, "How to Have Promiscuity in an Epidemic," *October* 43 (1987): 256.

[37] Ibid., 259

[38] Rubin, "Thinking Sex," 149.

[39] Tim Dean, *Unlimited Intimacy: Reflections on the Subculture of Barebacking* (Chicago; London: The University of Chicago press, 2009).

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[40] Lauren Gail Berlant, *Cruel Optimism* (Durham: Duke University Press, 2011), 1; Wendy Hui Kyong. Chun, *Programmed Visions: Software and Memory* (Cambridge, MA: MIT Press, 2011), 9.

[41] Ibid.

[42] I refer to the sexual system or "sexuality" as what Michel Foucault characterizes as a "multiplicity of discourses produced by a whole series of mechanisms operating in different institutions," that is continuously developing and too complex to be totally described, see, *The History of Sexuality, Vol. 1*, trans. Robert Hurley (New York, NY: Vintage Books, 1978) 33-5.

[43] "Major area of contest" is drawn from Rubin's diagram of the sex hierarchy in, "Thinking Sex," 155.

[44] See, David M. Halperin, *What Do Gay Men Want?: An Essay on Sex, Risk, and Subjectivity* (Ann Arbor, MI: University of Michigan Press, 2007); Iryna B. Zablotska et al., "Gay Men's Current Practice of HIV Seroconcordant Unprotected Anal Intercourse: Serosorting or Seroguessing?," *AIDS Care* 21, no. 4 (April 2009): 501–10, https://doi.org/10.1080/09540120802270292; Limin Mao et al., "'Serosorting' in Casual Anal Sex of HIV-Negative Gay Men Is Noteworthy and Is Increasing in Sydney, Australia:," *AIDS* 20, no. 8 (May 2006): 1204–6, https://doi.org/10.1097/01.aids.0000226964.17966.75.

[45] See the solutions proposed in, for example, Jonathan Colasanti and Wendy S. Armstrong, "A Glimpse of the Early Years of the Human Immunodeficiency Virus Epidemic: A Fellow's Experience in 2014," *Open Forum Infectious Diseases* 1, no. 2 (2014), https://doi.org/10.1093/ofid/ofu035; Fulton County Task Force on HIV/AIDS, "Phase III Progress Report: Building the Strategy to End AIDS in Fulton County" (Fulton County, GA: Fulton County, July 31, 2017); Department of Health and Human Services, "Ending the HIV Epidemic: A Plan for America," February 7, 2019, https://www.hhs.gov/sites/default/files/ending-the-hiv-epidemic-fact-sheet.pdf.

[46] HHS Press Office, "HHS Proposes New Rules to Improve the Interoperability of Electronic Health Information," February 11, 2019, https://www.hhs.gov/about/news/2019/02/11/hhs-proposes-new-rules-improve-interoperability-electronic-health-information.html.

[47] Office of the National Coordinator for Health Information Technology (ONC), "Federal Health IT Strategic Plan, 2015-2020" (Washington, D.C.: Office of the Secretary, United States Department of Health and Human Services, 2015), https://www.healthit.gov/sites/default/files/9-5-federalhealthitstratplanfinal_0.pdf, 25.

[48] Office of the National Coordinator for Health Information Technology (ONC), "NOTICE OF PROPOSED RULEMAKING: 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program" (Washington, DC: Federal Register, March 3, 2019), https://www.regulations.gov/document?D=HHS-ONC-2019-0002-0001.

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[49] ONC, "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Final Version 1.0" (The Office of the National Coordinator for Health Information Technology (ONC), 2015), https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf, *passim*.

[50] Georgia DPH. "Form HIV-562: ARTAS Informed Consent Form," n.d. https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV-562_ARTAS%20Informed%20Consent%20Form_1.24.13_0.pdf.

[51] Ibid.

[52] The use of "viral underclass" come primarily from considerations of people living with HIV in the criminal law, but can be extended elsewhere. See, Sean Strub, "Prevention vs. Prosecution: Creating a Viral Underclass," *POZ Magazine*, October 18, 2011, https://www.poz.com/blog/prevention-vs-prosec.

