Public Trust in Health Information Systems:
A Strong Fabric or the Emperor's New Clothes?

by

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INTRODUCTION

Sharing personal health information about individuals and populations is increasingly routine and integral to health care, public health, and research. Ideally, more data that is well organized and accessible improves diagnostics, lowers health care costs, helps identify better treatments, and informs policy. Yet the skeptical American might see the expansion of a health data infrastructure as a virtual panopticon[1] and instrument of social control in which individuals are merely isolated and quantified bits of information. Susan Gubar, who recently wrote a memoir recounting her experience with a series of botched surgeries she had to treat ovarian cancer, notes that a system that is merely an "anonymous smokescreen" is less trustworthy than one that achieves human accomplishments and makes human errors (Gubar, 2012). With the advent of electronic systems, the human component of the health system stands to fade since interpersonal interaction and communication becomes less frequent, thus making trust in the system a more precarious proposition, and making its study all the more exigent.

That electronic systems hold data on entire populations (i.e., millions of people), and that data is shared across a broader number of users further heightens the relevancy of public trust in health information sharing. Data sharing norms have shifted with the genomic revolution, the expansion of electronic health records networks, and the emergence of multi-stakeholder research networks. Examples of the trend toward integration include the proliferation of large population biobanks such as Michigan's BioTrust for Health and the VA Million Veteran's Project, health data infrastructure initiatives such as New York Department of Health's State Health Information Network of New York system (SHIN-NY), and innovations within and across health systems such as Kaiser Permanente and the HMO Research Network (HMORN).

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[1] The panopticon refers to Jeremy Bentham's model prison, made famous by Michel Foucault. The architectural model separated individual inmates into isolated cells in such a way that they were invisible to each other but always in the field of view of a central monitoring tower. While monitors would not necessarily always be watching, they *could* be. Foucault suggests the panopticon is a symbol of modern disciplinary power applicable not only to prisons but to any institution of social control (hospitals, schools, workplaces) (Foucault and Rabinow 1984).

The capacity for these organizations to function not only as data users but also as data brokers requires fluency in technical, scientific fields as well as in communications with the non-expert (i.e., the public). Conceptually, the Learning Healthcare System (LHS) detailed in a 2007-2011 Institute of Medicine Series exemplifies the vision of transformative data use for multiple purposes and across diverse user groups to accelerate the research trajectory from bench-to-bedside.

Health care professionals, including researchers, public health practitioners, health care providers, and administrators are seeing the transformation of their work with increased data access, and the concomitant shifts in rules and regulations. As these changes spark debate in the research and policy fields, data reflecting public opinion are conspicuously missing. Experts see the need and value of the public's trust in decisions to expand data use, but does the public trust the system to act on its behalf and in the public interest? The Institute of Medicine calls for "weaving a strong trust fabric" among all stakeholders in the next generation of data infrastructure, including the general public (Olsen, Aisner and McGinnis 2007, 149). This dissertation evaluates the texture and quality of the so-called trust fabric. Is it a weighty, durable material that can withstand time, diverse interests, need, and dissent? Or is it a case of the emperor's new clothes – made of enthusiasm and rhetoric, but, when challenged, revealed to lack substance?

Trust is important because it provides opportunities for greater efficiency in managing and sharing health information, which, in turn, may translate into greater satisfaction and confidence in the health system. Banking exemplifies the value and importance of trust: a customer invests his money to a bank for safe-keeping; the bank can then use that money for any number of larger investments that benefit the bank, and translate into the convenience of debit-cards, online banking, and the accrual of interest for the customer. The customer likely does not understand the rules and regulations governing the bank, nor does he need to. And yet the customer's confidence in the banking system to take good care of one's money, or as is the case in this dissertation, the health system's ability to take good care of one's health information ("system trust"), is critical to a system's functioning and operability.

Understanding the characteristics of the banking customer is an important first step in evaluating existing levels of confidence in the system, and what may be the barriers and facilitators of maintaining trust into the future. Examining trust in the health system starts with the same first step. Just as the banking system is a composite of different organizational types, or brokers, so too is the health system a network of institutions. Understanding trust between the individual and heath care providers, public health departments, and researchers as key brokers and users of health information should inform an understanding of trust in the health system generally. Finally, confidence in the policies and public protections in the health system should indicate the resilience of public trust. Similarly, the degree to which the individual feels autonomous to control how information is used could also be a key factor influencing system trust.

The goal of my dissertation is to identify key factors associated with public trust in a broadly-defined health system that shares data across organizations for various purposes: disease surveillance, research, and health care practice. Conducting a survey of the general public, my research addresses the following questions to better understand the parameters and dimensions of trust in data sharing within and across the boundaries of public health, health care, and research institutions:

1. **What are the individual-level characteristics of the trustor (i.e., the public) that predict trust in health systems?**
2. **What are the trustor characteristics that predict public trust in health and research data brokers? Which trustor characteristics and trusted data brokers predict trust in health systems?**
3. **What are the individual-level characteristics associated with, a) confidence in the policy environment in which health information occurs and b) with an individual's perceived autonomy and personal control over the use of health information? How does this confidence in the policy environment and perceived autonomy and personal control affect trust in the health system?**

In the following sections I first review the current landscape of health data and the emergent phenomenon of data brokerage that is facilitating data transformation and fluidity, as well as the policy environment that shapes this evolution. I then consider the definition and meaning of trust in the context of health care, and how concepts of trust may be shifting with the emergence of health data systems that are increasingly large and complex. Finally, I develop a conceptual model of public trust in a health system that broadly shares health information that will be tested by the research that follows.

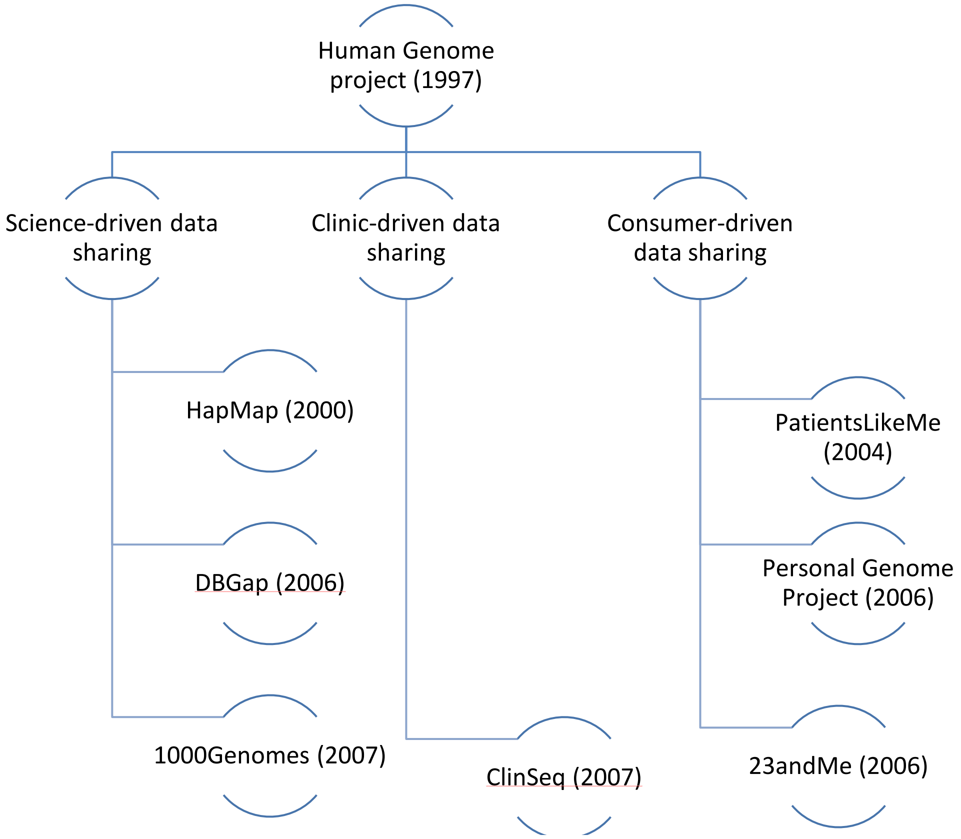
THE HEALTH DATA LANDSCAPE AND THE TRUSTED BROKER: CURRENT PRACTICE AND POLICY

The health data landscape

Although health data has been shared between diverse organizations (public health, research, healthcare, and insurance agencies) for decades, the quantity, quality, and rate of sharing has been propelled to new levels through advances in fields such as genomics. Throughout this section, I will use genomics as the primary example of a cross-cutting arena that is affected by the evolution of policy and expectations for data sharing, while noting that there are many other instances, such as the research collaborations across health systems (e.g., the HMO Research Network) and the increasingly sophisticated public health research and surveillance networks.

Technological advances such as genome-wide ChIP sequencing for DNA, RNA, and methylation have made it simpler and less expensive to measure vast arrays – terabytes– of molecular data, and to catalog and store sensitive health information linked to that molecular data (Altshuler, Daly and Lander 2008). Information technology permits re-purposing data by linking, bundling, and sending it for different uses and for different users. Through the use of barcoding, robotic retrieval, encryption and firewalls, data moves with increasing efficiency, security, and speed. Brokers, in the organizational form of biobanks, large research institutions, hospitals, and others, help manage multiple uses of large data sets. Genomics research in particular has evolved to the point where large data sets are required to generate sufficient statistical power for valid findings. Anticipating this challenge, the Human Genome Project successfully challenged the limits of traditional scientific enterprises by making raw data publicly available (Collins, Morgan and Patrinos 2003; Kaye et al. 2009).   In 2000, the International HapMap project continued this new trend by making one of its primary goals the sharing, within the scientific community, of anonymized haplotypes[2] from 270 individuals in six regions across the globe. It also carried forward the call for increasingly large data sets numbering in the hundreds of thousands (The International HapMap Consortium 2003).   The trend of increased genetic and health information gathering from the general public has continued along three trajectories described below (See Figure A).

Figure A. Data-sharing projects following the Human Genome Project (Year founded in parentheses)



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[2] A haplotype is a segment of DNA that tends to be inherited as a unit. Studying variations in these segments of DNA across individuals and populations, and how these differences, are correlated with diseases is one of the goals of the HapMap project.

First, actors in the public sector such as the National Institutes of Health (NIH), Centers for Disease Control and Prevention, and other federal agencies remain a major source of funding and development of large-scale, publicly available, data collection initiatives. These are run within the framework of basic science research and in clinical translation projects. DbGap and 1000Genomes, for example, are sequencing initiatives, while ClinSeq is undertaking an open-ended project to study heart disease that hopes to involve participants in follow up care based on study findings. Funded agencies (e.g., universities, research institutes) supply the repositories and catalogues of information developed by these initiatives with the aim of supporting and reducing the costs of future investigations.

At the state level, some public health departments find themselves accidental contributors to the growing number of large population data centers. For example, having collected samples via newborn screening that retain identifiers so they can be linked to health outcomes data in Medicaid records, cancer registries, immunization registries, etc., health departments are stewards of population-wide data collected without many of the selection biases that challenge the validity of research findings. The appellation, “research goldmine,” (Couzin-Frankel 2009) suggests their potential value to a robust health information infrastructure. In Michigan, the biobanking capacity of a health department has been institutionalized as the Michigan BioTrust for Health, though all states have administrative policy and state public health codes that determine the rules for using and accessing public health specimens and data.

Second, in the arena of health care, health systems such as the Veteran’s Administration, Kaiser Permanente, the Mayo Clinic, and Vanderbilt have invested in projects that link genetic information, electronic health records, and survey research to study the health implications of gene-environment interactions. The University of Michigan has recently started gathering permission from patients to store data and biospecimens in a biobank that can be a resource for research to answer questions as yet undefined.

Third, a direct-to-consumer approach enrolls individuals as partners, clients, and revolutionaries in the research enterprise. In 2004, PatientsLikeMe, a for-profit company, launched a health data-sharing platform accessible and usable by patients, researchers, and healthcare providers. PatientsLikeMe claims complete openness in information in exchange for social networks, support, and information for patients. For researchers and industry, the company provides access to potential research participants and data (*About Us*). The Personal Genome Project, a non-profit founded by Harvard University professor George Church, combines the public and private approaches by making volunteers' data available for free online, while engaging donors as clients and interactive participants in their health information. One of the ways in which these projects differ significantly from the public and health care examples cited above is that individuals are actively seeking participation and personal benefit not as patients but as purchasers of a service.

The role of public policy in the health data landscape

Federal, state, and organizational policy is meant to minimize deception and coercion, promote the conditions for trust, and to assure the ethical protection of individuals. Policy balances the interests of the individual with the public good attained through health research practice. It is important to articulate the boundaries of processes underlying data handling to identify the role of public policy in the health data landscape. Malin, El Emam, and O'Keefe (2013), for example, describe health data infrastructure as a tripartite system, divided into zones that are managed by socio-legal mechanisms on the one hand, and technical mechanisms on the other. In Zone 1, data are collected. Informed consent may be obtained, or clinical services provided. The researcher or clinician, in collaboration with data managers, defines the amount of data collected, what type of data, and in what format. In the second zone, data are used for primary purposes such as direct patient care or for a specific research use. Patient-provider or participant-researcher interactions may allow for return of specific findings based on the initial use of an individual's data. Data in this zone are shared only among those providing a direct service. In the third zone, data are used for secondary purposes and may be transformed in some capacity. Clinical data may be used for research or data may also be shared across institutions. In Louisiana, for example, the public health department links to Electronic Health Records to conduct surveillance of HIV services in the state (Herwehe et al. 2012).

There are numerous questions for policy and decision-making in each zone of data handling. These include considerations of what the public expects the scope of data sharing to be and to what extent existing policy, such as that for informed consent, can accommodate shifting data sharing norms and to what extent the policy might need to be changed. Table A lists additional examples. The most salient policy issues shaping the health data landscape within each zone of data handling involve informed consent, privacy and confidentiality, data access, and ownership, commercialization and benefit sharing. Current policies in these arenas are reviewed here.

Table A. Zones of data transformation (adapted from Malin, El Emam, and O'Keefe 2013)

Zone	Socio-legal considerations	Technical considerations
1. Collection	What are the public's expectations with regard to the types of data collected? What types of data are considered personal, identifiable, or sensitive? Is the public aware of privacy and security laws and regulations? Are they aware of limitations in legal protections? What is the scope of informed consent?	What are the public's expectations with regard to the security of health data? To what extent is the public aware of interoperability possibilities and constraints?
2. Primary Use	Who has access to health information for the provision of clinical services or health research? Under what conditions?	How is privacy assured at all levels of access? What types of authentication measures are in place? Are they effective?
3. Secondary Use	What constitutes ethical secondary uses of data? Is informed consent required for new data uses; under what conditions? Who may access data? When should data be made public, and under what conditions? What are the public's expectations for notification of use and/or findings?	Can data be shared across institutional boundaries? What are the barriers and facilitators to interoperability? What are the security and privacy measures available to assure minimal risk?

Informed consent. Informed consent is a cornerstone of ethical research, the most visible part of the trust fabric, and represents transparency between the expert researcher or care provider and participant or patient. In the U.S., the baseline requirements for its assurance in research are set out in the Federal Policy for the Protection of Human Subjects (45 CFR Part 46, i.e., the "Common Rule"), which applies to institutions that receive federal funding. This implicates nearly all academic, health care, and public health institutions. The Food and Drug Administration (FDA) also defines conditions and requirements for obtaining informed consent, and applies to all human subjects research. The Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule applies to so-called covered entities to the exclusion of public health data (Fairchild, Bayer and Colgrove 2007). While not explicitly a policy regarding consent, the HIPAA defines the scope of identifiability, a key consideration in evaluating the risk to individual participants and in waiving standard consent requirements. Institutional Review Boards (IRBs) are charged with the task of evaluating specific research and informed consent protocols (Clayton 2005). Waivers of consent apply if an IRB determines that:

> (1) The research involves no more than minimal risk to the subjects;
> (2) The waiver or alteration will not adversely affect the rights and welfare of the subjects;
> (3) The research could not practicably be carried out without the waiver or alteration; and
> (4) Whenever appropriate, the subjects will be provided with additional pertinent information after participation.
>
> (45 CFR §46.116)

IRBs vary significantly in interpreting minimal risk, consent waivers, and consent documentation (Vick et al. 2005; Dziak et al. 2005; Elger and Caplan 2006). Storage of data and samples in a biobank or database is generally considered "no more than minimal risk" and for legacy collections (i.e., data/ samples already collected that could potentially be used for new research), it may be deemed impracticable to obtain retroactive permission for storage given the size or age of biobank contents (Caplan 2009). Using stored data for research is less likely to be exempt from consent requirements, except when data is deemed adequately de-identified or does not qualify as human subjects research.

The purpose of informed consent is to articulate the risks and benefits of participating in research, and communicate the rights and roles of participant and researcher. As an early interaction with research participants, the process of informed consent has come to embody the terms of agreement between subject and investigator and, moreover to symbolize trust and respect (Clayton 2005; Caulfield et al. 2003). The open-ended nature of health data use, the flexibility in the scope of research that may be conducted, and unknown (and unknowable) future risks and benefits strain the traditional paradigm of one-subject, one-researcher, one-form.

Current models. Developing, implementing, and maintaining consent for research is one of the greatest practical barriers in health information policy. Operationalizing consent depends on whether proposed research uses already-existing samples and databases, or if the research requires samples and data collected prospectively. A vibrant debate exists in the literature over the effectiveness of different models for informed consent in the context of biobanking (e.g., Knoppers and Chadwick 2005, Clayton 2005, Maschke 2006, and Mongoven and Solomon 2012). Models include presumed consent, community consent, opt-out, blanket consent, authorization or tiered consent, and opt-in. These terms are defined in Table B.

Table B. Models of informed consent

Model	**Definition**
Presumed consent	Consent for use of samples is assumed. Usually applies to re-purposing of existing, de-identified, and/or anonymized samples
Opt-out	Data and samples can be stored and used for research, unless donors explicitly withdraw from biobank
Community consent	Data and samples used without individual informed consent. Community engagement/ awareness used to inform individuals of their participation and provide the opportunity to opt-out
Blanket consent	One-time consent for storage and open-ended future uses
Authorization/ tiered consent	Consent document specifies the type of research that can be used, conditions for return of results, and/ or conditions for re-contact
Opt-in	Consent obtained for storage, and for each research use
Open consent	Consent obtained at the time sample/ data attained. Data made publicly available, no privacy guarantees, no promise of personal benefit; withdrawal can be made at anytime. Predicated on principle of "veracity."

The mandatory nature of newborn screening and other public health programs has meant that consent is rarely obtained at the time of sample collection. In Washington, bloodspots are made available for research, but it is incumbent on the researcher to obtain informed consent. In Michigan, where the state has blood samples from an entire generation (>25 years), the federal Office of Human Research Protections (OHRP) advised the Michigan Department of Community Health (MDCH) that its storage and use of newborn screening blood spots constituted human subjects research necessitating IRB review. The MDCH IRB stated that new samples would need documentation of consent and, as of October 2010, the state has changed NBS cards to include space for parents to opt-in for research. The existing ~4 million samples were issued a five-year waiver of consent based on the impracticability of contacting subjects individually, contingent upon a good-faith effort to inform the public that the repository exists and that there are clear processes for those who choose to withdraw (Mongoven and McGee 2012).

Kaiser Permanente's Research Program on Genes, Environment and Health, is building a biobank by contacting 500,000 Kaiser members to obtain permission and DNA samples to study common chronic diseases such as heart disease, cancer, diabetes, high blood pressure, Alzheimer's disease, and asthma. The Mayo Clinic, Vanderbilt University, and the Veterans' Administration are following a similar protocol for obtaining consent. The National Children's Study will obtain informed consent from parents while children ages 7 and older will be asked to assent to continue participating in the study (Elger and Caplan 2006). The Personal Genome Project uses the open consent model, which makes data broadly available and makes no promises with respect to privacy, confidentiality, or personal benefit (Lunshof et al. 2008).

Privacy and confidentiality. Technological advances such as encryption, password protections, and firewalls have improved electronic data security immensely. The reduced risk of data resources being compromised has led to some level of complacency for privacy considerations (Malin et al. 2011). The main regulatory mechanisms for assuring privacy are HIPAA, Certificates of Confidentiality and the Genetic Information Non Discrimination Act (GINA). The HIPAA Privacy Rule establishes national standards to protect medical records' and other personal health information. The NIH issues Certificates of Confidentiality to prevent the forced disclosure of data for non-research purposes and currently the strongest protection available to prevent sharing of information about research participants in civil, criminal, administrative, or legislative proceedings at the federal, state, or local level. There is disagreement about whether or not the Certificate of Confidentiality is sufficient to protect participants. Critics argue that the Certificate of Confidentiality has not been tested extensively in court, and it is not clear whether it applies to public health departments as a state agency (Olson and Berger 2010; Gunn 2009; Beskow, Dame and Costello 2008). GINA provides a minimum of protection against discrimination in employment and health insurance based on genetic predisposition to disease. GINA does not apply to life, long-term care, or disability insurance.

In addition to the federal regulations cited here, most states have additional anti-discriminatory policies that apply to genetics. In Minnesota, state genetic anti-discrimination law figured prominently in the litigation filed against the state health departments to successfully challenge the public health authority to use dried bloodspots for purposes beyond newborn screening. A lawsuit in Texas also challenged the state's power to use newborn screening bloodspots for additional uses. These cases point to the sensitivity of health information, and of the evolving public perceptions of risk and harm to individual privacy. One of the salient features of both legal cases is that the *perception* of potential individual harm due to a breach of personal privacy, whether or not the risk of harm was actually high, was sufficient to generate a backlash. At the same time, having identifiable information that can later be linked to additional data sources is one of the features that makes data brokerage a valuable research enterprise. A fundamental challenge for health information brokers is to manage public expectations and trust, while exercising the power to control how much information is revealed and to whom and facilitating dissemination and broad access (Starr 1997).

Research using de-identified data is largely unregulated. It is generally assumed that research using de-identified information is by definition minimal risk, and therefore justifies broader access and waivers of consent. However, data-rich repositories that include genetic, demographic, geographical and medical data call into question guarantees of true anonymity or de- identification (Gymrek et al. 2013; Greely 1999). Mark Rothstein(2010) argues that in fact de-identification is not an absolute category, and that identifiability of data lies along a continuum from complete anonymity to clear identifiability with names, addresses, etc. The "dichotomy" between identified and de-identified is misleading; at worst, it mislabels de-identified data as failsafe insofar as privacy is concerned thus leaving individuals and groups vulnerable to data breaches. Most data has some level of de-identification, but a dedicated hacker could connect samples and/or information to a specific participant (Malin et al. 2011). Data in biobanks may be de-identified to researchers, but is identifiable to data brokers. Rothstein further argues that the lack of regulation for de-identified data leads to a lack of accounting for or evaluation of potential group harm.

Survey research evaluating the public's concerns about privacy suggests that it is a high salience issue, but that it is unclear to what extent fears about discrimination or a violation of privacy precludes trust and participation in research or biobanks. For example, Kaufman et al find that in a nationally representative sample, 90%t of respondents had privacy concerns, 56% were wary of researchers having their information, and 37% feared that study data could be used against them (2009). Nevertheless, Pullman et al found that concerns about confidentiality ranked low when assessing informed consent preferences, despite individual claims about privacy concerns (2012). Pullman's study applies most readily to the Canadian policy debates, where there is better access to health care, and potentially fewer concerns about genetic discrimination, but it is nonetheless suggestive of the importance of contingency and the need for a more thorough understanding of under what conditions privacy is of concern.