[53] On administrative violence, see, Dean Spade, *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law* (Brooklyn, NY: South End Press, 2011).

[54] Michelle Brown and Judah Schept, "New Abolition, Criminology and a Critical Carceral Studies," *Punishment & Society*, September 7, 2016, https://doi.org/10.1177/1462474516666281, 443.

[55] Hoppe, *Criminalizing Disease*, *passim.*

[56] For example, see, Joan Rodon Mòdol, "Citizens' Cooperation in the Reuse of Their Personal Data: The Case of Data Cooperatives in Healthcare," in *Collaboration in the Digital Age*, ed. Kai Riemer, Stefan Schellhammer, and Michaela Meinert (Cham: Springer International Publishing, 2019), 159–85, https://doi.org/10.1007/978-3-319-94487-6_8.

[57] Hasenbush, "HIV Criminalization in Georgia."

[58] Interview with a GDPH HIV surveillance manager conducted in spring 2018.

[59] People with AIDS Advisory Committee, "The Denver Principles," 1983, http://www.actupny.org/documents/denver_principles.pdf; American Health Information Management Association, "AHIMA Consumer Health Information Bill of Rights: A Model for Protecting Health Information Principles," *Journal of AHIMA* 86, no. 9 (September 2015): 40–41.

[60] Ibid.; Martha Kempner, "New Study Triggers Concerns Over Use of Molecular HIV Surveillance," *The Body Pro: The Complete HIV/AIDS Resource*, March 4, 2019, http://www.thebodypro.com/content/81639/concerns-over-use-of-molecular-hiv-surveillance.html.

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[61] American Health Information Management Association, “AHIMA Consumer Health Information Bill of Rights.”

Appendix

“The best way to proceed…is simply to keep track of all our moves, even those that deal with the very production of the account. This is neither for the sake of epistemic reflexivity nor for some narcissistic indulgence into one’s own work, but because from now on *everything is data*.”
-Bruno Latour, *Reassembling the Social*[1]

A Good Account of this Study

Herein, I present an overview of this dissertation’s key methods and sources in the form of a Latourian “good account” of the document. This is a mode of empirical explanation “that *traces a network*…a string of actions where each participant is treated as a full-blown mediator” and is “a narrative or a description or a proposition where all the actors,” human and non-human, “*do something* and don’t just sit there,” and where “each of the points in the text may become a bifurcation, an event, or the origin of a new translation.”[2] In order to stay true to this tall descriptive and methodological order, I work to articulate my positionality in the project’s archive, how the project took shape as its archive developed through processes of “accumulation” and “gathering” that I undertook for research,[3] and then how the shape of the inquiry both allowed for the analysis of the data and the production of the document in the form in which it is presented here.

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[1] Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory*. Oxford: Oxford University Press, 2005, 133.

[2] Ibid., 128.

[3] Marc Berg, “Accumulating and Coordinating: Occasions for Information Technologies in Medical Work.” *Computer Supported Cooperative Work (CSCW)* 8, no. 4 (December 1999): 373–401. https://doi.org/10.1023/A:1008757115404; John Law, *After Method: Mess in Social Science Research*. London ; New York: Routledge, 2004, 104-119 on gathering.

Therefore, the following constitutes an account of the work undertaken for this dissertation, a disquisition on the methodology I develop in the document, and a reflection on relevant aspects pertaining to the conditions of its production. I first discuss the background of the study before detailing my primary methods in document-based health policy analysis, ethnography, and qualitative fieldwork.

Primary document-based research began in Spring 2016. Fieldwork in Atlanta began in August 2016 and continued until early 2019. Temporally, the bulk of research on federal health IT and LGBTQ health policy preceded fieldwork. Data for health policy analysis come from document-based policy research and participant-observation fieldwork with federal, state (Georgia), and local (metro Atlanta-area) actors in health IT, public health, biomedical research, and clinical contexts. Human subjects research for this dissertation was approved and regulated by three entities: The University of Michigan Health and Behavioral Sciences IRB, the Georgia Department of Public Health IRB, and the research ethics oversight committee of a large public hospital system in Atlanta (HUM0010488). I also brokered agreements and Memoranda of Understanding with several organizations where I conducted fieldwork, working with key interlocutors and frequently with the guidance of IRB staff and my advisor.