Conceptual models of factors that promote data sharing posit that willingness to disclose information is positively associated with an individual's trust in a given system, and negatively associated with privacy concerns. In short, it is hypothesized that addressing privacy and security concerns will improve trust in health systems that share health information (Metzger 2004; McGraw et al. 2009; Bansal, Zahedi and Gefen 2010).

Data access. The federal government, through both regulation and funding policies, is changing the rules around data access. The Institute of Medicine has published a 17-volume series on the Learning Health System. The National Science Foundation supported a workshop to identify priorities for science and engineering research required to achieve a national-scale Learning Health System (2011) , and the large federal investments in electronic health information architecture and data networks exemplify today's Learning Health System movement. Fostering innovation, promoting efficiency in data collection and research, and accelerating scientific discovery from "bench to bedside" drive the investment in common data sets and biobanks in particular.

It is increasingly the norm that publicly funded data collection should result in data openly available to the research community. The NIH Data Sharing Policy, for example, requires that all projects receiving at least $500,000 in federal funding share de-identified data (Gitter 2010). The National Science Foundation has a similar requirement. These relatively new requirements have expanded the traditional Material or Data Transfer Agreement and have led to novel oversight mechanisms for data access such as the formation of Scientific Review Boards to evaluate the legitimacy of potential researchers, or including data access review as a part of IRB approval, though this latter option has been criticized as over-burdensome on already strained ethics review committees (Kaye et al. 2009). Categorizing the scope of third-party access and controlling the types of data available are alternative policy options, though the administrative implications are formidable and typologies are subject to change. The definition of identifiable data, for example, is highly malleable and subject to interpretive variation (Knoppers and Saginur 2005; Cambon-Thomsen, Rial-Sebbag and Knoppers 2007; Greely 1999).

The Health Information Technology for Economic and Clinical Health Act (HITECH), Title XII of the American Recovery and Reinvestment Act of 2009 (ARRA, Public Law 111-5), provides unprecedented investment in electronic health record infrastructure expanding the availability of information across zones and between user groups. Meaningful Use objectives tied to the implementation of the HITECH Act are a set of measurable outcomes meant to demonstrate value and assure accountability for the expenditure that promises increased interoperability of health information and improved patient care. Notably, one of the aims of meaningful use is to "bolster public trust in electronic information systems by ensuring their privacy and security" (Blumenthal 2010; Blumenthal and Tavenner 2010). Similarly, the proposed changes to the Common Rule that would require consent for research using de-identified, existing biospecimens are meant to assure trust in biomedical research.

Ownership, Commercialization, and Benefit Sharing. Intellectual property interests conflict with the principle of broad data sharing and are often associated with decreased trust (See e.g., Thiel et al. 2013). Concomitant questions regarding who owns data, analysis, and research findings, rights to patenting and commercialization, and who are the beneficiaries of research are complex and contentious. With regard to ownership there is confusion even amongst researchers. A small study of academic scientists found that most confused ownership and the duties of control maintenance samples in long-term storage (Cadigan et al. 2011). In Michigan, the MDCH concluded that the Department retains "conditional ownership" of newborn screening bloodspots. The MDCH is a steward of the blood samples and data, but will destroy research samples upon request and is accountable to Michigan's residents. When data ownership questions have been tested, ownership has generally favored the researcher over the participant, and the institution over the researcher. In *Moore v. Regents of the University of California,* for example, the court found that research participants cannot expect commercial gain from research using voluntarily donated samples; in *Washington University v. Catalona* (2007) the court found that research data belonged not to principal investigator but to Washington University (Skloot 2010; Charo 2006).

Research participants are often motivated by an altruistic contribution to the greater, healthier good while financial incentives drive a significant portion of the scientific enterprise. In public opinion studies, support for biobanks ebbs and flows depending on the types of research being conducted; people readily support research that is perceived to promote the common good (e.g., for health), but are reluctant to participate when the benefits are less altruistic (e.g., for commercial gain (Rose 2006), or insurance decisions(Godard, Marshall and Laberge 2007)). The perception of commercial gain is almost as important as actual profits. In Texas, a reporter used an open records request to obtain documentation that revealed a concerted effort on the part of health department officials to limit public awareness of the use of newborn screening bloodspots for research and perhaps, most damaging to the state, evidence that the state had given over 800 samples to a US military effort to create a Mitochondrial DNA database. Specifically, a 2012 *Texas Tribune* reported that "The researchers wanted "anonymous and maternally unrelated" blood samples from Texas Caucasians, African-Americans and Asians — and from Hispanics and Native Americans in particular — to round out their genetic record" (Ramshaw 2010). The department of health services was ill-prepared to explain its compliance with the request from the military for anonymized samples or to explain how it negotiated contracts to run the screening program itself. Sensationalized media headlines, "Baby Blood Bartered by the State" and "Texas Sold Babies' Blood to Pentagon and Private Firms, Class of Parents Says" (stoked a public outcry in response to what appeared to many as the sale of blood spots and a privacy violation.

These examples suggest that how data is transformed, for whom, and to what ends matters to the general public. Governance of the health data system, then, involves understanding not only the potential value and use to researchers and health care professionals, but also to the general public. Managers governing the fluidity of data within and across the zones described in Table 1 are a type of broker insofar as they interface with a range of stakeholders and negotiate the terms of data usage and sharing. As will be described below, effective brokers can communicate in the language and practice of lay publics, medical professionals, and technical and scientific experts to address the socio-legal and technical mechanisms and policy environment shaping data transformation and flow.

Trusted brokers in the health data landscape: Boundary workers in a trading zone

The publicly funded, health care, and direct-to-consumer approaches to large-scale data collection add the role of data broker to organizations. *Health data brokers steward, translate, and repackage information.* They are a form of embodied trust that is likely to become an increasingly important part of data infrastructure assuring the quality of public trust. They are traditionally used in banking to facilitate the movement of money, but can be used in a variety of public and private contexts to handle interactions between parties that otherwise do not need to negotiate. Rather than embark on a formal working relationship with multiple data centers at multiple research institutions, for example, a single scientist may opt to work with a single broker who can provide access to a wide range of sources. In the context of the learning health system, the trusted broker is defined broadly as “an agent or entity with the public and scientific confidence to provide guidance, shape priorities, and foster the shift in the clinical research paradigm” (Olsen, Aisner and McGinnis 2007, 6). These agents encompass actors in a wide range of institutions including hospitals, public health departments, researchers, universities, pharmaceutical companies, insurance companies, non-profits, advocacy groups, or private firms such as Google, Amazon, and Verizon, that collect, store, and share health data.

As worksites managing and maintaining trust, brokers fulfill a social contract and navigate local and global social, political, and cultural tensions bound up in the interests of diverse stakeholders. In the parlance of Science and Technology scholars, trusted brokers operate as boundary workers (Downey 2001) in trading zones (Galison 1996, 1997), and function as gateways (David and Bunn 1988). These terms are described below.

Boundary work applies technical, legal, and professional rules, as well as exercising autonomy. Health information is highly regulated and data systems require highly skilled work. Despite the plethora of procedural guidelines, boundary work is necessary in light of the fact that "no matter what automated protocols are in place at any given moment, they will be imperfect and incomplete; disparate information networks can only work together through the efforts of specific workers who *maintain* the links, *transform* the content, and *police the boundaries* between those networks" (Downey 2001, 225, emphasis added). In guarding the boundaries of information, boundary workers assure the trustworthiness of data sharing by defining the scope of use and preventing inappropriate breaches. Boundary workers, in this case brokers, can speak to several different groups in their own languages, bringing together and facilitating the work of diverse fields.

Boundary work is neither static nor rote, but it is contained. The *trading zone* describes a transformative arena in which collaboration can occur despite differences. Trading zones are local spaces in which concrete tasks and practical questions are addressed. Peter Galison coined the term in the context of computing (1996) and microphysics and engineering (1997). The boundary work of their trusted brokers also has global meaning as a *gateway* in the large, and highly complex, national and global health infrastructure. Brokers actively translate data from various sources, and have the capacity to reshape data to suit the needs of specific users. Beyond simply being an arena for specific data-driven projects, brokers link networks and systems promoting their interoperability. One of the mechanisms for improving the usability of gateways is standardization, which can be determined by custom, institutional agreement, or regulation (Egyedi 2001; David and Bunn 1988). Technology is often a critical component of what constitutes a gateway, but just as important are the social and political commitments to integrate concomitant standards and usage into communities of practice (Edwards et al. 2007).

Depending on one's relationship to the trusted broker, its function and meaning can and will vary. To the general public, health information brokers are foremost stewards of sensitive and highly personal information. To researchers, they are bankers, loaning valuable information, or librarians, carefully cataloguing and archiving a treasured resource. For physicians, they share clinically relevant information. Rather than needing to negotiate the terms of a relationship, the data broker allows users to maintain their autonomy, while still providing access to information across multiple sources. The trading zone facilitates intellectual, material, and social work. While the stakeholders engaged in work with a trusted broker are part of the larger health infrastructure, each represents a subculture – medicine, basic science, patient, etc. Within the trading zone, theory converses with experiment converses with practice. Substantive objects and people, such as blood, tissue samples, study participants, physicians, data managers, and even money, are exchanged as goods and services. Through negotiation, chance, and struggle, social and technological arrangements emerge (Galison 1997).

Can the trusted data broker realize the utopian vision of the neutral trading zone, the efficient gateway, and the quiet boundary worker? Will brokers transform the intractable problems of healthcare? This is unlikely. The data contained in health information systems can be used to exercise power over others, define research agendas and priorities for solving social problems to the benefit of some and the loss of others, and to categorize and classify individuals as deviant or elite. Individuals and communities do not necessarily stand to gain equitably. As largely invisible entities, the activity of trusted brokers is becoming increasingly entrenched, and therefore black-boxed, in health infrastructure. Operating outside the view of the public's daily life, trustworthiness of in the actions of data brokers becomes paramount since the unknown can become a source of suspicion and perceived deception, which damage a culture of trust.

THE SHAPE OF TRUST IN LARGE HEALTH DATA SYSTEMS

Linguistically, the necessary components of trust are the trustor (subject), trustee (direct object) and an expected future outcome (indirect object). The act of trusting itself has several variants but tends to focus on a willingness to impart authority and accept vulnerability to another in the fulfillment of a given set of tasks. A number of factors can influence the capacity and inclination to trust including the trustor's past experience or willingness to trust on the one hand, and the trustee's competency, reliability, reputation, honesty, or interestedness in the trusted relationship on the other (Mollering 2005; Nannestad 2008; Cook, Hardin and Levi 2005; Cook, Levi and Hardin 2009; Cook 2001). The trustor or trustee can be an individual, organization, or institution while the expected future outcome can be as quotidian as picking up the kids from school or as weighty as performing neurosurgery or managing issues of national security. Moderating trust are questions of risk and relationship. In contexts of complete certainty or of no consequence or risk of harm trust becomes inconspicuous since the question of whether an expectation will be fulfilled is a forgone conclusion. Trust is further shaped by the quality, length, and nature of the relatedness of the trustor and trustee. Whether a trust relationship is just beginning, being maintained, or deteriorating matters in the syntax of trust(Rousseau et al. 1998).

In this dissertation, the trustor is an individual, the trustee is an institution (research, health, public health) or organization, and the task is the re-purposing or transformation of health data for multiple users from data collection to primary use to secondary uses. ***Trust is defined as a cognitive expectation or willingness to impart authority and accept vulnerability to another in fulfilling a given set of tasks.***

Trust research has spanned decades and disciplines. The fields of psychology, political science, economics, organizational theory, and sociology have developed multiple theoretical and empirical studies of trust. Economists and political scientists tend to view the trustor and trustee as rational actors motivated by self-interest (See e.g., Hardin 2002; Johnson and Mislin 2011; Ostrom and Walker 2003). Calculative trust, one of several types of interpersonal trust, also focuses on its rational basis (Rousseau et al. 1998; Mizrachi, Drori and Anspach 2007). Others see trust as an affective state that reflects the belief that others will be motivated by knowing that they are being counted on (Jones 1996). The trust necessary for strong communal ties has been associated with macrosocial phenomena such as vibrant market economies (Fukuyama 1995) or democracies (Putnam 2000). In the context of health care, trust at the level of the doctor-patient relationship highlights the significance of vulnerability and risk (Hall et al.

2001). Studies of diminishing trust in the health professions consider its significance for doctors, patients, and the health care system (Jasanoff 2007; Garrett 2003; Mechanic 1996, 1998). In this dissertation, I focus on trust in the system of institutions that have health information and share it, and how this relates to characteristics of the trustor (individual), trust in information brokers (health care providers, public health departments, and university researchers), as well as the current policy environment and opportunities to express personal autonomy in the health system. The findings could be used to make inferences in various disciplines; I focus on the policy and health services research implications.

As noted in the previous section, health data systems are complex, particularly from the perspective of individuals (i.e., non-experts) not directly involved with or knowledgeable about their mechanisms (i.e., non-experts). They consist of rule-based, interdependent entities linked across networks. While they may attain equilibrium, they are open systems that are susceptible to unpredictable events or disruptive change (Page 2011). Their diversity suggests their capacity for Keats' negative capability, the capacity to live with constant uncertainty, and a "first-rate intelligence" that can be tested by "the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function" (Fitzgerald 1936). The multiple interests of the agencies and actors at play in the health information system, as well as the complex policy environment send myriad messages about their motivations, promises, and concerns. The extent to which the general public is able to attain negative capability, and discern trustworthiness is a key issue underlying the proposed research and its policy implications.

In the context of this ordered chaos, functionalists view trust as a mechanism for diminishing complexity forging the space for social relationships (Niklas 2000). Viewing trust only as a way of simplifying intricate systems, however, dilutes important factors such as power, agency, and culture that make trust in complex systems different from interpersonal or organizational trust. Structuralist approaches are a useful point of departure for understanding the links between the social and institutional networks of health information systems and trust. Anthony Giddens, for example, describes the circular flow (what he calls reflexivity) of knowledge through abstract and tangible forms of modern social life that create the texture of social structures, as well as new forms of knowledge. Individuals interacting with abstract systems lack the technical expertise to navigate all fields with complete information but can develop the experience, awareness, and confidence that a set of institutions is or is not reliable, honorable, and competent (i.e., trustworthy). Trust and risk are continuous and contingent rather than a series of discrete decision points (Giddens 1991, 1994).

This dissertation focuses on individuals' trust in health information systems. It will contribute to a limited body of literature on the role of the trustor, which tends to be underemphasized in trust research. Mizrachi, Drori, and Anspach (2007) argue that, in fact, attempts at isolating different types of trust diminish the relevancy of the trustor's agency and autonomy and provide an incomplete picture of how trust operates in daily life. They suggest that trust encompasses multiple types and that individuals work with available forms of trust (trust repertoires) to fit a given context and need. In order to develop policies that are trusted and, in turn, assure the trustworthiness of the health system, a deeper understanding of the precise toolkits that individuals use in assigning trust is critical.

Common to most views of trust are three assumptions: First is that the trustor is knowledgeable and aware of her part in the information system. Second, the trustor has access to and trusts the brokers of health information in the health system; and third, the trustor has the power to exercise autonomy in maintaining a trust-based relationship (Gilson 2003).[3] Trust can be guarded via well-known policies of transparency, audit, communication, and assurance of individual and social benefits on the one hand, while, on the other, active forms of trust can be pursued when data transitions across Zones 1, 2, and 3. In the complex system of health information the validity of these assumptions is largely untested. Given the fuzzy relationship between the public (trustor) and health data brokers (trustee) particularly as data becomes increasingly removed from its original use, the resilience of these assumptions is determinative in how trust can be attained and sustained over time.

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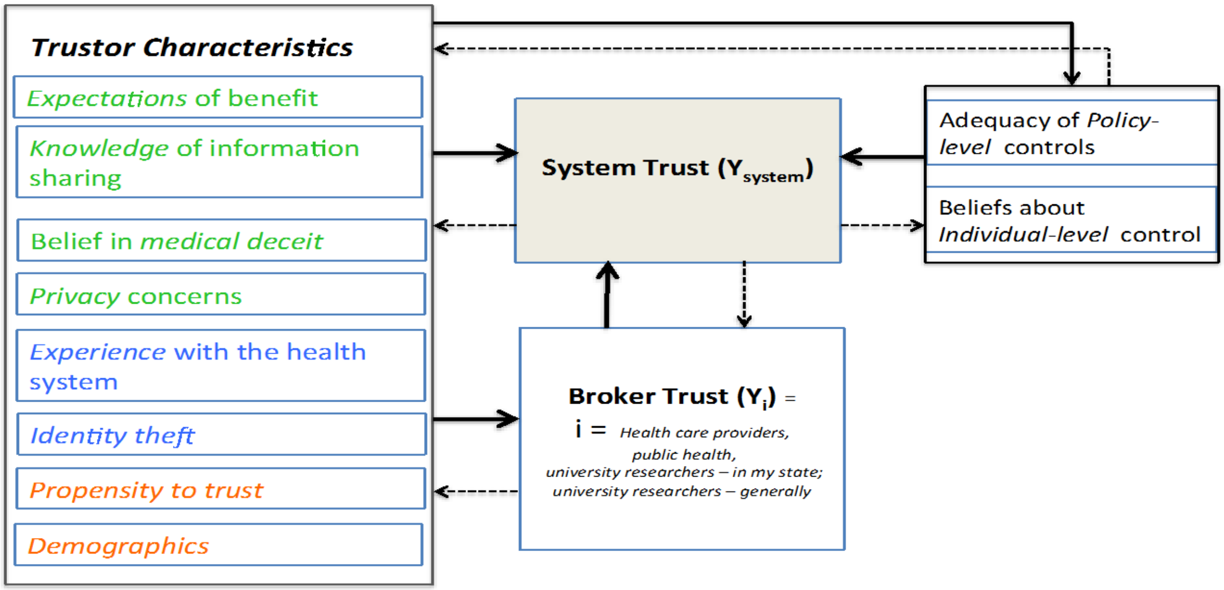
[3] There are some who have argued that there is a type of trust (virtual trust) in which the trustor is in fact forced into trusting by circumstance. An example is that one might have no choice but to trust a doctor in a town with only one physician (Ducournau and Strand 2009). This is a form of trust in name only and may be better described as coercion (Wynne 2006).

A CONCEPTUAL MODEL OF TRUST IN DATA SHARING IN THE HEALTH SYSTEM

Trust is a relational dynamic in which system trust is reinforcing or diminishing the importance of various factors that lead an individual to trust or mistrust the system; while this interrelatedness may confound true causal mechanisms, one can nonetheless identify key characteristics of trustor, trustee, and the environment that determine states of high or low trust. The model proposed for this study is one that focuses on the experience, beliefs, as well as psychosocial and demographic factors of an individual vis-à-vis the health system (Research Question 1); the public's trust in health information brokers and how this trust relates to trust in the system of brokers (Research Question 2); and, perceptions of the policy environment and personal autonomy, and how these relate to system trust (Research Question 3). Figure B summarizes this model. The solid arrows indicate that the focus of the research and data analysis is on the linear relationship between system trust and its key individual-level predictors. The dashed arrows suggest that the relationships are bi-directional and interrelated.

Figure B. Postulated conceptual model of trust in health information sharing



System trust

The postulated conceptual model includes four dimensions of system trust: fidelity, competency, integrity, and global trust. Surveys of trust in the health system typically encompass these and other dimensions, including: communication, honesty, confidence, competence, fidelity, system trust, confidentiality and fairness (Ozawa and Sripad 2013), the choice of dimensions for the present analysis expands on the work of Mark Hall and colleagues in developing the Wake Forest Scale that has been applied to a number of relevant dimensions of the health system at large including trust in physicians (Hall et al. 2002, 2001), the medical profession (, 2002), and insurance companies (Beiyao Zheng et al. 2002). Other scales of trust in the health setting, organizations, and technology use dimensions that are consistent with the Wake Forest Scales (See e.g., LaVeist et al on race, trust, and health (2003, 2009); McKnight, Choudhury, and Kacmar on technology (2002) ; and Siegrist on GMOs (2000, 2010, 2012)). In examining fidelity, integrity, competency, and global trust dimensions, fidelity captures benevolence, i.e., the act of a trustee prioritizing the needs and interests of the trustor (Mayer, Davis and Schoorman 1995). Integrity is defined as honesty or following the principles of non-deception. Competency refers to the ability and expertise to minimize errors and achieve goals. Global trust is an integrative concept that captures an individual's general perception of trustworthiness. It is meant to capture aspects of trust that are more intuitive than rational or calculative (Hall et al. 2001).

Trustor characteristics

From the perspective of the individual, trust drives a single action or opinion, but is motivated by multiple emotive, cognitive and behavioral aspects of an individual's belief structure (Lewis and Weigert 2012, 1985). The trustor is bound to draw on intuition and cultural repertoires (toolkits), as well as direct knowledge of the other (trustee), and learned patterns of behavior. Extending current research (described in Chapter I), I developed a series of measures related to the trustor's capacity and willingness to trust the health system – defined as the network of organizations that has health information and shares it. Demographic and psychosocial variables captured information about life circumstances that shape life chances, social experience, and dispositions or attitudes about social systems (Cockerham 2005); variables measuring the frequency of interaction with the health system and other large complex information systems evaluated experiential constructs. Cognitive/ emotive elements of trust were measured by evaluating specific knowledge, attitudes, and expectations the public holds with respect to the health system and data sharing.

Trust in health information brokers

Opportunities to negotiate trust, or what Anthony Giddens would call “access points” (1991) put trustors and trustees in direct contact and are critical for explicitly building and negotiating trust relationships. In the research and health care context, these access points translate to interactions between physicians and patients that then have consequence to the reputation of the hospital or health system. Another more indirect example is that of a research subject interacting with a staff person in the informed consent process. The tenor of the interpersonal interaction may impact opinions and beliefs about research generally, the institution supporting it, and the researcher regardless of whether the interaction is a true reflection of intent or practice.

In surveys of trust in physicians and scientists, individuals are often asked about their beliefs about the trustee’s capacity to make decisions that reflect the best interests of the patient or public. This often means acting in the patient or public’s best interests, not acting from purely economic motives, and having a good track record of behaving responsibly (Hall et al. 2001; McAllister 1995; Earle 2010) . Given the role of public health departments as key brokers in the sharing of health information they have been included in this analysis, though there is little previous empirical study of how individuals shape their opinions and beliefs about these health institutions. Media coverage of legal action against the state health departments in Texas and Minnesota involving use of newborn screening bloodspots cited skepticism over the responsible use of health information, as well as concerns about whether health departments were acting in the best interests of the public as major motivations behind the litigation. Chapter II examines the predictors of trust in health information brokers as well as the relationship between trust in these brokers and system trust.

Policy environment and personal autonomy

Uncertainty moderates the trust relationship; without risk, trust is not necessary as there are no consequences to failing to fulfill the obligation in question(Hardin 2002). The Health Information Portability and Accountability Act (HIPAA), the Federal Privacy Act, and the Genetic Information Non-Discrimination Act (GINA) are examples of regulatory controls aimed at reducing the risk of, and harm caused from, sharing and misuse of health data. In addition to legislation and regulations, institutional policies, culture, and ethical norms similarly affect some forms of risk. De-identification – the process of removing or coding information that could directly link individual identities with health data – has been the standard for protecting individual privacy. However, as data sets get larger, DNA sequencing becomes less expensive, and information is more broadly accessible on the Internet, guarantees of anonymity are less credible (Gymrek et al. 2013).

Creating a robust policy environment that can minimize harm that might come if the terms of trust are violated is one way to address risk and uncertainty. If policy sufficiently guards against harm from health information sharing, trust may be strengthened or deemed unnecessary. Beliefs that policy does not adequately protect against harm may be associated with lower levels of trust.

In the political context, failing to demonstrate individual or social benefits of welfare policies has had a crippling effect on their maintenance and on public trust. For example, Herrington (2006) has shown that in the absence of direct benefits, beliefs in government incompetency coupled with mistrust of government have created a self-fulfilling prophecy in which assistance programs have failed to maintain public support not because they are ineffective but because the population believes they are ineffective. This belief weakens public support and thus public funding, creating programs that are in fact less trustworthy and less effective at achieving their goals.

As health information systems become increasingly large, they may begin behaving in ways that mirror complex systems. Trust in large health information systems should mirror trust in political systems rather than the dominant forms of trust in a single health care provider. If health information systems can demonstrate the benefits of health information sharing, they would proactively assure trust in the health system. Such demonstrations might seek out the large proportion of people who believe the health system actively deceives the public. Alternatively, individuals may be given sufficient autonomy and control to be able to set the terms and conditions of trust as well as the expected outcomes of an arrangement. An individual's ability to choose her behavior in the health system to access information and services may empower her to offer trust and authority to made decisions about how health information is used. An examination of these personal control mechanisms and their impact on system trust is the focus of Chapter III.

CONCLUSION

Grand promises of a better, healthier future are made on behalf of health care, public health, and research. Genomics promises an era of personalized medicine, in which a doctor can analyze one's genome to provide recommendations for preventive measures, precise diagnoses, and effective treatment plans. Public health surveillance envisions complete access to a wide range of environmental, personal health, and population-level statistics to deliver real-time control and prevention of potential outbreaks such as *E. coli* or pandemic flu. Health care providers, equipped with the right electronic health records, can reduce the incidence of medical error significantly (Etheredge 2007). No doubt some of these promises will be realized. However, some of these claims may be unduly inflated, delivered inequitably, or have the potential to backfire if they fail to meet public expectations.

Trusted brokers will need to contend with a difficult historical experience even as those building health data systems work toward a magnificent future. Many of the biggest tragedies in medical ethics were made under the guise of good intentions. Initiated in a time when the medical community and government institutions were largely left on their own to regulate the ethics of their work, the Tuskegee Syphilis Study had as one of its goals a to be of “benefit to physicians who were treating syphilitic blacks” (Jones 1981, 191-2). Henrietta Lacks, whose HeLa cell line is now central to countless cancer studies, was not directly harmed when her physician kept her unique, excised tumor cells. But, years later, when her family came to know about the cells’ continued utilization in scientific research felt their undisclosed use was a violation of the terms of conditions and of research ethics (Skloot 2010). For decades eugenics was a proud and active role for public health. The 1927 Supreme Court case *Buck v Bell* upheld forced sterilization in the interest of the social good. The key lesson from these examples is, “not that health sciences had values, but that it had bad values” (Pernick 1997). In each of these cases fields of practice were isolated from the public eye. Exposing the status quo operations within these arenas opened opportunity for reflexivity.

One of the consequences of changing research paradigms is stressing the ethical and normative structures of science, thus challenging traditional research governance. As a result of the ethical breeches of the early- to mid-twentieth century, informed consent has become a cornerstone of research. Consent is a material form that not only reflects this past but symbolizes a trusted relationship between scientist and subject, and expresses a shared understanding (risks and benefits) of engaging in a given research project. In the context of multi-purpose data collection, informed consent no longer fits the model of one-subject, one-researcher, one-form. Instead, a participant is asked to consent to a process of ethical and scientific oversight and may not be explicitly informed each time his or her data is used (Lunshof et al. 2008; Caulfield et al. 2008). A trusted broker is appointed to sit at the intersection of science researcher, institution, and the public to assure ethical and acceptable use. As the moniker suggests, this paradigm shift in research increases the salience of trust in scientific practice.

Innovation in health system engineering often starts with the premise that healthcare in the United States is too expensive (which it is) and, consequently, that solutions ought to be found in the private-sector market. The market place, however, is too narrowly constructed, and the distinction between public and private is fuzzy at best. Understanding the work of trusted brokers means understanding the boundaries and culture of their trading zone, their strengths and limitations as gateways linking networks of networks, and, above all, what makes them trusted.

The current health infrastructure is increasingly information-based (Friedman, Wong and Blumenthal 2010), without a concomitant awareness among the general public of the boundaries of information sharing. What is more, health and public health governance does not have the reach or adaptive ability to micro-manage. The system is too large, too decentralized, and too complex. For the creation, maintenance, and sustainability of the evolving health system, the rate limiting factor is not financial, intellectual, or technological capacity, but trust of the scientific and political spheres to use information respectfully and responsibly. The trusted broker may be capable of fostering this relationship across the diverse actors it engages. I would argue that to achieve near- and long-term sustainability, the broker cannot black-box or take for granted its trusted status. Fulfilling the social contract requires active maintenance and investment in assuring trust.

Manuel Castells cautions that the “network society” continues to build and empower the elite class, while subordinate functions, and the people who perform them, are left ever-more fragmented, isolated, and disconnected (Castells 2010). Trusted brokers will increasingly need to navigate both levels of health infrastructure in order to obtain and sustain the trust of its multiple stakeholders. A variety of actors are potentially equipped to take on this task of engendering public and scientific confidence, and a new era of health informatics. Just as the failures could ripple across diverse networks, so might successes improve transparency and accountability system-wide. This success could be an opportunity for increased awareness of health, science, public health, and for building the public’s trust.

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CHAPTER I

Analytical Paper 1: Trustor Characteristics as Predictors of System Trust

INTRODUCTION

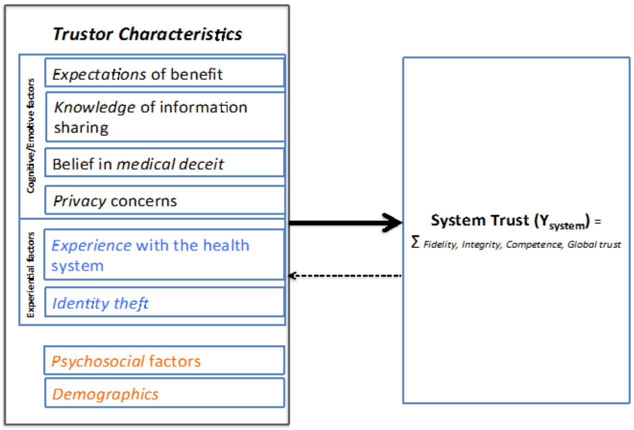
National information networks that have emerged in the past ten years, such as Clinicaltrails.gov, DbGAP, the HMOResearch Network, and the Newborn Screening Translational Research Network, promote and facilitate information sharing in a broadly defined health system. By facilitating work and collaboration among health care providers, public health departments, and researchers, the implicit promise of policies that promote data sharing is increased efficiency and accelerated translation of clinical research into health care and public health practice. Underlying the concomitant changes in data stewardship and brokerage accompanying an increasing number of data sharing networks use is confidence in the public's trust in health care and public health practice and research.

Trust in the health care context is often defined in terms of a *cognitive expectation or willingness to impart authority and accept vulnerability to another in fulfilling a given set of tasks*. A number of factors can influence the capacity and inclination to trust including the trustor's past experience, beliefs, or attitudes on the one hand, and the trustee's competency, reliability, reputation, honesty, or interestedness in the trusted relationship on the other (Hardin 2002, 2004; Cook, Hardin and Levi 2005; Nannestad 2008; Cook, Levi and Hardin 2009; Farrell 2009). The trustor or trustee can be an individual, organization, institution, or system. *In the present analysis, I focus on characteristics of the trustor (i.e., individuals) that would influence their trust in an expanding health information system.* The health system is defined as the organizations – health care providers, payors, public health departments, and university researchers – that have health information and share it.

In Figure1.1, I illustrate the postulated conceptual model, empirically tested in this paper, of the trustor characteristics that are likely associated with overall health system trust. As depicted by the larger arrow in Figure 1.1, the model being evaluated is one that focuses on the experience, beliefs, as well as psychosocial and demographic factors of an individual and its relationship to trust in the health system. These trustor characteristics are reflective of how the trustor might evaluate the trust between himself and the health system. At the same time, and as the dotted arrow in Figure 1.1 suggests, it bears noting that trust is a relational dynamic in which system trust is reinforcing or diminishing the importance of the various factors that lead an individual to trust or mistrust the system. The bi-directionality of the dynamic makes it impossible to identify true causal mechanisms.

From the perspective of the individual, trust drives a single action or opinion, but is motivated by multiple emotive, cognitive and behavioral aspects of an individual's belief structure (Lewis and Weigert 1985, 2012). The trustor is bound to draw on intuition and cultural repertoires (toolkits), as well as direct knowledge of the other (trustee), and learned patterns of behavior. Extending current research (reviewed below), I developed a series of measures related to the trustor's capacity and willingness to trust the health system. Demographic and psychosocial variables captured information about life circumstances that shape life chances, social experience, and dispositions or attitudes about social systems (Cockerham 2005); variables measuring the frequency of interaction with the health system and other large complex information systems evaluated experiential constructs. Cognitive/ emotive elements of trust were measured by evaluating specific knowledge, attitudes, and expectations the public holds with respect to the health system and data sharing. In the following sections, I describe each of the

Figure 1.1 Conceptual Model: Trustor characteristics as predictors of system trust



dimensions of trust and trustor considered in the conceptual model.

System trust

The proposed conceptual model includes four dimensions of system trust: fidelity, competency, integrity, and global trust. Surveys of trust in the health system typically encompass several dimensions, including: communication, honesty, confidence, competence, fidelity, system trust, confidentiality and fairness (Ozawa and Sripad 2013), the choice of dimensions for the present analysis expands on the work of Mark Hall and colleagues in developing the Wake Forest Scale that has been applied to a number of relevant dimensions of the health system at large including trust in physicians (Hall et al. 2002b; Rajesh et al. 2003), the medical profession(Hall et al. 2002a; Dugan, Trachtenberg and Hall 2005), and insurance companies (Goold, Fessler and Moyer 2006; Beiyao Zheng et al. 2002). Other scales of trust in the health setting, organizations, and technology use dimensions that are consistent with the Wake Forest Scales (See e.g., LaVeist et al on race, trust, and health (Boulware et al. 2003; LaVeist, Isaac and Williams 2009); McKnight, Choudhury, and Kacmar on technology (McKnight, Choudhury and Kacmar 2002); and Siegrist (2000) on GMOs). In examining fidelity, integrity, competency, and global trust dimensions, fidelity captures benevolence, i.e., the act of a trustee prioritizing the needs and interests of the trustor (Mayer, Davis and Schoorman 1995). Integrity is defined as honesty or following the principles of non-deception. Competency refers to the ability and expertise to minimize errors and achieve goals. Global trust is an integrative concept that captures an individual's general perception of trustworthiness. It is meant to capture aspects of trust that are more intuitive than rational or calculative (Hall et al. 2001).

Trustor characteristics

Psychosocial and demographic factors. Regardless of the context for trust, some individuals are more likely to exhibit trusting attitudes than others. Individual-level factors create world-views, embody social structures, and reflect the experience of everyday life. These include psychosocial factors such as self-esteem, altruism, self-efficacy, one's general outlook on life, and a generalized trust or expectancy that people are reliable (Das and Teng 2004). An individual's socialization will shape his or her deference to the scientific community and willingness to accept the vulnerability of trusting its authority and actions. These factors, as well as other demographic factors such as education, race and ethnicity, employment status, *et cetera*, inform an individual's habitus, or social position, and ultimately his/her cultural capital (Bourdieu, Pierre 1984) and trust repertoire (Mizrachi, Drori and Anspach 2007) that shape agency, power, and capacity to act. Patterns of social experience shape an individual's self-esteem and other psychosocial factors. These become particularly relevant antecedents to trust in cases involving unfamiliar actors or unfamiliar actions since the trustor has little more on which to base his trust beyond these intrinsic characteristics.

Cognitive/ Emotive Characteristics: Knowledge. Overall, few among the general public understand what health information systems and sharing and lack knowledge about what information can be shared, how health care providers might use it, what public health does, and how research works. Increased public funding for electronic health record infrastructure provided in by the American Recovery and Reinvestment Act (2009) coupled with dramatic cuts to public funding for research and public health, however, increasingly make salient questions about the public's role in information sharing. As a fundamentally political debate, knowledge and legitimacy claims about the value of larger health information infrastructure as a social priority are subject to deconstruction and diverse reconstruction as experts – scientists, health care providers, and public health practitioners – and special interest groups mold competing narratives that aim to sway public opinion and garner support in the political sphere (Jasanoff 1987).

While the relationship between knowledge and trust has not been a focus of research in health care, research in the public understanding of science field has used qualitative and quantitative methods to evaluate the question of whether the lack of support for science is simply a question of a knowledge deficit (Sturgis and Allum 2004; Allum et al. 2008; Roberts et al. 2013; Connor and Siegrist 2010; Siegrist and Cvetkovich 2000). Evans and Durant, for example, showed that more knowledgeable individuals were more likely to support general science research, but were less likely to support controversial scientific endeavors such as human embryology (Evans and Durant 1995). Bruce Wynne's classic study of Cumbrian sheep farmers, which examined lay versus professional expertise, strongly suggested that increased knowledge among the "non-expert" public does not necessarily translate into increased trust in the "expert" (Wynne 1992). In expanding the networks for health information, public engagement is identified as the key mechanism for building trust and acceptance, often under the assumption that this interactional form can improve knowledge and communication that will, in turn, fill a "knowledge deficit" and ultimately heighten support for innovations (Petersen 2007). In the research presented here, I developed a set of fact-based questions to measure an individual's knowledge about current, common policies and practices for data sharing among health care providers, insurers, researchers, and public health to investigate whether and in what direction knowledge might be associated with health system trust.

Cognitive/ Emotive Characteristics: Beliefs about medical deception. In the absence of direct knowledge about information use, the public may still hold attitudes and beliefs about how the system works and whether or not it is trustworthy based on its historical record or reputation. In the case of health, health care providers command a high level of trust (*Trust in Professions* 2014). However, systemic discrimination and historic violations of trust have been linked to skepticism toward the health care system and medical research, especially among African Americans (Boulware et al. 2003). In addition, religious and anti-allopathic medicine subgroups of the population also have deeply engrained mistrust of the health system.

Today's anti-vaccination movement has gained traction to the extent that epidemics of measles and pertussis (vaccine preventable illnesses) are becoming more prevalent. A recent public poll found that nearly 50% of Americans believe at least one of six medical conspiracies (Oliver and Wood 2014):

> (1) The Food and Drug Administration is deliberately preventing the public from getting natural cures for cancer and other diseases because of pressure from drug companies.
> (2) Health officials know that cell phones cause cancer but are doing nothing to stop it because large corporations won't let them.
> (3) The CIA deliberately infected large numbers of African Americans with HIV under the guise of a hepatitis inoculation program.
> (4) The global dissemination of genetically modified foods by Monsanto Inc is part of a secret program, called Agenda 21, launched by the Rockefeller and Ford foundations to shrink the world's population.

> (5) Doctors and the government still want to vaccinate children even though they know these vaccines cause autism and other psychological disorders.
> (6) Public water fluoridation is really just a secret way for chemical companies to dump the dangerous byproducts of phosphate mines into the environment.

The belief that the medical establishment acts deceptively and in ways that warrant mistrust as the default stance toward the health system may be having deleterious effects on trust system-wide. Onora O'Neill, in her lectures examining the state of trust in contemporary society, ascribes deception as the biggest contributor to today's "culture of suspicion" and the pervasive sensation that trust is in crisis (2002).

Cognitive/ Emotive Characteristics: Trustor privacy concerns. Concerns about privacy, which increase perceptions of risk in health information sharing, are similarly likely to reduce trust in the health system. Technological advances have improved electronic data security immensely since encryption, password protections, and firewalls reduce the risk of data resources being compromised. And yet, data breaches are common and can be quite large affecting the security of information for millions of individuals (*Breaches Affecting 500 or More Individuals* n.d.). Survey research evaluating the public's concerns about privacy in biobanking – a comparable arena in which data is collected and stored for future research use – suggests that privacy is a salient issue (Kaufman et al. 2009). Trust increases or decreases based on an individual's confidence in the ability of a system to protect individual privacy (Hurwitz 2013). And yet, the extent to which fears about discrimination or a violation of privacy impact trust is undetermined (Kaufman et al. 2009; Pullman et al. 2012).

Cognitive/ Emotive Characteristics: Expectations. In accounts of interpersonal trust, an expectation of benefit is often closely connected to trust. Annette Baier (1986) sees expected benefits as a byproduct of trust, which is motivated by goodwill. Applied in this context, an individual might trust the health system to share information because they view data sharing positively. Russell Hardin, who views trust as a form of risk-assessment, however, views expectations as an indicator of one's interestedness in being part of a trusting relationship. The public might trust the health system to steward and share health information because they will see some form of benefit in the future such as improved health or improved quality of care.

Various national and international reports (Institute of Medicine (US) 2011; Milstein 2013; Committee on the Learning Health Care System in America 2012; Coloma et al. 2011), direct-to-consumer (e.g., PatientsLikeMe), and private big data initiatives such as Blue Cross Blue Shield's "Blue Health Intelligence" make the claim that expanding information infrastructure and making data sharing more efficient will improve the quality of health care and improve health. Understanding the public's view of these goals and their general view of data sharing sheds light on the expectations they hold in entering into a relationship in which trust plays a central role. The greater the perceived benefit or the higher the expectation, the more likely the public is to trust the health system

Experience: Health System, Identity Theft. Finally, trust is likely to be influenced by the amount of direct experience an individual has with the trustee (Hurwitz 2013). Prior experience with the actors in a complex system creates a type of awareness and understanding that helps make large and abstract systems accessible, reducing uncertainty and increasing trust (Gefen, Karahanna and Straub 2003; Giddens 1991). Nonetheless, while some prior experience or familiarity with the object of trust is necessary for cognitive trust, such experience only offers the possibility that an individual might come to trust without actually guaranteeing it (Lewis and Weigert 2012). Drawing on Luhmann's theory (Niklas 2000) that familiarity increases trust insofar as it reduces uncertainty, I assessed whether or not respondents had any contact with the health system either by seeing a primary health provider, having insurance, or interacting with the public health system. In this first paper examining predictors of system trust, experience is evaluated as whether an individual has had experience with none of these institutions, or with one, two, or three of them, without differentiating which. Beyond the health system, incidents reported in the media of large data breaches at major retail stores (e.g., Target, Home Depot) suggest that identity theft might be a growing issue. Experience with these events could have effects on willingness to engage in electronic information sharing generally, and by extension, in the health context.

METHODS

Questionnaire development

Predictors of trust in the health system, broadly defined as a web of relationships among health care providers, departments of health, insurance systems, and researchers were measured by a 117-item survey (See Appendix C). The survey included the trustor characteristics described above in the conceptual model (Figure1.1) as well as additional questions about trust in specific institutions (health care providers, researchers, and public health), quality of experience, perceived control, and adequacy of policy oversight. Measures of the dependent variable – System Trust – and the independent variables used in this paper were adapted from prior studies and contextualized for the health system as needed (Hall et al. 2002a, 2001, 2002). Sources included the California Health Foundation's 2005 National Consumer Health Privacy survey(Bishop, Holmes and Kelley 2005) and methods used in risk analysis literature {\See e.g., \Visschers 2011; (Siegrist, Connor and Keller 2012) to develop measures of knowledge, experience, and expectations. Questions from the Medical Mistrust Index (Boulware et al. 2003; LaVeist, Isaac and Williams 2009), and related studies of privacy of health information were adapted to assess privacy concerns and beliefs about deceptive behavior in the health field (Anderson and Agarwal 2011; Bishop, Holmes and Kelley 2005) . The Health Privacy Survey also informed questions about expectation of benefit and knowledge. Questions from the General Social Survey (Smith et al.), National Election Survey (Feldman and Steenbergen 2001), the General Self-efficacy Scale (Schwarzer and Jerusalem 1995) and the Rosenberg Self Esteem scale (Rosenberg et al. 1995) were used to survey psychosocial factors. Questions developed by the Federal Trade Commission (2003) about identity were also included in the survey (*Identity Theft Survey Report* 2003). A complete description of the questionnaire development and validation is described in Appendix B, Survey Design and Documentation.

Respondents answered questions about "how true" they believed a series of statements to be along a 4-point, unipolar Likert scale: "Not at all true" (1), "Somewhat true" (2), "Fairly true" (3) and "Very true" (4). These statements captured information about system trust, beliefs about privacy and medical deception, and psychosocial characteristics. Questions about expectations of benefit and having a favorable view of data sharing also used a four-point scale, but the answer choices were different (See Questions “viewshare,” “sharequality,” and “share improve” in Appendix D). Questions about knowledge of information were asked as True/False questions.

Sample

Respondents were surveyed using GfK’s probability-based, nationally representative sample consisting of non-institutionalized general population adults (KnowledgePanel) in February 2014. Eligible participants were randomly selected and contacted via email to invite participation. Of 2,082 individuals contacted to participate, 52.9% agreed. Of the 1,103 responses collected, 41 were excluded due to constant refusal and an additional 51 respondents were excluded from data analysis due to item-missingness. The median completion time of the final survey was 22 minutes. Post-stratification weights corresponding to the U.S. Census demographic benchmarks for age, sex, household income, education, and race and ethnic background were calculated by GfK for this survey sample to reduce bias from random sampling error. Details about the GfK methodology are provided in Appendix C.

Statistical analysis

Descriptive distributional statistics were estimated on all variables to identify outliers or other distributional characteristics that may influence regression modeling (See Tables 1.1-1.6). Indices were calculated for System Trust and key trustor characteristics (e.g., privacy index, esteem index, etc.) as the sum of the participant’s responses to those survey questions divided by the number of questions. Questions that were highly correlated ($|r| > 0.70$) or were asked to measure similar constructs were candidates for the creation of indices (See Table 1.8 and Appendix A). Chronbach’s alpha was calculated to validate the internal consistency of the indices and is reported in the descriptive tables.