Some names of individuals and organizations are de-identified. Others are not. This is based on researcher discretion, the terms of agreements in place with organizations and individuals, and ethics oversight approvals reflected on informed consent forms. Further, some interlocutors have been anonymized, pseudonymized, or have had non-substantive details about personal or organizational characteristics changed to further obscure the identities of actors and/or to fit the parameters of fieldwork agreements and ethics approvals. Some individuals are composites of multiple people. In a few cases, a single person who would be very easily identifiable based on context is presented as multiple people in different parts of the narrative. Several dates and event titles have been slightly changed to protect the privacy of participants.

Health IT Policy Research

Health IT policy research proceeded in several distinct waves and on an ongoing basis during the duration of the research. Federal health IT policy research focused on grey literature produced by federal agencies and select civil society organizations and private sector actors in the health IT industry, and took place through synthetic analysis of a variety of materials. I adopt the Fourth International Conference on Grey Literature's definition of grey literature as "[that] which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers."[4]

Research in federal health IT policy primarily includes the reading, excerption, and systematic analysis of material produced during major health IT lawmaking, policy-making, and implementation processes by Congress (mostly limited to final laws rather than legislative record), the Congressional Budget Office, the White House, the Office of Management and Budget (OMB), Government Accountability Office (GAO), the HHS Chief Technology Officer, all-HHS committees such as the HHS Data Councils, NIH, HRSA, CDC, ONC, CMS, Institute of Medicine (IOM), and other federal agencies most of which are within HHS such as the Agency for Health Quality and Research (AHRQ) and the CMS Innovation Center.

Critical governing documents examined include publications related to EHR adoption, health information exchange, and interoperability that have been produced by ONC. These include HHS-wide health IT plans such as the *Federal Health IT Strategic Plan*, materials

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[4] Fourth International Conference on Grey Literature. "What Is Grey Literature?" The New York Academy of Medicine, 1999. http://www.greylit.org/about.

associated with the *Interoperability Standards Advisory* (published annually following a public comment period since 2015), documents produced during development of the *Shared Nationwide Interoperability Roadmap* from 2014-2015, and the industry response to the proposed *Draft Trusted Exchange Framework and Common Agreement* (TEFCA) in 2018.

I systematically gathered and stored documents from federal agency, civil society, and health IT advocacy organizations' websites and utilized the Federal Register online portal to conduct analyses of proposed rules, public comments, and final rules – especially rulemaking processes led by ONC. I also consumed a large volume of health IT industry trade media and health policy media, including journalistic content as well as technical guidance issued by branches of HHS, white papers, and reports published by trade press outlets and private firms. These include, but are not limited to the HIMSS media network, HIMSS Information Xchange, HISTalk, POLITICO Morning eHealth, Kaiser Health News, STAT News, and Xtelligent Healthcare Media.

To store and analyze policy data, I organized documents using a uniform naming convention, qualitatively read them and then excerpted key sections into files organized by topic and theme using heading. I closely read and iteratively coded excerpts in the body of the text. I reassembled and manipulated excerpted text in these thematic files, incorporating more data and doing additional research until I reached saturation (which I define as the point at which I have stopped learning new information after a period of trying to do so). I continually summarized findings in subheadings above individual sources and document sub-sections. I conducted federal, state, and local health policy analysis in several distinct waves beginning in the spring of 2016, and continued to do so on an ongoing basis for the duration of dissertation research. This approach has allowed me to cultivate a holistic understanding of the trajectory of health IT in the United States since 2009 and to closely analyze selected critical documents.