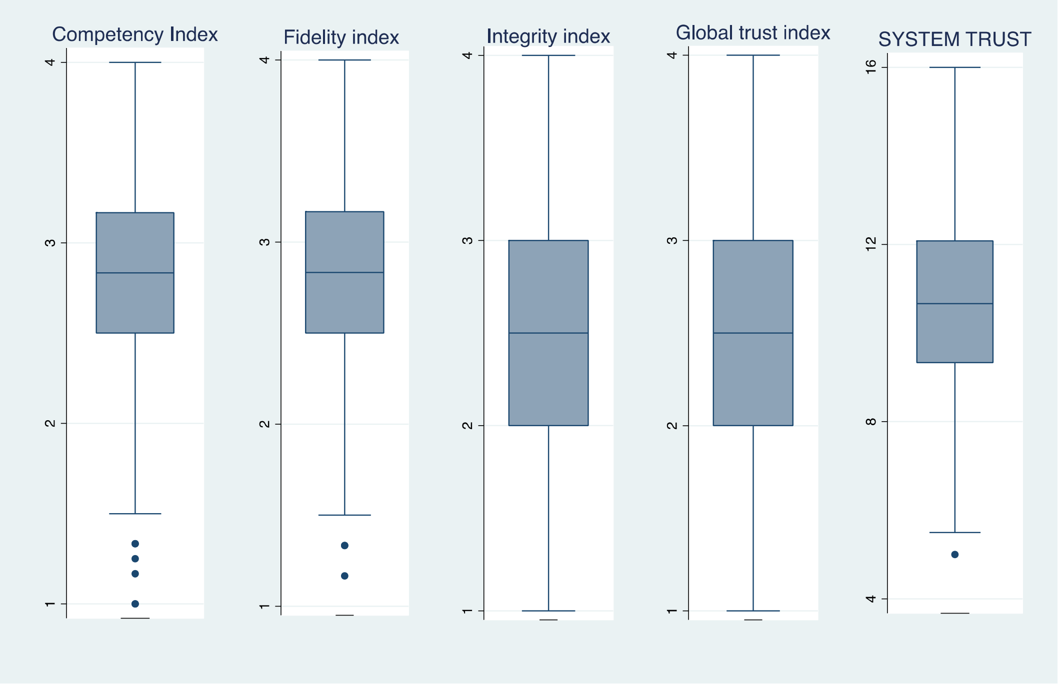
Weighted Ordinary Least Squares (OLS) Regression analysis was used to estimate the linear relationship between overall trust in the health system and each factor separately before estimating a multivariable model using all independent variables. Additional weighted stepwise regression models employed standard inclusion and exclusion selection methods (inclusion criteria ($p<0.05$) and backward elimination using exclusion criteria ($p \geq 0.10$)) to identify more parsimonious models of system trust. Given the number of variables used in the multivariable regression models, the probability of making Type I errors (i.e., rejecting the null hypothesis when it is true leading to the identification of too many factors as "significant") is relatively high (Cabin and Mitchell 2000). Bonferroni corrections were applied to stepwise regression models to generate more conservative estimates of statistical significance ($p= \alpha/k$; $\alpha=0.05$ and k= number of parameters). Standardized regression models were used to assess the relative magnitude of the effect of each of the independent variables on system trust.

Adjusted R^2 as well as the Aikake Information Criteria (AIC) and Bayesian Information Criteria (BIC) to evaluate model fits. Smaller values for the AIC and BIC indicate a better model fit than larger values. BIC is frequently a more conservative estimate of model fit since it penalizes more strongly for the number of parameters than the AIC (Cameron and Trivedi 2010). Finally, Pearson product-moment correlation coefficients to examine the relationships between independent variables were evaluated for statistical significance at the $\alpha=0.05$ level and using Bonferroni corrections to apply more conservative estimates of statistical significance ($p= \alpha /k$).

RESULTS

The outcome variable of system trust was derived from 1,011 individuals' valid responses to the 20 questions measuring their beliefs about the fidelity, competency, integrity, and global trustworthiness of the organizations that have health information and share it. Fidelity, competency, integrity, and global trustworthiness indices were normally distributed along a continuous scale how true a set of statements were for an individual (Range: 1-4). The mean of the fidelity index and the mean of the competency index were both 2.8. The mean of integrity and global trustworthiness indices was 2.5. System trust, derived from the sum of dimension-specific indices, has a scale of 4-16 and the range of observed values was 5-16 with a mean of 10.7 and standard deviation of 2.0. Figure 1.2 shows box-plots that depict the distribution of system trust and its four dimensions.

Figure 1.2 Competency, Fidelity, Integrity, Global trust and System trust indices



Descriptive statistics for trustor characteristics including cognitive/emotive, experiential factors, and demographic/ psychosocial variables are listed in Tables 1.1-1.6. The sample is split nearly evenly with respect to men and women; 76% are white, non-Hispanic; 9% are black, non-Hispanic; 10% are Hispanic; and 5% are other. Forty percent have less than a bachelor's degree education; and 60% have annual household incomes <$50,000. Half of respondents are working as an employee, and an additional 7% are self-employed. Approximately one in five are retired (22%), and a comparable proportion are laid off or on disability (14% and 7%). To a question rating self-reported health, asked as "In general, would you say your physical health is… Excellent/ Very Good/ Good/ Fair/ Poor," the mean response was 2.52, 95% CI: 2.47-2.58. On the political spectrum of liberal, moderate, or conservative, nearly one quarter identified as liberal (23.8%), 36% identified as moderate, and 40% as conservative. At the time the survey was given, about 40% of respondents had a favorable view of the Affordable Care Act/ Obamacare – comparable to a Kaiser Family Foundation poll that asked a similar question at the same time and found 35% of Americans had a favorable view of the ACA, 47% unfavorable, and 18% were unsure.

Table 1.1 Descriptive statistics: Demographic factors	**Frequency (n = 1,011)**
Sex	
Male	49.3%
Age	
18-29	15.4%
30-44	21.7%
45-59	30.2%
60+	32.7%
Race/ ethnicity	
White	75.8%
Black, NH	9.2%
Hispanic	9.7%
Other, NH	5.3%
Education	
Less than High School	8.9%
High School	31.1%
Some college	28.7%
BA or above	31.3%
Income	
Less than $50,000	60.4%
Employment status	
Has employer	50.0%
Self-employed	7.3%
Laid off	13.6%
Retired	22.3%
Disability	6.8%
Self-reported health	
Range: 1 (Excellent) to 5 (Poor)	Mean: 2.5 (SD=0.92)
Political affiliation	
Liberal	23.8%
Moderate	35.9%
Conservative	40.3%
Support for Affordable Care Act	
Given what you know about the Affordable Care Act (Obamacare), do you generally: approve (1) or disapprove (4) (mean; range 1-4)	Mean: 2.9 (SD=1.1)

Psychosocial factors included variables measuring self-esteem, altruism, self-efficacy, having a negative outlook, and generalized trust (See Table 1.2). Indices measuring self-esteem, altruism, and self-efficacy were based on four questions each; Chronbach's alpha for self-esteem questions was 0.75; α= 0.69 for altruism, and α=0.79 for self-esteem. Having a negative outlook and generalized trust were evaluated based on a single questions used the General Social Survey, “I think the quality of life for the average person is getting worse, not better” and “Generally speaking, most people can be trusted). All psychosocial factors were measured along a 4-point scale; the mean of self-esteem was found to be 3.4 (SD=0.59); 2.7 for altruism (SD=0.65); 2.9 for self-efficacy (SD=0.64); 2.13 for negative outlook (SD=1.0); and 2.3 for generalized trust (SD=0.82).

Privacy (Table 1.3b), among the cognitive/ emotive characteristics, emerged as an important issue for about three quarters (73%) of respondents, but far fewer cited privacy as a major concern or that they were afraid privacy was at risk. Twenty-seven percent of respondents thought that the privacy of health information was seriously threatened, or that private health information could be used against them; an equal proportion thought that their health care provider might share embarrassing information. Only 15% stated that they intentionally withheld information from health care providers because they are untrustworthy. The mean of the privacy index was 2.18 (95% CI: 2.14-2.22); the internal consistency of the index, measured by Chronbach’s alpha, was $\alpha = 0.78$.

Beliefs that the medical and research community act deceptively are more widely held and of greater consequence than might be expected (See Table 1.3a). Approximately 40% of the population holds one of the following four beliefs: 1) “The government does not tell the public the truth about the dangers of vaccines”; 2) “Some medical research projects are secretly designed to expose minority groups”; 3) “The health care system experiments on patients without them knowing about the experiments”; and 4) “Health professionals don’t tell you everything you need to know about medicines.” A majority finds it plausible that the dangers of vaccines are being hidden, while a smaller number believe that the medical community is performing experiments on them without their knowing. The Chronbach’s alpha for these four questions used to generate a deception index was 0.79. In a simple regression on system trust, the deception index the explained ~25% of the variability in trust in the health system (p<0.001).

Table 1.2 Descriptive statistics: Psychosocial factors	**Frequency (% “Very or Somewhat True”)**	**Mean (SD)**
Self-esteem		
I take a positive attitude toward myself	79.0%	3.16 (0.86)
I wish I could have more respect for myself (Reverse coded)	84.5%	3.39 (0.86)
I feel that I have a number of good qualities	85.1%	3.33 (0.78)
All in all, I am inclined to feel that I am a failure (Reverse coded)	93.5%	3.72 (0.64)
Self esteem index (Chronbach’s α=0.75)	Median: 3.5	3.40 (0.59)
Altruism		
I always find ways to help others less fortunate than me	49.2%	2.57 (0.83)
The dignity and well-being of all should be the most important concern in any society	66.5%	2.92 (0.92)
One of the problems of today’s society is that people are often not kind enough to others	67.2%	2.98 (0.91)
All people who are unable to provide for their own needs should be helped by others	43.9%	2.49 (0.93)
Altruism Index (Chronbach’s α=0.69)	Median: 2.8	2.74 (0.65)
Self-efficacy		
I can manage to solve difficult problems if I try hard enough	79.8%	3.18 (0.79)
If someone opposes me, I can find the means and ways to get what I want	36.2%	2.25 (0.82)
I am confident that I could deal efficiently with unexpected events	71.3%	2.94 (0.83)
I can solve most problems if I invest the necessary effort	78.4%	3.15 (0.81)
Self-efficacy Index (Chronbach’s α=0.79)	Median: 3.0	2.88 (0.64)
Negative Outlook		
I think the quality of life for the average person is getting worse, not better	32.5%	2.13 (1.01)
Generalized trust		
Generally speaking, most people can be trusted	38.9%	2.26 (0.82)

Approximately 70% of respondents stated that they expect that information sharing will improve the quality of health care that they receive or will improve the health of people living in the U.S. Seventy percent of respondents also stated that given what they know, they have a generally favorable view of data sharing (See Table 1.4). However, very few know about common policies and practices related to data sharing. Of the ten questions evaluating knowledge, respondents answered an average of six correctly (See Table 1.5). Most (88%) were aware that public health departments collect information. With regard to permission, 75% responded correctly that permission is not required for research using de-identified data and 67% knew information could be used in studies without knowledge or permission. At the same time, only 53% knew that permission is not required for all health research and 51% knew that researchers did not always need permission to access information contained in medical records.

Most (71%) respondents were aware that information may be part of an economy (i.e., that institutions may charge money for data access). Of the ten questions asked, there was less awareness of physician control of information in medical records (59%), data ownership (54%), and the scope of legal restrictions on discrimination based on genetic information (36%).

Table 1.3a Descriptive statistics: Beliefs about medical deception	**Frequency (% "Very or Somewhat True")**	**Mean (SD)**
The government does not tell the public the truth about the dangers of vaccines	29.7%	2.08 (1.00)
Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS	8.9%	1.42 (0.73)
The health care system experiments on patients without them knowing about the experiments	13.6%	1.66 (0.81)
Health professionals don't tell you everything you need to know about medicines	29.5%	2.15 (0.94)
Deception Index (Chronbach's α=0.79)	Median: 1.8	1.83 (0.69)

Table 1.3b Descriptive statistics: Beliefs about privacy	**Frequency (% "Very or Somewhat True")**	**Mean (SD)**
Keeping my electronic personal health information private is very important to me	73.0%	3.18 (0.97)
I worry that private information about my health could be used against me	27.2%	2.03 (0.99)
There are some things I would not tell my health care providers because I can't trust them with the information	28.1%	2.01 (1.01)
Doctors could share embarrassing information about me with people who have no business knowing	15.8%	1.64 (0.89)
I believe the privacy of my electronic personal health information is seriously threatened	27.2%	2.05 (1.00)
Privacy Index (Chronbach's α=0.78)	Median: 2.0	2.18 (0.71)

Table 1.4 Descriptive statistics: Expectations of health information sharing	**Frequency**	**Mean (SD)**
Given what you know about information sharing among organizations in the health system, do you generally have a favorable or unfavorable opinion of it? (Reverse coded) (1=Very favorable; 4= Very unfavorable)	70.4% "Fairly or Very favorable"	2.75 (0.69)
What effect do you think that health information sharing is likely to have on the quality of health care that you receive? (1= Not likely to *decrease quality*; 4= Very likely to *increase quality*)	64.9% "Fairly or Very likely to increase quality"	2.75 (0.86)
How likely do you think it is that health information sharing will improve the health of people living in the United States? (1= Not likely to *improve health*; 4= Very likely to *improve health*)	47.4% "Fairly or Very likely to improve health"	2.46 (0.94)
Expectation of improvement Index (Chronbach's α=0.79)	Median: 2.7	2.61 (0.83)

Despite low levels of knowledge about the health system, nearly all (94%) of the respondents had some experience measured as contact with the health system – suggesting that even if they were unfamiliar with policy and practices for data sharing, they likely have at a minimum what Henry Collins refers to as "beer mat expertise" (Collins and Evans 2007) or a general familiarity with the system on which to base their attitudes and beliefs.

Table 1.5 Descriptive statistics: Knowledge	**Frequency (% correct)**
State and local health departments collect information from physicians and clinics to monitor the health of communities	87.7%
Permission is NOT required for research using your health information if your identity (name, address) has been removed	75.4%
Institutions may charge money to researchers to access health information	70.6%
Your health information may be used in multiple studies without your permission or knowledge	66.8%
Health insurance companies are prohibited from using your health information to deny your coverage	61.1%
Your physician determines all uses of information in your medical record	59.3%
You own your health information	53.8%
A person's permission is required for all health research	52.9%
Researchers always need to obtain permission from you to access your medical record	51.0%
All forms of discrimination based on genetic information are prohibited by law	35.9%
Knowledge: Average total score (out of 10)	***6.1 (SD=2.0)***

Table 1.6 Descriptive statistics: Experience	**Frequency**
Contact with system: Primary care provider; insurance; interaction with the public health system	
Has had experience with none of these	5.6%
Has had experience with 1 of these	14.9%
Has had experience with 2 of these	72.1%
Has had experience with 3 of these	7.4 %
Identity theft / privacy breach: Has your personal information been stolen/misused?	No: 78.4%

Predictors of system trust

Trustor characteristics explained approximately half of the variability in system trust (See Table 1.7). The complete multivariable model did not explain significantly more than the Bonferroni-corrected stepwise model ($p>0.05$). Based on comparison of the AIC and the BIC, the stepwise model is more efficient at predicting system trust as compared to the multivariable regression model that includes all variables.

In the Bonferroni-corrected stepwise regression model, eight variables emerge as particularly salient in predicting system trust: Having an expectation of benefit (favorable view of data sharing and expecting improvements index), knowledge, belief in medical deception, education, and three psychosocial factors (generalized trust, self-esteem, and altruism).

Having a positive view of data sharing and expectations of benefit contribute the most to predicting system trust (b*=0.352 and b*=0.279 respectively). System trust increased at a rate of nearly one-to-one relative to whether a respondent views data sharing favorably or unfavorably (b=1.0, p<0.001). Other positive predictors of system trust include self-esteem (b=0.255, b*=0.080), altruism (b=0.304, b*= 0.098) and generalized trust (b=0.287, b*=0.119). Belief in medical deception is negatively associated with system trust (b=-0.506, b* = -0.179) and knowledge (b= -0.119, b*=-0.119). Education was also negatively associated with system trust. Those with a college degree had a 0.6-point lower score on the system trust index as compared to those with less than a high school degree (p=0.009). Several factors that one might expect to see in a model predicting trust are not in the final stepwise model; notably, privacy, and experience with the health system and with identity theft. Other factors that were not included in the final model include self-efficacy, having a negative outlook, and nearly all demographic factors.

Table 1.7 Predictors of system trust	**Multivariable OLS (all predictors)**			**Multivariable Stepwise w/ Bonferroni Correction**		
	Model R^2		0.52	***Model R^2***		0.50
	AIC (df)		3582.90(34)	**AIC (df)**		3599.79(11)
Model fit	**BIC (df)**		3750.14 (34)	**BIC (df)**		3653.89 (11)
	b	**b***	**p-value**	**b**	**b***	**p-value**
Cognitive/ Emotive Factors						
Expectation of Benefit: Favorable view of data sharing	0.972	0.339	<0.001	1.007	0.352	<0.001
Expectation of Benefit: Improvement Index	0.661	0.270	<0.001	0.682	0.279	<0.001
Knowledge	-0.105	-0.105	<0.001	-0.119	-0.119	<0.001
Privacy Index	-0.214	-0.076	0.015			
Deception Index	-0.381	-0.132	<0.001	-0.506	-0.175	<0.001
Experience factors						
Contact with system: Primary care provider; insurance; interaction with the public health system						
Has had experience with none of these	Ref	Ref	Ref			

Has had experience with 1 of these	0.234	0.043	0.364			
Has had experience with 2 of these	0.008	0.002	0.974			
Has had experience with 3 of these	0.097	0.014	0.746			
Identity theft	0.289	0.059	0.023			
Psychosocial factors						
Self-esteem index	0.055	0.017	0.590	0.255	0.080	0.002
Altruism index	0.388	0.125	<0.001	0.304	0.098	0.002
Self-efficacy index	0.215	0.067	0.035			
Negative outlook	-0.119	-0.060	0.056			
Generalized trust	0.243	0.101	0.001	0.287	0.119	<0.001
Demographic factors						
Sex						
Male	0.095	0.024	0.355			
Age						
18-29	Ref	Ref	Ref			
30-44	-0.024	-0.005	0.875			
45-59	0.007	0.001	0.966			
60+	0.031	0.007	0.886			
Race/ ethnicity						
White	Ref	Ref	Ref			
Black, NH	0.152	0.024	0.403			
Hispanic	-0.236	-0.041	0.150			
Other, NH	0.009	0.001	0.973			
Education						
Less than High School	Ref	Ref	Ref			
High School	-0.089	-0.020	0.661	-0.090	-0.021	0.672
Some college	-0.468	-0.106	0.023	-0.473	-0.107	0.024
BA or above	-0.513	-0.117	0.018	-0.584	-0.133	0.009
Income						
Less than $50,000	0.052	0.013	0.653			
Employment status						
Has employer	Ref	Ref	Ref			
Self-employed	-0.439	-0.055	0.068			
Laid off	-0.027	-0.005	0.865			
Retired	0.170	0.033	0.428			
Disability	0.007	0.001	0.978			
Self-reported health						
Excellent (1) Poor (5)	-0.047	-0.023	0.464			
Political affiliation						
Liberal	Ref	Ref	Ref			
Moderate	0.031	0.007	0.826			
Conservative	0.201	0.049	0.224			
Support for Affordable Care Act:						
Approval (1)/ Disapproval (4)	0.090	0.048	0.122			

b= regression coefficient; b* = standardized beta coefficient

Knowledge, privacy, and belief in medical deception were negatively correlated with having a favorable view of data sharing. Using the Bonferroni criteria, privacy and belief and medical deception were negatively correlated with having an expectation of benefit. Knowledge and privacy were positively correlated suggesting that those with greater knowledge had greater concerns about privacy. The relationship between knowledge and belief in medical deception, however, was not statistically significant under the Bonferroni criteria. The correlation between privacy and belief in medical deception was fairly high (*r*=0.47), with privacy explaining 24% of the variability in belief in medical deception. Examining the relationships between knowledge, privacy, belief in medical deception, and the psychosocial factors, knowledge was not significantly correlated with any of them. Privacy and belief in medical deception were positively associated with altruism and having a negative outlook (i.e., the belief that the quality of life for the average person is getting worse, not better), and negatively associated with generalized trust. Belief in medical deception was also negatively associated with self-esteem (*r*=-0.17) (after Bonferroni adjustment). The correlation between the independent variables suggests that some of them may not have appeared as significant in the multivariable models because of the observed underlying correlation between them.

Table 1.8 Trustor characteristics: Correlation table

	Favor. view	**Expect. index**	**Knowl.**	**Privacy index**	**Decept. index**	**Esteem index**	**Altruism index**	**Self-efficacy index**	**Neg. outlook**	**Gen. trust**
Favorable view of data sharing	1.000									
Expectations index	_0.7352*_	1.000								
Knowledge	_-0.1313*_	-0.0883*	1.000							
Privacy index	_-0.3808*_	_-0.4012*_	_0.1410*_	1.000						
Deception index	_-0.3041*_	_-0.3698*_	0.0819*	_0.4677*_	1.000					
Esteem index	0.0994*	_0.1620*_	0.0959*	-0.0936*	_-0.1681*_	1.000				
Altruism index	0.0966*	_0.1317*_	-0.017	_0.1210*_	_0.1469*_	_0.1803*_	1.000			
Self-efficacy index	0.0993*	_0.1533*_	0.0742*	0.044	-0.046	_0.5200*_	_0.2634*_	1.000		
Negative outlook	_-0.1636*_	_-0.2490*_	0.0748*	_0.2932*_	_0.3569*_	_-0.1806*_	_0.1482*_	-0.010	1.000	
Generalized trust	_0.2219*_	_0.2283*_	-0.0681*	_-0.1213*_	_-0.1181*_	_0.1691*_	_0.2148*_	_0.2564*_	_-0.1562*_	1.000

*p<0.05; _italics: p<.05/k_

DISCUSSION

The main positive indicators of trust are those related to having greater expectations and positive opinions about health information sharing, while the main negative indicators are knowledge and that deception is endemic to the health system. In a secondary analysis (not shown), factors most closely associated with a respondent's view of data sharing include beliefs about privacy ($b^* = 0.25$, $p<0.001$) and whether they believe health information sharing will improve health quality and/or outcomes ($b^*=0.40$, $p<0.001$). The strength of the relationship between system trust and having an expectation of benefit and a favorable view of data sharing suggest that the type of trust operant in the health system may be more of a political trust. This type of trust is more likely to be operant in larger abstract systems, and accounts for expectation of benefit and not just a willingness to be vulnerable, a key driver of trust in interpersonal relationships and doctor-patient interactions.

Indeed, in the political context, failing to demonstrate individual or social benefits of welfare policies has had a crippling effect on their maintenance and on public trust. For example, Hetherington (2006) has shown that in the absence of direct benefits, beliefs in government incompetency coupled with mistrust of government have created a self-fulfilling prophecy in which assistance programs have failed to maintain public support not because they are ineffective but because the population believes they are ineffective. This belief weakens public support and thus public funding, creating programs that are in fact untrustworthy and ineffective at achieving their goals. Demonstrating the benefits of health information sharing would be a proactive way for data users to assure trust in the health system. Such demonstrations should seek out the large proportion of people who believe the health system actively deceives the public. As stated earlier, one-fourth of the variation in system trust was due to variation in people's belief in medical deception suggesting that social movements motivated by conspiratorial beliefs are having deleterious effects on trust in the health system with ripple effects beyond the specific issue they engage.

A related finding is that the more educated and those who know more about how information is used in the health system, are less likely to trust the system. This suggests that what you might call “smart skeptics” may be driving lack of trust in the health system. In short, the more you know, the less you trust in the organizations that have your health information and share it. A simple chi-square test of association found that knowledge and having a favorable view of data sharing were significantly associated ($\chi^2 = 18.4$, $p<0.001$). The odds of viewing data sharing unfavorably was 1.52 times greater than the odds of viewing data sharing favorably, if you have above average knowledge. The relationship between knowledge and system trust was negative, i.e., the more a respondent knew about common policies and practices in information sharing, the lower his system trust score ($b^*= -0.12$, $p<0.001$). While one might hypothesize that the proportion of those that believe in the health system’s deceptive practices have lower overall knowledge of the health care system, our data weakly suggest the opposite ($OR=1.25$, $p=0.04$).

This finding is particularly relevant to both proponents and critics of the so-called deficit model of public support for science, which purports that the public would support science, if only it understood it better. In fact, when it comes to support for health information sharing, the opposite seems to be true for those who seek knowledge. Rather than seeking to “fill” the deficit of information or providing direct counter-evidence to existing knowledge and beliefs, trust-building may be more effective if it focuses on mechanisms that make information about data use more transparent, accessible, and clearly meeting the demand for benefit.