Federal ethnography in health IT policy has included participation in major conferences, interviews with health IT policy researchers and advocates, and interviews with select federal agency professionals. I attended sessions related to health IT, EHRs, cloud computing, health applications of blockchain, and public health surveillance at the 2017 annual meeting of the American Public Health Association (APHA) in Atlanta and at the 2017 International AIDS Conference in Amsterdam. I also attended the 2017 ONC Annual Meeting in Washington, DC.

I am an active agent in the materialization of the nationwide health IT infrastructure, and not only in the manner that John Law has noted, whereby social scientists help to enact their objects of analysis in the world through the production of research accounts. Rather, as an engaged researcher, I am situated within the project of building nationwide interoperability in a direct fashion, as a stakeholder-participant. While attending the 2017 ONC Annual Conference in Washington, DC, which happened to coincide with the 2017 Annual Meeting of the American Anthropological Association, I was invited to join the Interoperability Task Force of HIMSS. I have since continuously served on HIMSS task forces and working groups related to interoperability and trusted exchange. On these committees, which shape how HIMSS assembles guidance and recommendations submitted to ONC, I work to voice the interests of safety net providers, the HIV community, and LGBTQ health stakeholders. I have also advised federal LGBTQ health policy actors on sexual orientation and gender identity (SO/GI) interoperability standards. Becoming an active member of the health IT policy community has been hugely informative and enriching. My ongoing engagements in that space serve as a discursive backdrop for this dissertation.

State and municipal health IT research has taken place in Atlanta since August of 2016. I have interviewed and regularly participated in webinars and other events hosted by Georgia HITEC (GA-HITEC), the regional health IT extension center for Georgia housed within Morehouse School of Medicine's National Center for Primary Care. GA-HITEC is operated in partnership with ONC, CMS, Morehouse, and the Georgia Department of Community Health (DCH). In addition to providing small practices with EHR implementation and utilization assistance, GA-HITEC also houses Georgia Health Connect (GaHC), a statewide information exchange that is part of the multi-health information exchange (HIE) public-private Georgia Health Information Network (GaHIN) collaboration. DCH and GA-HITEC are the coordinating entities for health information exchange in Georgia. I have also analyzed a selection of key documents related to HIEs and health IT architecture in the state, such as the *Georgia Health Information Exchange Strategic & Operational Plans*.

Research about Georgia and metro Atlanta's health IT architecture has also included fieldwork in the areas of HIV/AIDS care, prevention, and surveillance. As the chapters on HIV demonstrate, and as I discuss in the introduction, the U.S. HIV infrastructure largely maintains its own health IT systems to facilitate the exchange and management of data. My ethnographic research in this area includes interviews with epidemiological and health IT personnel at the Department of Public Health (DPH), the Infectious Disease Clinic of a major hospital system ("The IDC"), and with clinical IT and quality management professionals in the Atlanta Ryan White infrastructure.

LGBTQ Health Policy Research

Policy analysis work in LGBTQ health proceeded in phases and focused on the development of the new consensus in LGBTQ health, LGBTQ incorporation at HHS, and the development of the nationwide interoperable health IT infrastructure. Much of this research focused on understanding the incorporation of sexual orientation and gender identity (SO/GI) standards into the nationwide interoperable health IT infrastructure.

In addition to documents cited in chapters, documents reviewed to assess the new consensus in LGBTQ health included a wide array of publications by advocacy organizations, civil society groups, and federal agencies. Most of these exist in the grey literature. The major body of publications were from federal government agencies, and specifically agencies within HHS. However, federal documents also included Obama White House publications such as the "Presidential Memorandum on Hospital Visitation" of 2010 that, in addition to mandating that hospitals allow partners to visit their ailing spouses, gave the HHS Secretary broad leeway to pursue goals related to LGBTQ health wellbeing. I analyzed all-HHS documents as well as documents produced by specific agencies.

All-HHS documents included the 2011 LGBT Data Progression Plan released by the Office of Minority Health, 2011-2017 reports of the all-HHS LGBT Issues Coordinating Committee, LGBT inclusion provisions in the guiding documents of the HHS Data Councils, and the three reports of the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity. I followed the outcomes of the IOM report recommendations closely. I reviewed the process by which NIH implemented these recommendations, first with a Request for Input (RFI) on LGBTQ health in 2013 and then the launch of the NIH's sexual and gender minority heath strategic plan for FY 2017-2020. I also filed a Freedom of Information Act (FOIA) request for all the public comments submitted in reply to the 2013 RFI. I received and reviewed all 140 replies, with submitter information redacted by HHS. I systematically reviewed the *National HIV AIDS Strategy* (*NHAS*, released in 2010), *NHAS: Updated to 2020* (released in 2015), and *NHAS* progress reports.

In addition to federal agency documents, I reviewed publicly-available publications by The Williams Institute at the University of California, Los Angeles School of Law – a hub for LGBTQ demographic research – and as many reports pertaining to LGBTQ health that I could locate that were published between 2009-spring 2016. This included a wide array of reports from LGBTQ organizations as well as healthcare professional guidelines and facility accreditation standards produced by organizations such as The Joint Commission. Document storage and analysis proceeded in a fashion similar to that described in the health IT section, above.

I conducted many hours of fieldwork and interviews with LGBTQ health educators in Georgia. I conducted two days of interviews at Fenway Health in 2017. I also attended many of Fenway's webinars, SO/GI office hours, and reviewed as many of the organization's publications and training modules as I could, attempting (but ultimately falling short of) a full census. I assisted Fenway, a local LGBTQ health organization in Atlanta, and an HIV training institute in conducting a webinar for Georgia-based providers on LGBTQ cultural competency.

Ethnographic Data Collection and Analysis

The bulk of the dissertation's ethnographic data draws upon over two years of fieldwork and engaged scholarship in metropolitan Atlanta's LGBTQ health, HIV/AIDS, and safety net healthcare communities. I also conducted fieldwork at Fenway Health in Boston, at the 2018 International AIDS Conference in Amsterdam, at the 2017 ONC Annual Meeting in Washington, DC, and at the 2017 American Public Health Association Annual Meeting in Atlanta. I conducted several phone interviews with federal employees and one with an individual based in Los Angeles. I conducted over 200 interviews.

Fieldwork data analysis took place on an ongoing basis and during dedicated periods aimed at producing analysis for specific themes or chapters. I took extensive fieldnotes during interviews and substantive fieldwork engagements. These data are stored chronologically in a series of digital fieldnotes and ethnography workbooks. I loosely annotated these documents, re-reading and revisiting them as needed. Following interviews and fieldwork engagements, I often wrote short descriptions of what took place along with my main takeaways. I kept a daily journal in addition to fieldnote journals. Transcripts for key interviews were generated by a professional transcription service; I transcribed some materials myself. I read transcripts qualitatively, cross-reference them with fieldnotes and interview notes, identified key themes and iteratively coded them. I excerpted key sections of transcripts into spreadsheets, organized by theme, with topic-specific and *ad hoc* coding schematics. In my daily journal and in standalone documents, I also regularly wrote thematic analytic memos, or memos specific to individuals or organizations. These often evolved into chapter sections or arguments that cut across the dissertation.

During fieldwork, I also attended or viewed many technical assistance and educational sessions and webinars – both archived and live – hosted by entities such as the Health Services and Resources Administration (HRSA), Fenway's National LGBT Health Education and Training Center, TargetHIV (a technical assistance clearing house for the Ryan White community), the Office of the National Coordinator for Health Information Technology (ONC), the Health Information Management and Systems Society of North America (HIMSS), the Georgia Department of Public Health (GDPH), various branches of Fulton County government, the Emory Center for AIDS Research (CFAR), and the CFAR Community Liaison Council (CFAR-CLC), the Morehouse School of Medicine Transdisciplinary Collaborative Center for Health Disparities Research (TCC), the Georgia Health Information Technology Extension

Center (Georgia HITEC), the Southeast AIDS Education and Training Center (SEAETC), and the Georgia AIDS Education and Training Center (Georgia AETC).