One of the greatest challenges for health care, research, and public health will be to balance what is practicable and desirable from their perspectives with public expectations. Getting permission for all research uses, for example, would introduce novel forms of selection bias in study designs and contacting large populations to opt-in to research may prove infeasible. Similarly, ownership of information is complex and misunderstood. In many cases, data brokers in public health, insurance, and health care provision have invested meaningfully in resources to gather information. These brokers see data as public and private goods required for delivering and researching health and health care. Trust-building will need to balance the interests and needs of the public on one hand and the data brokers and users on the other.

Recognizing that trust is *not* based on knowledge, and thus building trust is *not* merely a question of experts filling a knowledge "deficit" among the lay public, what is trust based on? To some degree, trust is based on individual psychosocial factors such as generalized trust, altruism, and self-esteem that may be difficult for public policy to address. However, trust may be strengthened by building confidence in policies and practices that keep data confidential and reduce the probability of harm that may come from data sharing. Individuals who are worried that health information can be used against them, or that health care providers cannot be trusted with certain types of information are less likely to trust the health system. These findings support the recommendation of the recent President's Council of Advisors on Science and Technology report on Big Data that encourages policy to broaden its focus to include not only data collection and analysis, but also the "actual uses of big data" (2014).

Notably, privacy seems to have less influence on system trust than might be expected given the attention to privacy in the media and popular culture. In a sub-analysis examining the predictors of privacy, income emerged as the only demographic factor associated with privacy such that those with higher incomes had somewhat greater privacy concerns than those with incomes below the national median, after controlling for all other trustor characteristics (b = 0.15, p=0.001). Also related to privacy was belief in medical deception (b=0.36, p<0.001). These findings suggest that while assurances of privacy as a core value of health organizations are still important in understanding the public's attitudes and beliefs about they health system, addressing privacy is likely to fall short if it is the only tool used to build trust.

The organizations that make up the health system and seek the public's trust will need to explore methods for trust building that lie beyond the assurance of privacy and begin to communicate the benefits of health information sharing. Other activities that might build trust, such as allowing personal control over what information is used and using technology that can innovate consent processes that are more dynamic and engaging, should also be explored. Governance models that include independent oversight, watchdog organizations, or otherwise assure accountability might also provide the confidence necessary to create a strong fabric of trust. These questions of personal and policy-level mechanisms for building and sustaining trust will be investigated further in Chapter III.

Limitations

There are several limitations to this analysis that should be noted. First, the stepwise regression model in particular is a conservative model such that factors that did not appear in the final model may nonetheless be important. One would expect privacy to be a key predictor of trust. Similarly, experience likely plays a greater role in trust than predicted in the statistical model presented here and may need to be measured more specifically by differentiating between types and quality of experience. Identity theft, while not a significant predictor in this analysis, may become a more salient factor as it becomes more prevalent and harm comes to more individuals from this experience.

A full model of trust ought to consider additional factors beyond those of the trustor. For example, relationships between trustor and health information brokers in public health, research, and health care are likely to inform opinions and beliefs about trust in the health system. These will be explored further in the next chapter. Also, the role of policy and individual control in reducing uncertainty and risk in health information sharing will attenuate or exacerbate trust concerns. These policy and individual access factors are addressed in Chapter III. Possible moderators and mediators of trust, such as risks and benefits, would also be included in a more complete model of trust in the health system, but are beyond the scope of this analysis. Similarly, this analysis did not take into account non-linear relationships or interaction terms.

The data is cross-sectional and can only identify factors associated with system trust. Longitudinal studies, particularly those that allow the evaluation of interventional impacts on system trust should be undertaken. Such studies should also further test the bi-directionality and causal pathways in the relationship between system trust and trustor characteristics. Finally, trust is multi-dimensional and abstract. The analysis presented here suggests that what matters in predicting trust is highly contingent on how trust is defined, by whom, and to what end. Trust building, if it is to be a priority for the health system, needs to be more specific in its rhetoric and may be served by the development of an ontology of trust in information.

Despite these limitations, trustor characteristics accounted for a large proportion of the observed variability in system trust. The brokers of health information will want to monitor the attitudes and beliefs of the public regarding health information sharing to assure trust in those activities. Demonstrating the benefits of health information sharing is critical in sustaining trust, while evaluating skepticism or perceived deception would provide indicators that trust is failing.

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CHAPTER II

Analytical Paper 2

Health System Trust and Information Brokers in Health Care, Public Health and Research

BACKGROUND

The nation's health information systems are becoming increasingly integrated, open, accessible, and large – inclusive of data and biological materials from entire populations. Institutions that hold vast quantities of information have the expanded capacity to re-purpose or transform data according to user and information need. Researchers from a variety of institutions can, and have incentives to use data stored in biobanks for multiple studies. Electronic health records can be used for clinical care and care coordination, as well as research and administrative claims processing. This rapid exchange of information is envisioned as an integral part of a learning health system "in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience" (Committee on the Learning Health Care System in America 2012, 136).

Such a system is contingent on the effective brokerage of health information across diverse user groups. Brokers have traditionally been used in banking to facilitate the movement of money, but can be used in a variety of public and private contexts to handle interactions between parties that otherwise do not need to negotiate. Rather than embark on a formal working relationship with multiple data centers at multiple research institutions, for example, a single scientist may opt to work with a single broker who can provide access to a wide range of sources. In the context of the learning health system, the trusted broker is defined broadly as, "an agent or entity with the public and scientific confidence to provide guidance, shape priorities, and foster the shift in the clinical research paradigm" (Olsen, Aisner and McGinnis 2007, 6). Brokerage is a form of assuring trustworthiness that is likely to become an increasingly important part of health data infrastructure.

Brokers encompass a wide range of actors and institutions including health care providers, hospitals, public health departments, researchers, universities, pharmaceutical companies, insurance companies, non-profits, advocacy groups, or private firms that collect, store, and share health data. For many of these stakeholders, the role of broker is often hidden, and would be a novelty, particularly to the non-expert public. For example, patients and research participants are rarely aware of secondary data uses, even when they are described in informed consent documents (Safran et al. 2007).

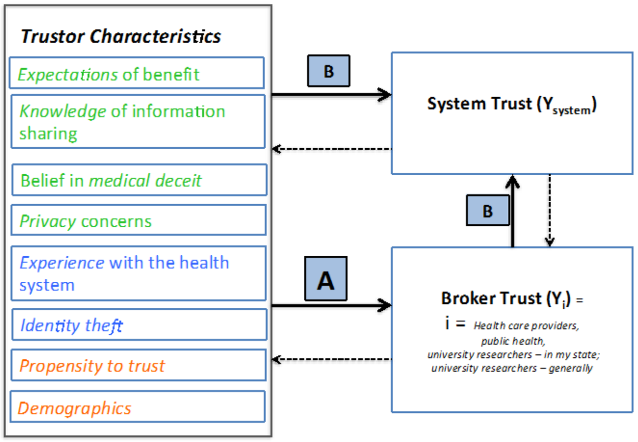
As representatives of the health system, health care providers, researchers, or public health departments might serve as key information brokers, embodied representations of abstract, complex networks. They provide what Anthony Giddens calls "access points" or opportunities for interaction, which build experience, knowledge, and intuition that serve as the basis for trust or mistrust. Public trust in brokers in health care, public health, and research can become a social and system resource that can reduce administrative burdens, increase organizational efficiency, and impart authority from the trustee to the trustor to make decisions (Kramer and Cook 2004). While the public may have trust in the system as a whole (See Chapter I), trust in the brokers of information and the liaisons to these brokers provide the interpersonal relationship that form another layer of trust in the health system's constituent institutions. Trust in information brokers and trust in the health system are interrelated and mutually constitutive.

Studies of trust and health have generally examined trust in health care providers and, to a lesser degree, trust in health systems. In a 2013 literature review of studies measuring trust in the health system, 23 of 42 articles focused on the relationship between health care providers and patients, while only 12 investigated system trust (Ozawa and Sripad 2013). Studies of trust in researchers focus on scientists investigating contentious areas such as stem cell research, global warming, or nanotechnologies (Lee, Scheufele and Lewenstein 2005; Critchley 2008; Nisbet and Myers 2007). Trust in public health departments has not been evaluated *per se*, though there has been research on trust in public health programs such as vaccines (Benin et al. 2006) and emergency preparedness (Blanchard et al. 2005) as well as extensive study of trust in government (Hetherington, Marc J. 2006; Nye, Zelikow and King 1997; Braithwaite and Levi 1998) . Comparing trust across institutions that comprise the health system has yet to be fully explored.

Research examining the relationships among individuals, brokers, and the health system is particularly relevant as the boundaries of the institutional components of the health system – health care, public health, and research – are increasingly less defined in both practice and perception. With the emergence of the broker role and the disintegration of clear limits between research, practice, and public health, trust or mistrust stands to be more fluid. Trust in physicians remains high relative to other professions, for example, but this trust has seen evidence of erosion over the past decades with the chronic crisis in health care financing and the emergence of managed care (Timmermans and Oh 2010) as well as social movements raising fears about the dangers of vaccines (Cooper, Larson and Katz 2008). This fluidity of trust is also apparent in theories of trust that note that institutional trust underwrites interpersonal trust and vice versa (Misztal 1996). In other words, there are institutional constraints that shape the rules for interpersonal relationships within and across institutions. One would expect that trust in others would deteriorate as trust in our common institutions deteriorates and vice versa. By the same token, one would expect interpersonal trust and trust in institutional brokers to enhance trust in the system.

Figure 2.1 illustrates the postulated conceptual model, empirically tested in this paper, of the trustor characteristics and broker trust factors that are likely associated with overall health system trust. The bidirectional arrows suggest that the relationships among interpersonal trust, trust in brokers, and system trust are bidirectional and dynamic. Individuals vary in their cognitive/ emotive characters (i.e., knowledge and beliefs), psycho-sociology and demographics, as well as their experiences with the health system and brokers of information. Expanding on previous research (Chapter I) examining the relationship between system trust and these trustor characteristics, the present analysis examines two questions germane to understanding the so-called trust fabric. First, *what are the trustor characteristics that predict trust in the brokers of health information such as health care providers, public health departments, and university* *researchers (Fig 2.1-A)?* And second, *what are the trust in broker factors, after considering trustor characteristics, that predict system trust (Fig 2.1-B)*?

Figure 2.1 Conceptual Model: Trust in brokers, trustor characteristics and system trust



Trustor Characteristics

In the present analysis, I examine the characteristics of the trustor that are associated with variables in trust of health information brokers. The larger arrow in Figure 2.1 shows the key trustor characteristics of interest which include the experience, beliefs, as well as psychosocial and demographic factors of an individual vis-à-vis the health system. These factors are reflective of how a trustor might evaluate the trust between himself and the health system. The dotted arrows in Figure 2.1 indicate that while the analysis focuses on system trust and trust in brokers as primary outcomes of interest, trust is part of a two-way relational dynamic.

Individuals experience trust as a solitary motive for behavior or belief, while the source of this trust stems from complex belief structures (Lewis and Weigert 1985, 2012). The trustor is bound to draw on intuition and cultural toolkits, as well as direct knowledge of the other (trustee), and learned patterns of behavior. Extending current research (presented in Chapter I), I developed a series of measures related to the trustor's capacity and willingness to trust. Demographic and psychosocial variables capture information about the life circumstances that shape life chances, social experience, and dispositions or attitudes about social systems (Cockerham 2005). Experiential constructs were captured by evaluating the frequency of interaction with the health system and other large complex information systems. Variables measuring specific knowledge, attitudes, and expectations the public holds with respect to the health system and data sharing reflect cognitive and emotive elements of trust.

Broker trust

Definitions of trust often focus on a *cognitive expectation or willingness to impart authority and accept vulnerability to another in the fulfillment of a given set of tasks*. In surveys of trust in physicians and scientists, individuals are often asked about their beliefs about the trustee's capacity to make decisions that reflect the best interests of the patient or public. This often means acting in the patient or public's best interests, not acting from purely economic motives, and having a good track record of behaving responsibly (Earle 2010). Given the role of public health departments as key brokers in the sharing of health information they have been included in this analysis, though there is little previous empirical study of how individuals shape their opinions and beliefs about public health (Cairns et al. 2011). In a literature review on trust in communicable disease public health, Cairns et al. cite limited support for the hypothesis that public health departments are generally trusted by the general public as an authority for credible health information, but their role as a government organization coupled with mistrust in government makes their trustworthiness somewhat precarious. Furthermore, high profile events such as the anthrax mail events in 2001 and the rollout of the Affordable Care Act's healthcare.gov website that make government agencies appear incompetent or that their information is incomplete, inconsistent, or inaccurate have diminished trust in governmental public health (Blanchard et al. 2005; Saltman).

Questions about health information brokers can be framed generally or specifically, and the level of specificity is likely to matter in evaluating trust. For example, it is not unusual to find that the public supports a particular representative in Congress, but has little confidence in the legislative branch. To evaluate the impact of differentiating between general versus specific cases, survey respondents were asked to answer questions about university researchers generally or "in my state."

System trust

At the system level, the proposed empirical model includes four dimensions of trust: fidelity, competency, integrity, and global trust. Fidelity captures benevolence, i.e., the act of a trustee prioritizing the needs and interests of the trustor (Mayer, Davis and Schoorman 1995). Integrity is defined as honesty or following the principles of non-deception. Competency refers to the ability and expertise to minimize errors and achieve goals. Global trust is an integrative concept that captures an individual's general perception of trustworthiness. It is meant to capture aspects of trust that are more intuitive than rational or calculative (Hall et al. 2001). Other surveys of trust in the health system encompass one or more of these dimensions, as well as others such as communication, honesty, confidence, confidentiality and fairness (Ozawa and Sripad 2013). The choice of dimensions for the present analysis expands on the work of Mark Hall and colleagues in developing the Wake Forest Scale that has been applied to a number of relevant dimensions of the health system at large including trust in physicians (Hall et al. 2002b; Rajesh et al. 2003), the medical profession(Hall et al. 2002a; Dugan, Trachtenberg and Hall 2005), and insurance companies (Goold, Fessler and Moyer 2006; Beiyao Zheng et al. 2002).

METHODS

Predictors of trust in the health system, broadly defined as a web of relationships among health care providers, departments of health, insurance systems, and researchers were measured by a 117-item survey (See Appendix D). The survey included the trustor characteristics described above in the conceptual model (Figure 2.1) as well as additional questions about trust in specific brokers (health care providers, researchers, and public health), quality of experience, perceived control, and adequacy of policy oversight. Measures of the dependent variable – System Trust – and the independent variables used in this paper were adapted from prior studies and contextualized for the health system (See Chapter I and Appendix B for additional details about survey development and validation).

Respondents answered questions about "how true" they believed a series of statements to be along a 4-point, unipolar Likert scale: "Not at all true" (1), "Somewhat true" (2), "Fairly true" (3) and "Very true" (4). These statements captured information about system trust, trust in information brokers (health care providers, public health departments, and university researchers generally and "in my state") beliefs about privacy and medical deception, and psychosocial characteristics. Questions about expectations of benefit and having a favorable view of data sharing also used a four-point scale, but the answer choices were different (See Appendix D). Questions about knowledge of information were asked as True/False questions. To evaluate whether general versus specific framings of health information brokers matters in the evaluation of trust, questions about university researchers were presented either as statements about university researchers *generally*, or as statements about university researchers *in my state.*

Sample

Respondents were surveyed using GfK's probability-based, nationally representative sample consisting of non-institutionalized general population adults (KnowledgePanel) in February 2014. Eligible participants were randomly selected and contacted via email to invite participation. Of 2,082 individuals contacted to participate, 52.9% agreed. Of the 1,103 responses collected, 41 were excluded due to constant refusal and an additional 51 respondents were excluded from data analysis due to item-missingness. The median completion time of the final survey was 22 minutes. Post-stratification weights corresponding to the U.S. Census demographic benchmarks for age, sex, household income, education, and race and ethnic background were calculated by GfK for this survey sample to reduce bias from random sampling error. The GfK methodology is detailed in Appendix C.

Statistical analysis

Descriptive distributional statistics were estimated on all variables to identify outliers or other distributional characteristics that may influence regression modeling. Indices were calculated for trust in health care providers, trust in public health, trust in university researchers generally, and trust in university researchers "in my state." Indices measuring trust and key trustor characteristics (e.g., privacy index, esteem index, etc.) were calculated as the sum of the participant's responses to those survey questions divided by the number of questions. Chronbach's alpha was used to evaluate the validity of indices. Indices measuring trust in information brokers only included questions that addressed the same issues for all brokers. Paired sample t-tests tested the differences in the mean of institutional trust indices (Gujarati and Porter 2009).

Ordinary Least Squares (OLS) Regression analysis was used to estimate the linear relationship between individual characteristics and trust in brokers: health care providers, public health, and researchers generally and "in my state." Correlative relationships between variables were estimated using Pearson's correlation coefficient (See Appendix A). Weighted multivariable OLS models examining all predictors in a single model were followed by weighted stepwise regression models (inclusion criteria, $\alpha < 0.05$, and backward exclusion criteria, $\alpha \geq 0.10$). Bonferroni-adjusted models were used to reduce the probability of type I error. Standardized coefficients (b*) were calculated to assess the relative magnitude of the relationship between trust and its predictors.

System trust was the dependent variable in a final set of OLS models (multivariable and stepwise regression) that included the factors evaluating key trustor characteristics as well as the indices capturing trust in brokers. Similar questions were used in the broker indices. The questions addressed beliefs about health care providers, public health departments, and researchers generally and "in my state and their respective interestedness in making money above the interests of the individual, caring about the individual, and having a good track record of using information responsibly.

Questions evaluating trust in university researchers were bifurcated (50:50) in the random sampling to evaluate the influence of anchoring the question to researchers "in my state" versus generally. To account for this bifurcation, OLS regressions examining predictors of system trust included the main effect of trust in university researchers, an indicator of which set of survey questions were answered (university researchers generally (X=0) or "in my state" (X=1)), and the interaction between these two variables. In cases where trust in university researchers did not have an effect on system trust, none of these terms would be significant; if trust in university researchers “in my state” were significant, the indicator and interaction term would be significant; if trust in university researchers generally were significant, then the trust in researchers variable and indicator would be significant; and if both were significant predictors of system trust, all three variables would be significant.

The fit of the multivariable models that included all predictors versus stepwise regression models was evaluated using the Aikake Information Criteria and Bayesian Information Criteria (AIC and BIC). BIC is frequently a more conservative estimate of model fit since it penalizes more strongly for the number of parameters than the AIC (Cameron and Trivedi 2010). Smaller values of the AIC and BIC indicate improvements in model fit.

RESULTS

The outcome variable of system trust was derived responses to the 20 questions measuring their beliefs about the fidelity, competency, integrity, and global trustworthiness of the organizations that have health information and share it. Fidelity, competency, integrity, and global trustworthiness indices were normally distributed along a continuous scale “how true” a set of statements were for an individual (Range: 1-4). The mean of the fidelity index and the mean of the competency index were both 2.8. The mean of integrity and global trustworthiness indices was 2.5. System trust, derived from the sum of dimension-specific indices, has a scale of 4-16 and the range of observed values was 5-16 with a mean of 10.7 and standard deviation of 2.0. Figure 1.2 shows box-plots that depict the distribution of system trust and its four dimensions.

Descriptive statistics for trustor characteristics including cognitive/emotive, experiential factors, and demographic/ psychosocial variables are listed in Table 1.1. The sample is split nearly evenly with respect to men and women; 75% are white, non-Hispanic; 9% are black, non-Hispanic; 10% are Hispanic; and 7% are other. Forty percent have less than a bachelor’s degree education; and 60% have annual household incomes <$50,000. Half of respondents are working as an employee, and an additional 7% are self-employed. Approximately one in five are retired (22%), and a comparable proportion are laid off or on disability (14% and 7%). To a question rating self-reported health, asked as "In general, would you say your physical health is…Excellent/Very Good/ Good/Fair/Poor," the mean response was 2.52, 95% CI: 2.47-2.58. On the political spectrum of liberal, moderate, or conservative, nearly one quarter identified as liberal (23.8%), 36% identified as moderate, and 40% as conservative. At the time the survey was given, about 40% of respondents had a favorable view of the Affordable Care Act/ Obamacare – comparable to a Kaiser Family Foundation poll that asked a similar question at the same time and found 35% of Americans had a favorable view of the ACA, 47% unfavorable, and 18% were unsure (*Health Tracking Poll: Exploring the Public's Views on the Affordable Care Act (ACA) | the Henry J. Kaiser Family Foundation* n.d.).

Psychosocial factors included variables measuring self-esteem, altruism, self-efficacy, having a negative outlook, and generalized trust (See Table 1.2). Indices measuring self-esteem, altruism, and self-efficacy were based on four questions each; Chronbach's alpha for self-esteem questions was 0.75; **α=** 0.69 for altruism, and **α=**0.79 for self-esteem. Having a negative outlook and generalized trust were evaluated based on a single questions used the General Social Survey, "I think the quality of life for the average person is getting worse, not better" and "Generally speaking, most people can be trusted). All psychosocial factors were measured along a 4-point scale; the mean of self-esteem was found to be 3.4 (SD=0.59); 2.7 for altruism (SD=0.65); 2.9 for self-efficacy (SD=0.64); 2.13 for having a negative outlook (SD=1.0); and 2.3 for generalized trust (SD=0.82).

Privacy (Table 1.3b), among the cognitive/ emotive characteristics, emerged as an important issue for about three quarters (73%) of respondents, but far fewer cited privacy as a major concern or that they were afraid privacy was at risk. Twenty-seven percent of respondents thought that the privacy of health information was seriously threatened, or that private health information could be used against them; an equal proportion thought that their health care provider might share embarrassing information. Only 15% stated that they intentionally withheld information from health care providers because they are untrustworthy. The mean of the privacy index was 2.18 (95% CI: 2.14-2.22); the internal consistency of the index, measured by Chronbach's alpha, was **α** = 0.78.

Beliefs that the medical and research community act deceptively are more widely held and of greater consequence than might be expected (See Table 1.3a). Approximately 40% of the population holds one of the following four beliefs: 1) “The government does not tell the public the truth about the dangers of vaccines”; 2) “Some medical research projects are secretly designed to expose minority groups”; 3) “The health care system experiments on patients without them knowing about the experiments”; and 4) “Health professionals don’t tell you everything you need to know about medicines.” A majority finds it plausible that the dangers of vaccines are being hidden, while a smaller number believe that the medical community is performing experiments on them without their knowing. The Chronbach’s alpha for these four questions used to generate a deception index was 0.79. In a simple regression on system trust, the deception index the explained ~25% of the variability in trust in the health system ($p<0.001$, results not shown).

Approximately 70% of respondents stated that they expect that information sharing will improve the quality of health care that they receive or will improve the health of people living in the U.S. Seventy percent of respondents also stated that given what they know, they have a generally favorable view of data sharing (See Table 1.4); however, very few know about common policies and practices related to data sharing. Of the ten questions evaluating knowledge, respondents answered an average of six correctly (See Table 1.5). Most (88%) were aware that public health departments collect information. With regard to permission 75% responded correctly that permission is not required for research using de-identified data and 67% knew information could be used in studies without knowledge or permission. At the same time, only 53% knew that permission is not required for all health research and 51% knew that researchers did not always need permission to access information contained in medical records. Most (71%) respondents were aware that information may be part of an economy (i.e., that institutions may charge money for data access). Of the ten questions asked, there was less awareness of physician control of information in medical records (59%), data ownership (54%), and the scope of legal restrictions on discrimination based on genetic information (36%).