Research in the Ryan White community has included long-term engagements with the Fulton County Ryan White office, the Metropolitan HIV Health Services Planning Council, and a majority of Ryan White-funded agencies in Atlanta. For most of 2017, and portions of 2018, I attended participated in regular meetings of the Quality Management and Assessment committees of the planning council, and meetings of the full planning council, which included regular data reports and analyses of data generated by Ryan White agencies, all of which are required to report data in CAREWare.

During my engagements with clinical organizations, I gathered as many operational materials as possible in order to enhance information gathered during interviews. I have also interviewed health informatics researchers associated with Emory University and Morehouse School of Medicine who utilize both clinical EHR data and datasets generated during clinical trials. As an engaged researcher, I also communicate findings back to agencies and the community. I have attended and presented at a multitude of local conferences. A great deal of fieldwork data come from interviews and with health IT and quality management personnel in Atlanta’s HIV ecology.

I also attended – and in some cases participated in – planning meetings and other activities by community-based organizations and government offices in metropolitan Atlanta. These included committees of the Metropolitan Atlanta HIV Health Services Planning Council, the Philip Rush Center, the Health Initiative: Georgia’s Voice for LGBTQ Health, the Fulton County Task Force on HIV/AIDS, and other entities. For example, I served a member of the Intercultural Awareness Subcommittee of the Fulton County Task Force on HIV/AIDS from

October 2016 to the conclusion of the Task Force's work in July of 2017, and as a Steering Committee member of the Georgia LGBTQ Health Collaborative (an effort of The Health Initiative) for most of 2017.

I was also the "Sexual Health, HIV, and Social Justice Program Fellow" at The Health Initiative and The Phillip Rush Center from January to April of 2018 – a part-time position which became a contractor role. In that capacity, I conducted organizational assessments for the feasibility of HIV testing and the building of a referral network at The Rush Center, and ultimately produced two "roadmap" documents for building such a program.

Limitations: LGBTQ Health, Health IT, and HIV

In the realm of LGBTQ health, I do not focus on civil rights protections contained in section 1557 of the Patient Protection and Affordable Care Act (ACA), the civil rights provision of the legislation. I also did not use FOIA to seek exact details about the structure of Fenway Institute's National Cooperative Agreement grant with HRSA. Rather, I relied on publicly available information on HRSA and Fenway's websites.

The federal health IT laws and corresponding regulatory paradigm included in my analysis primarily stem from the HITECH Act and 21st Century Cures. These laws contain the congressional mandates for HHS to develop a nationwide interoperable health IT infrastructure. Relevant laws that I do not consider in great detail include the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Patient Protection and Affordable Care Act of 2010 (ACA or "Obamacare"), and the Medicate Access and Children's Health Insurance Program Reauthorization Act of 2015 (MACRA), the lattermost of which authorized CMS to develop the Merit-based Incentive Payment System (MIPS), Quality Payment Program (QPP) and Alternative Payment Model (APM) systems, all of which rely on advanced models of health IT utilization by providers. Each of these laws have produced regulations that exist in a critical relation to HITECH and Cures, but are ultimately secondary to the pursuit of the nationwide health IT infrastructure.

My research on HIV is limited in a several respects, primarily owing to the fact that my federal research is almost entirely document-based. I did not undertake systematic ethnography or fieldwork with federal HIV employees, although I did conduct several interviews with CDC and HRSA personnel. This limitation is intentional and built into the study design. The wide availability of HIV programming documents produced by HHS makes studying these domains in their federal dimensions rather straightforward. In Georgia, I secured the trust of, and thus a degree of access to, many HIV organizations and public health agencies. However, some fieldwork outreach attempts in this area went un-returned. I was limited in the number of times I could reach out to individuals by the terms of IRB regulations, and thus could not pursue some research avenues following non-response after three outreach attempts. This limited my research in the surveillance and prevention domains. I am presently at work on a paper about challenges in studying HIV infrastructures, which I discuss in several parts of this dissertation. However, I thank the Georgia Department of Public Health (GDPH) for being – on balance – open and transparent, particularly the HIV/AIDS Epidemiology Section. The staff of the GDPH IRB was also a pleasure to work with.

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