Nearly all (94%) of the respondents had some experience measured as contact with the health system – suggesting that even if they were unfamiliar with policy and practices for data sharing they had a general familiarity with the system on which to base their attitudes and beliefs. Three-quarters had a primary care provider whom they had seen in the past year. The quality of this experience was overall positive with 80.3% reporting having had a generally positive experience if they had a primary care provider. Eighty-three percent had health insurance coverage, comparable to the U.S. average of 85% (Henry J. Kaiser Family Foundation.). Among those with health insurance, about half said that their experience with the insurance provider was positive. Just over ten percent had had some contact with a health department either through provision of services such as WIC or information (See Table 2.1).

Table 2.1 Descriptive statistics: Experience with information brokers

	Frequency
Has a primary care provider	**81.7%**
Has seen primary care provider at least once in the past year	90.1%
Quality of experience	
Negative or neutral	1.2%
Neutral	18.5%
Positive	80.3%
Has insurance	**83.3%**
Quality of experience	
Negative	5.8%
Neutral	50.5%
Positive	32.7%
Has had experience with a public health department by having done any of the following:	
a. Received public health services (e.g., WIC)	
b. Had a child that received newborn screening (heel prick test)	
c. Been to a Community Health Center	
d. Contacted my state or local public health department for information (e.g., rabies exposure, environmental hazard)	
e. Contacted my state or local public health department to report a health concern (e.g., food poisoning)	
f. Been in contact with my state or local public health department for other reasons	**11.4%**

Examining trust in information brokers, i.e., health care providers, university researchers, and public health departments, trust in health care providers is highest, consistent with findings in the literature and public polling that suggest the public trusts physicians (See Table 2.3). In our sample, trust in researchers in one's state is comparable to trust in health care providers. The difference in trust in researchers generally as compared to health care providers, and the difference between trust in university researchers "in my state" and trust in university researchers generally is small, but statistically significant ($p<0.01$). On average the difference in trust is 0.11

points higher for trust in university researchers in one's state (95% CI: 0.03-0.20) as compared to researchers generally. Trust in public health is less than trust in health care providers and trust in researchers "in my state" ($p<0.01$). There is a modest correlation across institutions ranging from r =0.44 between health care providers and researchers "in my state" to r =0.68 between public health and researchers generally.

Table 2.2 Differences in trust in information brokers				
	Health Care Providers Mean = 2.99	**Researchers (IN MY STATE) Mean = 2.93**	**Researchers (Generally) Mean=2.82**	**Public Health Mean=2.84**
Health Care Providers Mean = 2.99	---			
Researchers (in my state) Mean = 2.93	0.04	---		
Researchers (Generally) Mean=2.82	0.18***	0.11**	---	
Public Health Mean=2.84	0.15***	0.078***	-0.003	---
***p<0.01; **p<0.05, *p<0.10; two-tailed test				

Predicting trust in data brokers

Trustor characteristics explained approximately 35-40% of the variability observed in trust in major information brokers – health care providers, public health departments, and university researchers. Table 2.3 summarizes statistics evaluating model fit including adjusted R^2, AIC and BIC. The stepwise regression models, which include six or seven variables, lose no more than 4% of the explained variability as compared to the multivariable models ($p>0.05$). While the AIC for the multivariable models is smaller than it is for the stepwise regressions when examining predictors of trust in public health departments and trust in university researchers generally, comparing the more conservative BIC estimates suggests that the more parsimonious stepwise models fit the data as well or better than regression that included all hypothesized predictors.

In stepwise regression models, used to identify a best set of predictors of trust in information brokers, having a generally positive view of data sharing was a key predictor of trust in public health departments ($b=0.21$, $b^*= 0.21$) and in university researchers in my state (b=0.18, b*= 0.20) and generally (b=0.18, b*= 0.17), but did not appear in the final model evaluating trust in health care providers. Rather, having a positive experience with one's health care provider in the past year was significantly associated having increased trust in the provider (b=0.16) relative to having had a negative experience. Psychosocial factors promoting trust in information brokers included self-esteem, which was associated with predicting trust in health care providers (b*= 0.13) and university researchers in my state (b*= 0.17), and having a negative outlook, which was associated with trust in public health departments (b*= -0.12) and university researchers in my state (b*= -0.16) (See Table 2.5).

Table 2.3 Trust in information brokers: Measures of model fit

	Adjusted R^2	AIC	BIC	df
Trust in Health Care Providers				
Multivariable model	0.37	1540.5	1737.2	40
Stepwise Regression model	0.35	1532.9	1562.4	6
Trust in Public Health				
Multivariable model	0.39	1616.5	1812.9	40
Stepwise Regression model	0.36	1637.7	1662.3	5
Trust in University Researchers *in my state*				
Multivariable model	0.43	704.4	868.4	40
Stepwise Regression model	0.40	696.1	720.7	6
Trust in University researchers *generally*				
Multivariable model	0.38	943.1	1116.2	40
Stepwise Regression model	0.34	944.9	970.8	6

Table 2.4 Predictors of trust in information brokers: Multivariable models

	Health care providers			**Public health departments**			**University researchers "in my state"**			**University researchers generally**		
	b	**b***	**p-value**	**b**	**b***	**p-value**	**b**	**b***	**p-value**	**b**	**b***	**p-value**
Cognitive/ Emotive Factors												
Expectation of Benefit: Favorable view of data sharing	0.086	0.094	0.019	0.182	0.187	<0.001	0.122	0.130	0.018	0.173	0.171	<0.001
Expectation of Benefit: Improvement Index	0.193	0.248	<0.001	0.162	0.195	<0.001	0.149	0.174	0.003	0.101	0.124	0.018
Knowledge	-0.003	-0.009	0.769	0.012	0.035	0.273	-0.008	-0.025	0.553	-0.006	-0.018	0.664
Privacy Index	-0.045	-0.050	0.237	-0.083	-0.087	0.025	-0.130	-0.137	0.010	-0.077	-0.080	0.100
Belief in medical deception Index	-0.241	-0.261	<0.001	-0.236	-0.239	<0.001	-0.184	-0.187	0.001	-0.275	-0.277	<0.001
Experience factors												
Has PCP												
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes – not seen in past year	0.001	<0.001	0.998	-0.574	-0.218	0.021	-0.142	-0.056	0.315	-0.248	-0.091	0.607
Yes – seen in past year	0.070	0.049	0.765	-0.557	-0.371	0.020	-0.112	-0.074	0.360	-0.416	-0.277	0.378
Quality of experience with PCP												
Negative	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Positive	0.115	0.088	0.065	0.071	0.051	0.220	-0.047	-0.034	0.550	0.023	0.016	0.758
N/A	0.079	0.051	0.742	-0.486	-0.294	0.052	-0.094	-0.056	0.547	-0.322	-0.198	0.509

Has Insurance												
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes – But has had a gap in coverage	-0.220	-0.082	0.439	-0.174	-0.061	0.364	-0.206	-0.082	0.454	-0.430	-0.133	0.165
Yes – No gap in coverage	-0.248	-0.152	0.355	-0.300	-0.172	0.085	-0.243	-0.142	0.326	-0.444	-0.249	0.135
Quality of experience with insurance												
Negative	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Positive	0.040	0.031	0.392	0.024	0.017	0.613	0.007	0.005	0.917	0.026	0.018	0.689
N/A	-0.294	-0.152	0.282	-0.362	-0.175	0.041	-0.286	-0.134	0.243	-0.470	-0.229	0.119
Has had experience with public health department	0.069	0.037	0.293	0.116	0.059	0.084	-0.077	-0.041	0.394	0.104	0.049	0.312
Identity theft	-0.069	-0.044	0.191	0.066	0.039	0.248	0.117	0.071	0.129	0.001	0.001	0.984
Psychosocial factors												
Self-esteem index	0.105	0.103	0.015	0.077	0.072	0.054	0.236	0.208	0.001	0.074	0.070	0.175
Altruism index	-0.033	-0.034	0.394	0.062	0.059	0.095	0.041	0.041	0.417	0.010	0.009	0.852
Self-efficacy index	0.021	0.020	0.586	-0.076	-0.070	0.070	-0.117	-0.109	0.075	0.049	0.044	0.344
Negative outlook	-0.031	-0.049	0.198	-0.057	-0.084	0.023	-0.079	-0.113	0.025	-0.063	-0.096	0.047
Generalized trust	0.007	0.010	0.787	0.005	0.006	0.866	0.039	0.047	0.317	0.045	0.055	0.204
Demographic factors												
Sex												
Male	-0.043	-0.034	0.254	0.027	0.020	0.485	-0.042	-0.031	0.470	-0.031	-0.023	0.573
Age												
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-44	-0.029	-0.020	0.636	0.117	0.075	0.083	0.116	0.075	0.202	-0.123	-0.078	0.153
45-59	<0.001	<0.001	0.995	0.138	0.090	0.055	0.127	0.083	0.196	-0.130	-0.084	0.133
60+	0.032	0.022	0.709	0.111	0.072	0.216	-0.077	-0.050	0.525	-0.197	-0.126	0.049
Race/ ethnicity												
White	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Black, NH	0.056	0.028	0.434	-0.076	0.075	0.277	-0.049	-0.024	0.614	-0.178	-0.079	0.075
Hispanic	-0.083	-0.045	0.215	-0.080	0.090	0.190	0.029	0.016	0.716	-0.047	-0.021	0.648
Other, NH	-0.126	-0.050	0.087	-0.107	0.072	0.137	-0.062	-0.019	0.614	-0.233	-0.094	0.026
Education												
Less than High School	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
High School	0.089	0.063	0.278	<0.001	<0.001	0.999	0.274	0.180	0.018	-0.122	-0.082	0.216
Some college	0.059	0.042	0.477	-0.075	-0.050	0.414	0.351	0.237	0.003	-0.103	-0.067	0.320
BA or above	0.091	0.065	0.286	0.079	0.053	0.393	0.420	0.284	<0.001	-0.017	-0.011	0.876
Income: Less than $50,000	0.051	0.039	0.262	-0.069	-0.050	0.137	-0.007	-0.005	0.915	0.041	0.029	0.509
Employment status												
Has employer	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Self-employed	-0.110	-0.043	0.178	<0.001	<0.001	0.997	-0.066	-0.026	0.588	0.270	0.096	0.030
Laid off	-0.020	-0.011	0.755	-0.005	-0.003	0.941	0.007	0.004	0.949	0.134	0.071	0.126
Retired	0.032	0.019	0.697	-0.127	-0.072	0.126	0.154	0.090	0.171	-0.018	-0.010	0.857
Disability	-0.004	-0.002	0.971	-0.072	-0.026	0.437	0.017	0.006	0.900	0.015	0.006	0.886
Self-reported health	0.027	0.042	0.276	-0.014	-0.021	0.538	-0.018	-0.026	0.614	0.030	0.043	0.320
Political affiliation												
Liberal	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Moderate	-0.025	-0.019	0.636	-0.025	-0.018	0.632	-0.114	-0.080	0.137	-0.113	-0.079	0.141
Conservative	0.003	0.002	0.963	-0.118	-0.084	0.038	-0.119	-0.086	0.148	-0.297	-0.210	<0.001
Support for Affordable Care Act	-0.005	-0.008	0.854	-0.034	-0.053	0.130	-0.022	-0.036	0.490	-0.007	-0.010	0.842

The index indicating belief in deceptive actions by the medical and research communities, for example that some medical research projects are secretly designed to expose minority groups and that health professionals don't tell you everything you need to know about medicines, was negatively associated with trust in all types of information brokers. Those who felt more strongly about deceptive behavior in the health system had less trust in the system (b = -0.3). The magnitude of this effect was comparable to the effect of having expectations for benefit in the case of health care providers and public health departments. For trust in university researchers, the effect of beliefs in deceptive behavior (b*=0.17 and b*=0.18) had about twice the impact on trust as compared to having an expectation of benefit (b*= -0.28 and b*= -0.34). There was a negative correlation between political identities and trust in university researchers generally. Specifically, those reporting a conservative ideology were less likely to trust this group than liberals (b= -0.32).

Factors that did not appear to be significant in the regression analyses conducted here include most demographic variables (e.g., sex, race, age, employment), the privacy index, and some psychosocial factors such as altruism and self-efficacy (See Table 2.5).

Table 2.5 Predicting trust in information brokers: Stepwise regression analysis

	Health care providers		**Public health departments**		**Researchers In my state**		**Researchers Generally**	
	b	**b***	**b**	**b***	**B**	**b***	**b**	**b***
Cognitive/ Emotive Factors								
Expectation of Benefit: Favorable view of data sharing			0.210	0.216	0.183	0.195	0.175	0.173
Expectation of Benefit: Improvement Index	0.236	0.303	0.192	0.231	0.147	0.171	0.150	0.184
Belief in medical deception Index	-0.306	-0.331	-0.269	-0.272	-0.279	-0.284	-0.340	-0.342
Experience factors								
Quality of experience with PCP								
Negative	Ref	Ref						
Positive	0.156	0.119						
N/A	-0.011	-0.007						
Psychosocial factors								
Self-esteem index	0.132	0.130			0.194	0.171		
Negative outlook			-0.078	-0.116	-0.115	-0.164		
Demographic factors								
Political affiliation								
Liberal								Ref
Moderate							-0.125	-0.087
Conservative							-0.321	-0.226

Predicting system trust

Indices measuring trust in health care providers, university researchers, and public health departments were each significantly associated with system trust when examined individually (results not shown). In the multivariable model, trust in health care providers (b=0.70, b*=0.22, p<0.001), public health departments (b=0.31, b*=0.11, p=0.004) contributed significantly to system trust after controlling for demographic, cognitive, emotive, behavioral, and psychosocial trustor characteristics. Trust in university researchers "in my state," but not trust in university researchers generally was associated with system trust in the multivariable OLS model (see Table 2.4).

The stepwise regression model examined system trust as the dependent variable and its predictors (trust in information brokers and individual trustor characteristics). The multivariable model that included all predictors explained 60% of the variability in system trust. The stepwise analysis led to a more parsimonious model for predicting system trust that still explains 56% of the variability in system trust. Examining the AIC and BIC values for the multivariable and stepwise regression models, the AIC for the multivariable model is slightly lower while the BIC is slightly higher as compared to the stepwise models. Because the stepwise model has fewer degrees of freedom and a lower BIC value, the stepwise model provides a slightly better fit for the data (See Table 2.3).

In the final stepwise model (See Table 2.6), expecting benefits from health information sharing, having a positive view of data sharing, and having trust in health care providers were the strongest predictors of system trust with standardized regression coefficients of approximately 0.2- 0.3. A one-point increase in the system trust index corresponded to a nearly one-point (b=0.9) increase in trust in health care providers. Having a positive view of data sharing has a similarly strongly association with system trust (b=0.9). Psychosocial factors associated with greater system trust were altruism (b=0.29) and generalized trust (b=0.26). On a comparable scale, education and increased knowledge were negatively associated with system trust. Those with a bachelor's degree or above were less likely be trusting of the health system as compared to those with less than a high school education by approximately 0.6 points (b= -0.60). Those who answered more of the knowledge-based questions correctly, were also less likely to trust the organizations that have health information and share it (b= -0.12). Notably, concerns about privacy and most demographic factors did not appear to be significant in the final regression model.

Table 2.6 Predictors of system trust

	Multivariable OLS			Stepwise regression	
Adjusted Model R^2			**0.59**		**0.56**
AIC			**3381.3**		**3424.3**
BIC			**3602.0**		**3488.0**
	b	**b***	**p-value**	**b**	**b***
Trust in information brokers					
Trust in Health Care Providers (Index)	0.703	0.223	<0.001	0.904	0.288
Trust in Public Health (Index)	0.308	0.105	0.004		
Trust in Researchers (Index)	0.351	0.258	0.018	0.100	0.034
Version (University researchers in my state v. generally)	-1.073	-0.264	0.015	-1.365	-0.336
Interaction: Index*Version	-0.004	-0.001	0.974	0.456	0.335
Cognitive/ Emotive Factors					
Expectation of Benefit: Favorable view of data sharing	0.821	0.285	<0.001	0.881	0.306
Expectation of Benefit: Improvement Index	0.442	0.181	<0.001	0.491	0.201
Knowledge	-0.113	-0.113	<0.001	-0.119	-0.119
Privacy Index	-0.139	-0.050	0.093		
Belief in medical deception Index	-0.078	-0.027	0.428		
Experience factors					
Has PCP					
No	Ref	Ref	Ref		
Yes – not seen in past year	-0.851	-0.110	0.326		
Yes – seen in past year	-0.888	-0.201	0.298		
Quality of experience with PCP					
Negative	Ref	Ref	Ref		
Positive	0.373	0.090	0.005		
N/A	-0.420	-0.086	0.629		
Has Insurance					
No	Ref	Ref	Ref		
Yes – But has had a gap in coverage	-0.031	-0.004	0.948		
Yes – No gap in coverage	-0.574	-0.112	0.195		
Quality of experience with insurance					
Negative	Ref	Ref	Ref		
Positive	0.141	0.035	0.192		
N/A	-0.381	-0.062	0.403		
Has had experience with public health department	0.125	0.021	0.473		
Identity theft	0.312	0.063	0.007		
Psychosocial factors					
Self-esteem index	-0.050	-0.016	0.598		
Altruism index	0.338	0.109	<0.001	0.290	0.094

Self-efficacy index	0.206	0.064	0.025		
Negative outlook	-0.070	-0.035	0.219		
Generalized trust	0.186	0.077	0.004	0.255	0.105
Demographic factors					
Sex (Male)	0.117	0.029	0.222		
Age					
18-29	Ref	Ref	Ref		
30-44	-0.029	-0.006	0.840		
45-59	-0.051	-0.011	0.719		
60+	-0.044	-0.010	0.803		
Race/ ethnicity					
White	Ref	Ref	Ref		
Black, NH	0.009	0.001	0.959		
Hispanic	-0.197	-0.034	0.210		
Other, NH	0.113	0.014	0.632		
Education					
Less than High School	Ref	Ref	Ref	Ref	Ref
High School	-0.202	-0.046	0.251	-0.181	-0.041
Some college	-0.494	-0.111	0.007	-0.518	-0.117
BA or above	-0.584	-0.132	0.003	-0.602	-0.136
Income: Less than $50,000	0.023	0.006	0.833		
Employment status					
Has employer	Ref	Ref	Ref		
Self-employed	-0.337	-0.042	0.117		
Laid off	0.011	0.002	0.937		
Retired	0.138	0.026	0.446		
Disability	-0.076	-0.009	0.754		
Self-reported health (range 1-5)	-0.018	-0.009	0.756		
Political affiliation					
Liberal	Ref	Ref	Ref		
Moderate	0.070	0.017	0.590		
Conservative	0.220	0.053	0.148		
Support for the Affordable Care Act	0.104	0.055	0.061		

DISCUSSION

The analysis presented here examined trust in various brokers of health information: health care providers, public health departments, and university researchers generally and, more specifically, university researchers "in my state." Of these, health care providers were found to be the most trusted of all information brokers examined. This trust may be at risk in expanding data sharing in a learning health system where data sharing will routinely extend beyond the bounds of expectations set in health care practice settings. By the same token, interactions with health care providers may provide a good entry point – or access point – for the public to learn about and register preferences for expanded data sharing practices in a learning health system.

To better understand the demographic characteristics associated with health care provider experience, I conducted a supplementary simple logistic regression to find that older respondents were six times more likely to report having had a positive experience with their primary care providers than younger participants (OR=6.3, $p<0.001$). Those with greater than median income were twice as likely to report having had positive experience with their primary care providers as compared to those with lower incomes (OR= 2.0, $p<0.001$). Other factors associated with having a recent positive experience with a primary care provider included self-esteem ($b^*= 0.13$) and having a positive view of data sharing ($b^*= 0.30$). While the data analyzed did not determine the extent to which these experiences spillover to trust in other brokers, there was a strong correlation between trust in health care providers and system trust (discussed below). This suggests that any experience with the health system may impact trust in areas beyond the context of one's direct experience. For example, visiting a physician for routine health care may affect trust not only in providers, but also the more abstract system of organizations that has one's health information and shares it.

With respect to policy and practice, medical professional organizations should consider statements or guidelines for practitioners to help manage the role and responsibility of brokers in balance with their roles as care providers and researchers to help protect the existing trust the public has in health care providers. Less well-known organizations, such as public health departments, might consider better communicating their value and trustworthiness, including their fidelity, competency, and integrity in matters of data sharing. Because of the difference in trust in local researchers versus researchers generally, organizations may want to evaluate a baseline of trust for their particular context to be able to monitor change over time. However, the results of this analysis suggest that looking only to one's own organizational context would be limiting and incomplete.

Beliefs about deceptive behavior were found to be negatively associated with trust in each of the broker-types examined. Measures that prevent or address the concerns underlying the belief that health care providers and researchers are surreptitiously harming the public should be a priority. Preventing such beliefs from spreading through the population may be attained by proactively providing assurances that individuals will not be harmed by discriminatory practices or communicating risk could be effective at gaining and maintaining public trust. Active mistrust in the health system is likely to be more difficult to address than maintaining trust (O'Neill, Onora 2002). Skepticism about vaccines, for example, has been shown to be impervious to informational campaigns (Freed et al. 2011) raising questions about how to counteract mistrust once it has gained traction.

The significance of psychosocial factors associated with trusted brokers suggest that individual attitudes and beliefs vary across the population and will have an impact on how trust is best created and sustained. The variability suggests a one-size-fits-all approach is unlikely to succeed. Demographic characteristics, that were not observed to be significant in the models evaluated here, are underlying factors predicting, for example, self-esteem (age, education, income, self-reported health). Other factors underlying self-esteem include knowledge (negatively associated), and expecting benefits from health information sharing. Having a negative outlook is associated with the index measuring belief in medical deception and expectations of benefit (Analysis not shown).

Trust in information brokers and trustor characteristics as predictors of system trust

Variables examining trust in brokers, particularly trust in health care providers, are important in a model examining system trust and its individual-level predictors. Questions regarding trust in health care providers and how the public views data sharing, as well as indices evaluating expectation of benefit have a relatively large explanatory value in considering system trust. Taken as a whole, the model explains nearly 60% of the variability in system trust. From a policy and practice perspective, the modest additive value of individual explanatory variables suggests that evaluating trust-building exercises may prove challenging. An intervention designed to promote the perceived value of data sharing, for example, may only have a small impact on trust. Trust-building activities, then, require a multi-faceted approach to address multiple dimensions of trust as well as diverse individual-level beliefs about health information sharing, and its risks and benefits. Evaluating trust-building should focus on process measures as well as changes over time in system trust.

Having a positive view of information sharing and expecting a benefit for health outcomes and health care quality are associated with system trust, supporting the idea that trust in health systems mirrors political trust. On the one hand, this type of trust runs the risk of eroding quickly if the expectation of benefit is not met. As Hetherington (2006) shows, in the context of trust in government, beliefs in government incompetency coupled with mistrust of government have created a self-fulfilling prophecy in which assistance programs have failed to maintain public support not because they are ineffective but because the population believes they are ineffective. This belief weakens public support and thus public funding, creating programs that are in fact untrustworthy and ineffective at achieving their goals. Failing to demonstrate individual or social benefits of welfare policies cripples their sustainability as well as public trust.

By the same token, demonstrating the benefits of health information sharing would be a proactive way for data users to assure trust in the health system. Successful demonstrations of benefit should, over time, create the corollary to the self-fulfilling prophecy described above, i.e., demonstrating the benefits of health information sharing can strengthen trust, simplify the policy environment, and create effective programs. In a study examining preferences for broad consent versus study-specific consent, for example, having a positive view of research was significantly associated with broad consent, the administratively and economically more efficient option (Platt et al 2012).

Notably, the framing of questions about researchers in general versus locally ("in my state") turned out to be relevant to levels of trust. Higher or lower levels of specificity in defining the broker of health information seem to influence the touch points used to form the basis of trust. Brokers that are more abstract, such as university researchers generally, and unknown, such as public health departments are associated with lower levels of trust probably because it is more difficult for the public to evaluate its trustworthiness. Health care providers, however, are specific individuals with whom most people have had first-hand experience with at some point in their lives, and who embody a set of expectations in concrete terms. Given the observation that trust decays with distance/ abstraction, clarifying details and giving embodied examples about who is using health information and to what ends could build trust by reducing this source of uncertainty.

Limitations

Several limitations of this study should be noted. First, as in previous studies (Chapter I), the statistical models are relatively conservative insofar as they identify only the most salient factors associated with trust in information brokers and in system trust. Some factors may not be statistically significant due to measurement error, or due to more complex causal mechanisms that can be inferred by the statistically significant correlations between independent variables (See Appendix A). Accounting for these relationships, as well as potentially non-linear and interaction effects, lay beyond the scope of this analysis.

Experience with certain aspects of the health system that are hidden to the general public, is likely to play a key role in trust building but given that so few individuals knowingly interact with these agencies, the data does not provide sufficient statistical power to analyze this group satisfactorily. Qualitative data evaluating how individuals identify the role and responsibilities of public health, for example, would help identify optimal ways of framing questions about unknown institutions. Also, a full model of trust should include a larger set of brokers including the payor community and for-profit agencies such as pharmaceutical companies. Future research might also look at the relationship between knowledge about the health system and information sharing practice, experience with the health system, and their additive effects on trust in the health system.

The data is cross-sectional and can only identify factors associated with system trust. Longitudinal studies, particularly those that allow the evaluation of interventional impacts on system trust should be undertaken. Such studies should also further test the bi-directionality and causal pathways in the relationship between system trust and trustor characteristics.

A full model of trust ought to consider additional factors beyond those of the trustor and the brokers of health information. For example, the role of policy and individual control (personal autonomy) in reducing uncertainty and risk in health information sharing will attenuate or exacerbate trust concerns. These will be explored further in the next chapter. Possible moderators and mediators of trust, such as risks and benefits, would also be included in a more complete model of trust in the health system, but are beyond the scope of this analysis. Finally, trust is multi-dimensional and abstract. The analysis presented here suggests that what matters in predicting trust is highly contingent on how trust is defined, by whom, and to what end.

Even as these limitations are addressed in future research, it is clear that health care providers could play a central role in maintaining trust not only in their profession, but in the health system as a whole. Communicating the benefits of health information sharing in ways that foster confidence and credibility will be critical to any efforts made to build or maintain trust. These efforts would likely to strengthen public trust as much, if not more, than efforts to fill a knowledge gap.

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CHAPTER III

Analytical Paper 3:
Adequacy of Policy-level Control and Beliefs about Personal Autonomy

BACKGROUND

In the United States, new learning health systems initiatives and ‘big data’ collaborations are rapidly expanding the depth and breadth of data sharing. Yet today’s standards for sharing health information across institutions greatly exceed the public’s understanding of how such integrated systems operate. For example, many people believe they own their health data and their health data is shared only when they give permission. Informed consent, gathered when an individual is enrolled in a particular study, frequently covers future studies as well. It is unlikely that the secondary uses of data are effectively communicated (Safran et al. 2007). In the case of Henrietta Lacks, whose cancer cell line fostered research for decades without the awareness of the patient or her family, this communication gap has forced an examination of common data sharing practices and the public’s confidence in the research enterprise (Skloot 2010).

Electronic health data in medical records is an ever more valued resource for innumerable research studies, but it is unclear whether and how to gather patient permission for diverse uses. The learning health system, the new vision for health and health care is contingent on integrated information systems that can function as a collaborative network “in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience” (Committee on the Learning Health Care System in America 2012, 136). It also relies on the so-called “trust fabric” that links the public, non-expert, with the expert users. The realization of this vision is predicated on a policy environment that is highly participatory and instantiates the values of trustworthiness, voluntariness, and governability (Institute of Medicine (US) 2011).

The present analysis addresses three questions regarding public perceptions and beliefs about key contextual factors – policy environment and personal autonomy – that may strengthen or erode the trust-fabric. First, to what extent are confidence in the policy environment, in which health information occurs is shared, and personal autonomy within the health system associated with system trust? Second, what are the trustor characteristics that are associated with confidence in the policy environment and personal autonomy? And third, to what extent are an individual's opinions about the policy environment and personal autonomy associated with trust in the health system, after accounting for trustor characteristics and trust in health information brokers?

Policy environment and personal autonomy are important insofar as they shape the level of risk and uncertainty an individual experiences in a relationship based on trust. Policies define the terms of engagement by providing rules about accountability. Personal autonomy enables flexibility and negotiation that can help a trusting partnership arrive at mutually agreeable terms and conditions. Defined as a cognitive expectation or willingness to impart authority and accept vulnerability to another in fulfilling a given set of tasks, trust is of greatest importance under conditions of high risk or uncertainty. Without risk, trust is not necessary as there are no consequences to failing to fulfill the obligation in question. Trust plays a minimal role in transactions with known outcomes or no risk of loss (Hardin 2002). A simple example of this can be found comparing cash versus credit as forms of payment. Cash transactions do not require any trust between buyer and seller since it is a form of immediate payment with a known and mutually accepted value, while transactions by credit require the seller to trust that the buyer (or other third party) will pay at a later date. Both types of interaction require some level of trust in the monetary system of which both buyer and seller are a part.

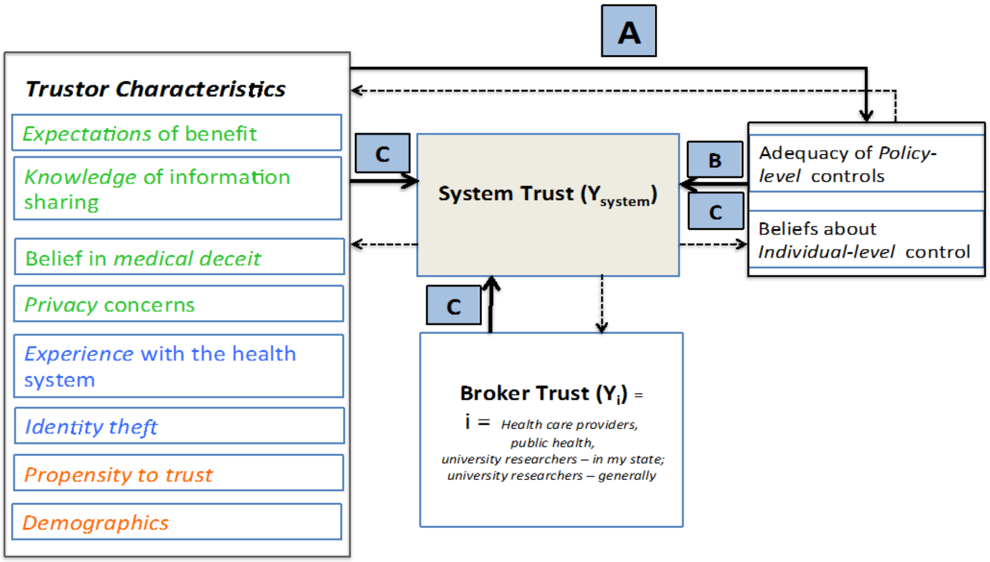
Creating a robust policy environment that can minimize harm that might come if the terms of trust are violated is one way to address the risk and uncertainty that comes with increased data sharing. The Health Information Portability and Accountability Act (HIPAA), the Federal Privacy Act, and the Genetic Information Non-Discrimination Act (GINA) are examples of regulatory controls aimed at reducing the risk of, and harm caused from, sharing and misuse of health data. In addition to legislation and regulations, institutional policies, culture, and ethical norms similarly affect risk perception, accountability, and transparency (See e.g., Onora O'Neill

2002). De-identification – the process of removing or coding information that could directly link individual identities with health data – has been the standard for protecting individual privacy and is a key mechanism for minimizing risk and assuring the trustworthiness of data exchange across diverse user groups.

Patient and participant-centric initiatives (PCIs) may be good mechanisms for assuring trust in information sharing (Thiel et al. 2014; Kaye et al. 2012; Dixon et al. 2014) . In the area of informed consent, IT tools that allow participants to more easily set the terms of their participation in research are currently being explored or are in the early stages of development (Thiel et al. 2014; O'Doherty et al. 2011). Patient "portals" in electronic health records are providing unprecedented access to information that was not possible with a purely paper-based system. Whether and how this window into one's own health data provides the sort of "access point" that can enhance trust in the health system remains to be seen.

In Figure 3.1, I illustrate the postulated conceptual model that places system trust at the center of multiple factors that both shape and are shaped by system trust. These factors include trustor characteristics and trust in information brokers, elaborated in previous chapters, as well as the policy environment and personal autonomy factors that are the subject of this paper. I begin by examining the trustor characteristics that predict opinions about the policy environment for health information sharing as well as beliefs about personal autonomy (See 'A' in Figure 3.1). Subsequently, I examine the relationship between system trust and policy environment and personal autonomy (denoted by the letter B in Figure 3.1). Policy and personal autonomy are then considered in the context of the trustor characteristics and trust in information brokers for a more complete consideration of the predictors of system trust. The solid arrows in Figure 3.1 point to the outcomes of interest in this paper, but, as suggested by the dotted arrows, trust is ultimately bidirectional and dynamic.

Figure 3.1 Postulated conceptual model



Green: cognitive/emotive factors; **Blue: Experience factors**; **Orange: Psychosocial and Demographic factors**

Trustor Characteristics

The characteristics of the trustor (i.e., individuals) that shape the extent of their trust in the brokers of health information are captured by variables measuring the experience, beliefs, as well as psychosocial and demographic factors of an individual vis-à-vis the health system. These characteristics are reflective of how the trustee might evaluate the trust between himself and the health system. At the same time trust both predicts and is predicted by an array of cognitive, emotive, experiential, psychosocial, and demographic individual characteristics. As an individual, one may experience trust as a solitary motive for behavior or belief, while the source of this trust stems from complex belief structures (Lewis and Weigert 1985, 2012). The trustor is bound to draw on intuition and cultural toolkits, as well as direct knowledge of the other (trustee), and learned patterns of behavior. As depicted in Figure 2.1, the specific constructs considered in evaluating trustor characteristics associated with system trust in the postulated model can be subdivided into three sets. The first set includes cognitive/ emotive characteristics (in green): knowledge, beliefs about privacy, beliefs about deception from the medical field, expectations of benefit, and an individual's general opinion of data sharing. The second set (in blue) measure experience with the health system in terms of quality and quantity, as well as experience with having one's identity stolen and misused. The third set of variables (in orange) measure psychosocial factors – self-esteem, altruism, self-efficacy, having a negative outlook, and generalized trust– as well as demographic factors.

Broker trust

Public trust in brokers in health care, public health, and university research can be a social and system resource for reducing administrative burdens, increasing organizational efficiency, and imparting decision-making authority from the trustee to the trustor (Kramer and Cook 2004). While the public may have trust in the system as a whole (See Chapter I), trust in the brokers of information and the liaisons to these brokers may provide the interpersonal relationship that will form a key element of system trust. In surveys of trust in physicians and scientists, individuals are often asked about their beliefs about the trustee's capacity to make decisions that reflect the best interests of the patient or public. This often means acting in the patient's or public's best interests, not acting from purely economic motives, and having a good track record of behaving responsibly (Hall et al. 2001; Goold, Fessler and Moyer 2006; Earle 2010). Given the role of public health departments as key brokers in the sharing of health information, they have been included in this analysis, though there is little previous empirical study of how individuals shape their opinions and beliefs about public health *per se.* A 2011 review, for example, examining trust and reputation in communicable disease public health found that only 30% of the literature reported on empirically tested evidence (Cairns et al. 2011).

Questions about health information brokers can be framed generally or specifically, and the level of specificity is likely to matter in evaluating trust. For example, it is not unusual to find that the public supports a particular representative in Congress, but has little confidence in the legislative branch. To evaluate the impact of differentiating between general versus specific cases, survey respondents were asked to answer questions about university researchers generally or "in my state."

Policy environment and personal autonomy

Policies set rules and guidelines; but in order to be effective, they must also be enforced. In the health information arena, policy strives to balance the need for accessibility among health care providers, public health departments, and university researchers on the one hand, and the privacy interests of the public on the other. DNA sequencing is becoming less expensive, data sets are getting larger and more complete, and information is more broadly accessible. Together, these trends make guarantees of anonymity less credible (Gymrek et al. 2013) . Data security is strong, but not impervious to hackers and unintentional information breaches. Since the passage of the HITECH Act (Section 13402(e)(4), 2009), which requires the Department of Health and Human Services to publicize information about data breaches involving HIPAA-covered entities, the largest reported incident involved the loss of 4.9 million records from Tri Care participants (*Breaches Affecting 500 or More Individuals*).

The nature of the trust relationship between the public and the health system will determine the extent of policy change required to address the risks associated with expanding health information sharing. With trust that information sharing will lead to desired health benefits, and that it will not cause undue harm, policy changes may not need radical shifts. Without trust or with increased fear of harm from data breaches, however, regulatory controls are likely to require greater oversight.

Beliefs that policy does not adequately protect against harm may be associated with lower levels of trust. In the political context, failing to demonstrate individual or social benefits of welfare policies has had a crippling effect on their sustainability as a public investment, and on public trust. For example, Hetherington (2006) has shown that in the absence of direct benefits, beliefs in government incompetency coupled with mistrust of government have created a self-fulfilling prophecy in which assistance programs have failed to maintain public support not because they are ineffective but because the population believes they are ineffective. This belief weakens public support and thus public funding, creating programs that are in fact untrustworthy and ineffective at achieving their goals.

At the same time, individuals may be given sufficient autonomy and control to be able to set the terms and conditions of trust as well as the expected outcomes of an arrangement. An individual's ability to choose her behavior in the health system to access information and services may empower her to offer trust and authority to make decisions about how health information is used. In the context of research, autonomy is often guaranteed by the freedom for an individual to withdraw from a research study. Perceived ease of use and accessibility of a system are indicators that an individual has the ability to exercise her autonomy.

System trust

The proposed empirical model defines system trust along four dimensions: fidelity, competency, integrity, and global trust. Fidelity is the act of a trustee prioritizing the needs and interests of the trustor (Mayer, Davis and Schoorman 1995), while integrity captures honesty or following the principles of non-deception. Competency means the ability and expertise to minimize errors and achieve goals and global trust captures an individual's general perception of trustworthiness. It is meant to assess intuitive, rather than rational, aspects of trust (Hall et al. 2001). Other surveys of trust in the health system encompass one or more of these dimensions, as well as others such as communication, confidence, confidentiality and fairness(Ozawa and Sripad 2013). The four dimensions chosen for this study rely on previous work applying the Wake Forest Scale (Hall et al. 2002b; Rajesh et al. 2003; Hall et al. 2002a; Dugan, Trachtenberg and Hall 2005; Beiyao Zheng et al. 2002).

METHODS

Statistical analysis

Descriptive distributional statistics were estimated on all variables to identify outliers or other distributional characteristics that may influence regression modeling. Indices, to summarize policy control and personal autonomy variables, trust in health information brokers (health care providers, trust in public health, trust in university researchers generally, and trust in university researchers "in my state"), as well as key trustor characteristics (e.g., privacy index, esteem index) were calculated as the sum of the participant's responses to those survey questions divided by the number of questions. Chronbach's alpha was used to evaluate the internal validity of indices.

Correlative relationships between policy and personal autonomy variables and other independent variables were estimated using Pearson's correlation coefficient (See Appendix A). To better understand the role of trustor characteristics in explaining variation in individuals' views of the policy environment and personal autonomy, I used multivariable OLS to estimate the regression relationship and the percent variation explained (R^2).

The main goal of this paper is to evaluate the relationship between policy environment, personal autonomy, and system trust before and after considering other factors such as trustor characteristics and trust in information brokers. Policy and personal control indices were used as dependent variables in multivariable OLS regression models to evaluate the association between policy and personal control and trustor characteristics. Subsequently, I used univariable regression modeling to evaluate the association between system trust and policy and personal autonomy variables and indices. Multivariable OLS models examined all predictors of system trust (policy environment, personal autonomy, trustor characteristics, and trust in brokers) in a single model. To identify a more parsimonious set of predictors of system trust, I used stepwise regression (inclusion criteria, $p<0.05$) and backward elimination (exclusion criteria, $p\geq0.10$). Bonferroni-adjustments to the stepwise models were applied to reduce the probability of type I error. Standardized coefficients (b*) provide information about the relative magnitude of predictors.

There is one set of survey questions that evaluates trust in university researchers that was bifurcated (50:50) in the random sampling to evaluate the influence of anchoring the question to researchers "in my state" versus generally. To account for this bifurcation, additional main effects and interaction terms were added to the model to represent this question and its sources of variability (See Chapter 1 for additional details).

The fit of the multivariable model that included all predictors versus the stepwise regression model was evaluated using the Aikake Information Criteria and Bayesian Information

Criteria (AIC and BIC). The smaller the AIC and BIC, the better the model fit. BIC is frequently a more conservative estimate of model fit since it penalizes more strongly for the number of parameters than the AIC (Cameron and Trivedi 2010).

RESULTS

Descriptive statistics

In the previous chapters I described the distributional parameters of trustor characteristics, trust in brokers, and system trust used in this analysis. Six questions (See Table 3.1) captured beliefs about the adequacy of regulatory and policy control over the health system's data sharing practices (policy environment variables). The six policy measures were normally distributed and had high internal consistency (Chronbach's α=0.82). About one-quarter to one-third of people felt the statements about the current policy environment were fairly or very true. For example, 24% stated that they felt access to electronic health information is adequately regulated, 25% said that electronic health information is sufficiently protected by current law and regulation, and 29% were confident in confidentiality standards. Twenty-six percent said that the health system is capable to self-monitor systems for health information sharing and 33% cited sufficient accountability among health researchers in conducting ethical research.

Questions evaluating an individual's comfort with accessing and controlling their health information (i.e., personal autonomy variables) (See Table 3.1) also had fairly high internal validity (Chronbach's α=0.68). Most people indicated comfort with getting information from their doctors; for example, 89% felt it was not at all or somewhat true that it was difficult to learn about health from their doctor and 63% felt comfortable getting a second opinion. Smaller proportions of people reported facility with knowing how their health information was used (17%), accessing their medical record online (22%), or withdrawing from research (24%).

Table 3.1 Descriptive statistics: Beliefs about policy environment and personal autonomy

	Frequency (% Very true or Fairly true)	Mean (SD)	Simple regression (R^2) (Y= System trust)[1]
Beliefs about policy environment			
Access to electronic health information is adequately regulated	24.33	2.02 (0.83)	**0.1962**
As a whole, the health system is capable of self-monitoring policies that regulate information sharing	26.35	2.06 (0.85)	**0.1106**
As a whole, the health system would be improved if it were monitored by a watchdog organization	32.03	2.13 (0.94)	0.0002
Electronic health information is sufficiently protected by current law and regulation	25.35	2.02 (0.85)	**0.1724**
Health researchers are sufficiently accountable for conducting ethical research	33.13	2.24 (0.86)	**0.1513**
I am confident in the standards for keeping personal health information confidential	28.78	2.11 (0.88)	**0.2177**
Policy Index (Chronbach's alpha = 0.82)	Median: 2.00	2.10 (0.63)	**0.2115**
Beliefs about personal autonomy			
The health care system is easy to use	22.70	1.91 (0.87)	**0.0667**
If wanted to withdraw from a research study, I would know how	23.83	1.85 (1.03)	**0.0425**
It is easy to access my medical record online	22.27	1.81 (0.98)	0.0004
It is difficult to learn about my health from my doctor (Reverse coded)	10.88	3.50 (0.75)	**0.0395**
I could access my medical record if I wanted to	94.07	2.43 (1.07)	**0.0441**
I feel comfortable getting a second opinion when I am told something about my health	63.48	2.87 (0.95)	**0.0506**
If I wanted to know how my health information had been shared, I would be able to	17.13	1.76 (0.86)	**0.0669**
Personal control index (Chronbach's alpha = 0.68)	Median: 2.29	2.31 (0.54)	**0.1187**

[1]Values in **bold** have p-values <0.001

System trust, policy environment, and personal autonomy

In simple regression analyses, all of the policy control questions were statistically associated with system trust, except one that asked whether the health system "would be improved if it were monitored by a watchdog organization" (See Table 3.1). The policy control index explained 20% of the variation observed in system trust ($p<0.001$). Personal autonomy variables had lower coefficients of determination (R^2) than the policy control variables in univariable models. Individual questions, while mostly statistically significant, explained less than ten percent of the variation in trust. The only personal autonomy question that was not related to system trust asked whether individuals felt it was easy to access their medical record. The personal control index explained nearly twice as much of the variation in system trust as compared to individual personal control variables (R^2=0.12, p<0.001).

Predicting confidence in policy environment and personal autonomy

Table 3.2 shows the results of the multivariable model of trustor characteristics as predictors of policy control and personal autonomy. Factors positively and significantly (p<0.05) associated with the policy control index included: having a positive view of data sharing (b=0.22); the expectation of improvement index (b=0.12); altruism (b=0.13); self-efficacy (b=0.11); and generalized trust (0.17). Those who had a neutral or no experience with one's PCP had higher scores on the policy control index as compared to those who had a negative experience (b=0.32). Knowledge (b=-0.07), self-esteem (b=-0.13), having a neutral or no experience with one's insurance company, and age were negatively associated with the policy control index. Trustor characteristics positively associated with personal autonomy included having a favorable view of data sharing (b=0.13), the expectation of improvement index (b=0.10), having a primary care provider (b=0.5) – as compared to not having a PCP, and having a positive (b=0.11) or neutral or no experience (b=0.48) with one's PCP – as compared to having a negative experience, self-efficacy (b=0.15), and generalized trust (b=0.06).

Table 3.2 Predicting policy environment and personal autonomy: Multivariable OLS

	Policy environment			**Personal autonomy**		
	b	**b***	**p-value**	**b**	**b***	**p-value**
Cognitive/ Emotive Factors						
Expectation of Benefit: Favorable view of data sharing	0.22	0.25	<0.001	0.13	0.17	<0.001
Expectation of Benefit: Improvement Index	0.12	0.15	<0.001	0.10	0.15	0.001
Knowledge	-0.07	-0.20	<0.001	-0.04	-0.14	<0.001
Privacy Index	-0.03	-0.03	0.372	0.02	0.03	0.511
Belief in medical deception Index	0.00	0.00	0.979	-0.01	-0.01	0.807
Experience factors						
Has PCP						
No (Ref)						

Yes – not seen in past year	0.23	0.09	0.069	0.47	0.22	0.050
Yes – seen in past year	0.10	0.07	0.386	0.50	0.42	0.030
Quality of experience with PCP						
Negative (Ref)						
Positive	0.03	0.02	0.569	0.11	0.09	0.036
N/A	0.32	0.21	0.012	0.48	0.36	0.045
Has Insurance						
No (Ref)						
Yes – But has had a gap in coverage	-0.25	-0.09	0.198	-0.45	-0.20	0.078
Yes – No gap in coverage	-0.30	-0.18	0.080	-0.41	-0.29	0.095
Quality of experience with insurance						
Negative (Ref)						
Positive	0.01	0.01	0.790	0.07	0.06	0.080
N/A	-0.44	-0.22	0.014	-0.46	-0.28	0.060
Has had experience with public health department	-0.08	-0.04	0.198	-0.07	-0.04	0.299
Identity theft	-0.08	-0.05	0.062	0.00	0.00	0.998
Psychosocial factors						
Self-esteem index	-0.13	-0.13	0.001	-0.06	-0.07	0.130
Altruism index	0.13	0.13	<0.001	0.03	0.03	0.442
Self-efficacy index	0.11	0.11	0.005	0.15	0.18	<0.001
Negative outlook	-0.01	-0.01	0.755	0.003	0.005	0.892
Generalized trust	0.17	0.22	<0.001	0.06	0.10	0.009
Demographic factors						
Sex (Male)	-0.05	-0.04	0.218	-0.005	-0.004	0.893
Age						
18-29 (Ref)						
30-44	-0.15	-0.10	0.017	-0.11	-0.09	0.068
45-59	-0.16	-0.11	0.017	-0.07	-0.06	0.255
60+	-0.10	-0.07	0.164	-0.03	-0.02	0.724
Race/ ethnicity						
White (Ref)						
Black, NH	0.07	0.04	0.351	-0.02	-0.01	0.779
Hispanic	-0.01	-0.01	0.850	0.08	0.05	0.162
Other, NH	-0.07	-0.03	0.353	0.07	0.03	0.367
Education						
Less than High School (Ref)				0.06	0.05	0.331
High School	-0.07	-0.05	0.361	0.09	0.07	0.193
Some college	-0.14	-0.10	0.069	0.07	0.06	0.319
BA or above	-0.16	-0.11	0.060	-0.01	-0.01	0.746
Income: Less than $50,000	-0.06	-0.05	0.167	0.06	0.05	0.331
Employment status						
Has employer (Ref)						
Self-employed	-0.03	-0.01	0.638	0.02	0.01	0.802
Laid off	-0.09	-0.05	0.151	-0.01	0.00	0.924
Retired	-0.06	-0.04	0.328	0.06	0.04	0.318
Disability	0.02	0.01	0.801	0.15	0.07	0.044
Self-reported health	0.02	0.03	0.474	-0.01	-0.02	0.558
Political affiliation						
Liberal (Ref)						
Moderate	-0.04	-0.03	0.442	-0.10	-0.09	0.054
Conservative	-0.04	-0.03	0.450	-0.06	-0.05	0.296
Support for the ACA	-0.03	-0.05	0.207	-0.02	-0.04	0.358

Predicting system trust

Multivariable models identifying predictors of system trust included personal and policy control indices as well as trustor characteristics (expectations, knowledge, privacy beliefs, beliefs about medical deception, psychosocial, and demographic factors elaborated in Chapter I as well as trust in brokers and experience factors described in Chapter II. As shown in Table 3.3, the multivariable model explained 62% of the variation in system trust, while the stepwise regression model explained approximately 57%. Comparing the multivariable model that included all factors to the stepwise regression, the AIC and BIC values are smaller for the stepwise regression (See Table 3.3), suggesting the more parsimonious model better fits the data than the model that includes all predictors.

In the Bonferroni-corrected stepwise model eight factors emerge as statistically significant. Positive predictors of system trust included the policy control index (b=0.51, trust in health care providers (b=0.89), trust in researchers “in my state” (b=0.39), having a favorable view of data sharing (b=0.79), having an expectation of benefit (b=0.44), identity theft (b=0.47), and altruism (b=29). The only negative predictor of system trust was knowledge (b=-0.10). Comparing the magnitude of the standardized coefficients, trust in health care providers and university researchers “in my state” and having a favorable view of data sharing had the greatest effect on system trust (b*=0.3). The policy control index and expectation of benefit index also had fairly large relative impact on system trust (b* = 0.2).

Notably, the measure of personal autonomy was not statistically significant after controlling for trustor characteristics and broker trust measures. Other factors that did not appear in the final model of system trust include the privacy and medical conspiracy indices, experience factors (except identity theft) and all demographic factors.

Table 3.3 Predicting system trust: Multivariable and stepwise regression models

	Multivariable model			Stepwise model		
	Model fit			*Model fit*		
Model R^2	0.6237			0.5726		
AIC	3323.21			3377.037		
BIC	3553.36			3430.901		
Predictors of System Trust	**b**	**b***	**p-value**	**b**	**b***	**p-value**
Control						
Policy index	0.43	0.14	<0.001	0.51	0.16	<0.001
Personal control/ autonomy index	0.14	0.04	0.173			
Trust in data brokers						
Trust in Health Care Providers (Index)	0.68	0.21	<0.001	0.89	0.29	<0.001
Trust in Public Health (Index)	0.32	0.11	0.003			
Trust in Researchers (Index)	0.34	0.25	0.022	0.06	0.02	0.654
Version (University researchers in my state v. generally)	-1.01	-0.25	0.020	-1.18	-0.28	0.012
Interaction: Index*Version	-0.04	-0.01	0.744	0.39	0.27	0.016
Cognitive/ Emotive Factors						
Expectation of Benefit: Favorable view of data sharing	0.72	0.25	<0.001	0.79	0.27	<0.001
Expectation of Benefit: Improvement Index	0.39	0.16	<0.001	0.44	0.18	<0.001
Knowledge	-0.08	-0.08	0.003	-0.10	-0.10	<0.001
Privacy Index	-0.13	-0.05	0.117			
Belief in medical deception Index	-0.09	-0.03	0.353			
Experience factors						
Has PCP						
No	Ref	Ref	Ref			
Yes – not seen in past year	-1.04	-0.13	0.242			
Yes – seen in past year	-1.04	-0.23	0.234			
Quality of experience with PCP						
Negative	Ref	Ref	Ref			
Positive	0.34	0.08	0.008			
N/A	-0.67	-0.14	0.452			
Has Insurance						
No	Ref	Ref	Ref			
Yes – But has had a gap in coverage	0.00	0.00	1.000			
Yes – No gap in coverage	-0.52	-0.10	0.286			
Quality of experience with insurance						
Negative	Ref	Ref	Ref			
Positive	0.11	0.03	0.298			
N/A	-0.26	-0.04	0.596			
Has had experience with public health department	0.17	0.03	0.321			
Identity theft	0.34	0.07	0.003	0.47	0.09	0.001
Psychosocial factors						
Self-esteem index	0.01	0.00	0.920			
Altruism index	0.28	0.09	0.002	0.29	0.09	0.002
Self-efficacy index	0.15	0.05	0.104			
Negative outlook	-0.07	-0.04	0.212			

Generalized trust	0.10	0.04	0.116	
Demographic factors				
Sex (Male)	0.13	0.03	0.161	
Age				
18-29	Ref	Ref	Ref	
30-44	0.06	0.01	0.661	
45-59	0.03	0.01	0.835	
60+	0.01	0.00	0.937	
Race/ ethnicity				
White	Ref	Ref	Ref	
Black, NH	-0.02	0.00	0.919	
Hispanic	-0.21	-0.04	0.173	
Other, NH	0.14	0.02	0.546	
Education				
Less than High School	Ref	Ref	Ref	
High School	-0.18	-0.04	0.302	
Some college	-0.44	-0.10	0.017	
BA or above	-0.51	-0.12	0.008	
Income: Less than $50,000	0.05	0.01	0.612	
Employment status				
Has employer	Ref	Ref	Ref	
Self-employed	-0.33	-0.04	0.132	
Laid off	0.08	0.01	0.598	
Retired	0.17	0.03	0.354	
Disability	-0.10	-0.01	0.663	
Self-reported health	-0.03	-0.01	0.633	
Political affiliation				
Liberal	Ref	Ref	Ref	
Moderate	0.10	0.02	0.453	
Conservative	0.24	0.06	0.115	
Support for Affordable Care Act	0.12	0.06	0.026	

DISCUSSION

Given the strong relationship between the policy control index and system trust, communicating effective policies will go far in assuring the public's trust in integrated health information sharing systems. At the same time, it is incumbent on health systems and those who steward and use health information to be able to demonstrate the ability of policies – regulations, standards, practice – to protect confidentiality and assure accountability and appropriate access. The findings presented here suggest that having a robust policy environment, that the public supports, should be an effective way to build trust in the health system. Having confidence in confidentiality standards and believing that access to electronic health information is adequately regulated explained as much as 20% of the observed variation in system trust, suggesting that these are good messages to communicate to the public.

Two measures that are commonly implemented or called upon to build trust in systems that share information –allowing easy access to medical records and creating a watchdog organization – were not associated with system trust. This finding points to the need for upstream public engagement that can solicit input on what policy and governance models would in fact build trust and what would merely be window dressing on an eroding and complex system. If watchdog organizations and access to medical records are, in fact, preferable to possible alternatives as policy interventions to assure trustworthy data sharing practice, the expert community needs to make this case to the public.

Underlying beliefs about a strong policy environment for data sharing are beliefs about the perceived benefit of data sharing and having a positive view of data sharing as well as psychosocial factors such as altruism, generalized trust, and self-efficacy. Knowledge, however, was found to be negatively associated with the policy environment index, suggesting that the so-called "smart skeptics" (see Chapter I) may be driving lack of confidence in health policy and, in turn, trust in the health system. This finding is particularly relevant to both proponents and critics of the so-called deficit model of public support for science, which purports that the public would support science, if only it understood it better. In fact, when it comes to support for health information sharing, the opposite seems to be true for those who seek knowledge. Rather than seeking to "fill" the deficit of information or providing direct counter-evidence to existing knowledge and beliefs, trust-building may be more effective if it focuses on mechanisms that make information about data use more transparent, accessible, and clearly meeting the demand for benefit.

A model of system trust

As the capacity of health information flow across the health system gains in terms of the amount of data and the frequency of data exchange, the health system may begin behaving in ways reflecting complex systems. As a result, trust in large health information systems may mirror trust in political systems rather than the dominant forms of trust in a single health care provider. If health information systems can demonstrate the benefits of health information sharing, they could proactively assure trust in the health system. Such demonstrations might seek out the large proportion of people who believe the health system actively deceives the public. Having a positive view of data sharing may be a good litmus test for whether and to what extent the public trusts the organizations that have their health information and share it. This finding is consistent with a recent Hastings Center Report on the ethical challenges of learning health systems highlights the need for bioethical frameworks to account for benefits to the social good (Faden et al 2013) , while also suggesting that meeting public expectations for what those benefits might be will be important to sustaining trust in a health system that broadly shares in information.

Trust in common brokers of health information– health care providers and local university researchers – is indicative of trust in the system as a whole. As health information systems become more highly integrated and the boundaries across organization-types becomes more fluid, trust in one partner will influence trust in others. In entering new relationships, organizational leaders may want to consider public trust not only in their own organizations, but also in their partners. Health care providers are likely to continue to be at the forefront of trust-building and maintenance, but may find their work more challenging as their patient's health information is accessible to a larger number of partners – some even beyond the awareness of a single practitioner. That trust in university researchers generally was less strongly associated with system trust than trust in university researchers "in my state" suggests that building trust may be most effective if approached from the local to the global, rather than the other way around.

This survey found that having had experience with some form of digital identity theft has an impact on trust in health information sharing, even after accounting for trustor characteristics, trust in health information brokers, confidence in the policy environment, and personal autonomy. This finding has two key implications. First, it suggests that when, as Taitsman, Grimm, and Agarwal (2013) claim, identity theft becomes an issue within the health care system, it will have deleterious effects on trust in the system at large and its component institutions. Second, even if the health care system is able to minimize the harm from identity theft within the health system, changes outside of the system that increase the probability of harm from digital identity theft may have an impact on trust in the health system. Seemingly unrelated events involving data breaches at large chain stores such as Target and Home Depot, for example, may challenge efforts to increase data fluidity in the health system if the public becomes wary of the exposure of personal information.

Personal control, privacy, and belief in medical deception indices were not significant in the stepwise regression model of system trust. This finding calls into question the primacy of these issues in discussions of trust in health systems, though they are likely to be key factors underlying the variables that were statistically significant. In supplementary analyses (not shown) personal control, privacy, and belief in medical deception are correlated with other predictors of system trust. Personal control measures, for example, are associated with privacy include knowing how to withdraw from research, learning about health from a doctor, and comfort with getting a second medical opinion ($p<0.05$). Privacy is associated with the belief that the health system is capable of self-monitoring regulatory policies, that the system would be improved by a watchdog organization, and confidence in confidentiality standards ($p<0.05$). Belief in medical deception is associated with difficulty accessing the health system (“It is difficult to learn about health from my doctor”) ($p<0.05$), controlling for all other covariates.

Limitations

There are several limitations to this analysis that should be noted. First, the stepwise regression model in particular is a conservative model such that factors that did not appear in the final model may nonetheless be important. One would expect privacy to be a key predictor of trust. Similarly, experience likely plays a greater role in trust than predicted in the statistical model presented here and may need to be measured more specifically by differentiating between types and quality of experience.

A full model of trust ought to consider additional factors such as the role of other types of brokers e.g., insurance companies or pharmaceutical companies. Possible moderators and mediators of trust, including risks and benefits, should also be included in a more complete model of trust in the health system, but are beyond the scope of this analysis. Similarly, this analysis did not take into account non-linear relationships or interaction terms.

The data are cross-sectional and can identify factors associated with system trust. Longitudinal studies, particularly those that allow the evaluation of interventional impacts on system trust should be undertaken. Such studies should further test the bi-directionality and causal pathways in the relationship between system trust and its predictors. Finally, it bears noting that trust is multi-dimensional and abstract. The analysis presented here suggests that what matters in predicting trust is highly contingent on how trust is defined, by whom, and to what end.

Despite these limitations, this paper has identified a set of factors which together explain over half of the observed variability in system trust. As health information becomes an increasingly pivotal part of health care research and practice, policy makers should not let privacy overshadow factors that are a greater concern for assuring trust. For example, resources would be well spent by addressing communications issues highlighting the ways in which data sharing provides personal and social benefit as well as reducing perceived harm or deception. These efforts would likely to strengthen public trust as much, if not more, than efforts to fill a knowledge gap or to shift responsibility for data use from the expert to the public. Upstream public engagement should solicit input on policy and governance models would in fact build trust rather than simply add window dressing to an already complex system.

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CONCLUSION

The three analytical papers in this dissertation examined public trust in health information sharing in a broadly defined health system. The first paper considered characteristics of the trustor that predicted system trust; the second examined the public's trust in health information brokers, and how this trust is associated with trust in the system generally. The third paper added two contextual factors – policy environment and personal autonomy – to the investigation of system trust and its predictors. These studies can inform our understanding of trust in electronic health information systems that are increasingly large, interoperable (linkable), and shareable across a greater number of users – health care providers, insurance companies, researchers, and public health departments, for example.

The Institute of Medicine describes the importance of a strong "fabric of trust" in such systems to protect the relationship between the public and the agencies and experts who use and share health data. As a mechanism for reducing complexity (Luhmann 2000), trust is of central importance for expanding health information systems with increasing webs of relationships and expectations among diverse data brokers and actors (Sweeney, 2014). The research presented in this dissertation provides preliminary evidence for addressing the challenge of knowing how and to what extent changing data sharing practices threaten or strengthen public trust in the health system. In this final chapter, I consider the implications of the key findings for policy, practice, and their evaluation, as well as for theoretical models of system trust, and areas of future research.

Throughout this dissertation, I have defined trust as a *cognitive expectation or willingness to impart authority and accept vulnerability to another in the fulfillment of a given set of tasks* (Baier 1986; Hall et al. 2001; Rousseau et al. 1998). As previously noted, a number of factors can influence the capacity and inclination to trust, including the trustor's past experience or willingness to trust, on the one hand, and the trustee's competency, reliability, reputation, honesty, or interestedness in the trusted relationship on the other (Nannestad 2008; Hardin 2002, 2004; Mollering 2005; Farrell 2009; Cook 2009; Cook, Hardin and Levi 2005). The nature, quality, and length of relationship between the trustor and trustee shape the nature of their relationship. Perceptions of risk and uncertainty moderate trust. Whether a trust relationship is just beginning, being maintained, or deteriorating matters in the syntax of trust (Rousseau et al. 1998).

Factors positively and statistically associated with system trust included: having an expectation of benefit from health information sharing, altruism, having a positive view of data sharing and confidence in the policy environment. Trust in health care providers and local researchers were also statistically significant indicators of system trust. Knowledge of health information sharing practices and policy and having had experience with identity theft were negatively related to system trust. Other factors examined in this study, such as beliefs about personal autonomy, privacy, and beliefs in medical deception, were not significant in models that accounted for all hypothesized trustor characteristics and beliefs. However, these factors are nonetheless likely to be important to examinations of trust because they are correlated with and may underlie some of the primary indicators.

POLICY IMPLICATIONS

Trust in the health system is ultimately assured and attained through the policies and practices that govern information sharing. Current policies such as the Health Insurance Portability and Accountability Act (HIPAA), the Common Rule, Genetic Information Non-discrimination Act (GINA), and Meaningful Use each govern norms for information sharing among data brokers and for communicating with the public about their rights and responsibilities. These regulations stand to build, maintain, or erode trust depending on how they are implemented. In this section, I discuss how my findings inform these policies as well as the implications for data brokers (health care providers, public health departments, and researchers).

Health Insurance Portability and Accountability Act (HIPAA)

Since its implementation in 1996, HIPAA has established the nation's standards for health information privacy, security, and, more recently, data breach notification. Based on the findings in this dissertation's survey, privacy is an important issue for most (73.0%) Americans, but there is little concern that security protocols are inadequate or that privacy is routinely threatened (72.8%). Given this finding, current HIPAA regulations are likely well-suited to assure trustworthiness in health privacy and security. Furthermore, recent concerns about de-identified data being, in fact, re-identifiable given the right information and statistical background [CITES] may be overstating the threat to public trust. The centrality of privacy in policy debates may be overshadowing other issues key to maintaining trust such as managing expectations and communicating benefits and limitations.

Communication is key to stemming vulnerability in trust due to beliefs that the health system is acting deceptively by hiding information about vaccines, pharmaceuticals, or clandestine experiments. Existing data breach reporting requirements could be strengthened so that they prevent the spread of mis-information and account for the consequences of data breaches. For example, reporting requirements could demand an explanation of the risk of harm associated with a given incident. Despite the fact that public health departments are exempt from HIPAA data sharing rules, they might want to consider being more transparent about what information they collect, how and where it is stored, and how public health surveillance benefits personal and public health. Researchers who conduct research using primary data collection as well as secondary research using de-identified data should consider mechanisms outside of informed consent to communicate how they prevent data breaches and what actions they take to mitigate harm should a data breach occur.

The Common Rule

The Federal Policy for the Protection of Human Subjects, known as the "Common Rule" represents the codification of the principles articulated in the 1979 Belmont Report. These core ethical principles for research involving human subjects reflect the values of respect for persons, beneficence, and justice, which are assured through personal autonomy, risk reduction, and fair treatment of research participants. Informed consent, discussed in the next section on governance implications, is the primary mechanism for communicating these principles to research participants but applies to a limited number of data use cases. Research using de-identified data, quality control studies, and public health surveillance are examples of activities that are exempt from requirements of informed consent.

Notably, individuals surveyed who had a better understanding of the rules and norms for data sharing, including requirements for informed consent, were less likely to be trusting of the health system. This suggests that in navigating the complexity of rules and regulations, public trust may be lost. Simplifying the rules for informed consent may go far in assuring trust in the health system and in data sharing. This could be achieved by establishing uniform rules across health care, public health, and research domains.

The Advance Notification for Proposed Rule Making (ANPRM) that proposes implementing a requirement for broad consent to future research uses when collecting data and biological samples for research could be a meaningful first step in achieving this goal, assuming it is done in ways that are clear. Changes proposed by ANPRM could increase the visibility of secondary data uses, which should foster trust by providing additional opportunities to promote confidence in the policy environment and to exercise autonomy in the researcher-subject relationship. However, should policy serve to increase administrative burdens and contribute to perceptions of deceptive practices, the unintended consequence of reducing system trust could also arise. Any amendments should be accompanied by a communications plan that informs individuals of their ongoing contribution to research as well as an articulation of value and impact of research to quality and health outcomes.

Genetic Information Non-discrimination Act (GINA)

Genomics is a key example of a cross-cutting arena that is affected by the evolution of policy and expectations for data sharing. Its proponents have been leaders in advocating the benefits and efficiencies of data sharing, while recognizing the demands their work places on ethical, social, and legal frameworks that shape norms in research and practice. The 2008 Genetic Information Non-Discrimination Act (GINA) aims to bar health insurance companies and employers from using genetic predisposition to disease as a means of denying benefits. While this sweeping legislation filled a large gap in civil rights, it fell short of prohibiting all forms of discrimination. Life, disability, or long-term care insurance are not covered by GINA, for example. It is important that health care providers understand the limitations of policies such as GINA and are willing and able to communicate them to their patients. Clinical actionability generally determines the value of returning research results to individuals, but potential consequences stemming from the limits of policies such as GINA should also be considered, particularly since the public is unaware of them. The survey findings presented in this dissertation further underscore the importance of communicating limitations and bridging the gaps in anti-discrimination laws such as GINA given the interrelatedness of trust relationships. Specifically, if trust is damaged between patient and provider, for example, this is likely to have deleterious effects on trust in the system and on trust with other brokers such as researchers.

Meaningful Use

Meaningful Use regulations outline reporting requirements for agencies implementing system-wide electronic health records and accessibility of health records for patients is a key component at each stage of implementation. As described in Chapter III, most Americans are not aware of the availability of their health records online and do not know how to access this information. Those who do have a greater sense of personal autonomy in navigating the health system do not necessarily have higher levels of trust in the health system, after accounting for other trustor characteristics. Beliefs about the sufficiency of the policy environment to protect and monitor health information sharing were, however, associated with system trust. This suggests that even if patient accessibility options are not exercised as Meaningful Use is implemented, policies that promote accessibility and transparency are important for maintaining public confidence in the system.

Policymakers and health and research organization leaders should be cautious in implementing accessibility policy since it has the potential for expectations to shift and undermine trust in the system. A shift in responsibility from the system to the individual underlies the rhetoric of personal control, and it is unclear whether the public is ready for this form of decision-making. Rather, assigning a trusted broker to make decisions on one's behalf holds greater promise for assuring trust.

The most likely candidates to take on the brokerage role are health care providers and local academic researchers who could serve as proxies (See Chapter II). Public health departments, as public agents, could take on the role of broker, but were not as trusted by the public making them less attractive in this role. Public health departments should engage more proactively with the public to seek greater visibility and trust. Despite the costs that this added responsibility would entail, the benefits would be seen by way of greater latitude in times of crisis. Even in times of less visible need, trust translates into public support and political will. If policy makers understand the value of public health, and have the confidence that public health departments are competent and trustworthy to do the work, public health departments are likely to be more effective in advocating budget increases.

The finding that there is a statistically significant relationship between system trust and trust in health care providers suggests the potential to use the clinical encounter as a key access point for sustaining trust as well as the importance of interpersonal relationships in the trust fabric. Future research should engage providers to assess whether and how providers see themselves in the role of broker and communicator. Exploring options for health care providers as well as other professionals who can promote confidence in health information sharing will be as important as developing the technological resources that can promote transparency and access to information. Developing and making explicit the two-way relationship in sharing the benefits of data brokerage is a promising source of trust building.

IMPLICATIONS FOR PRACTICE

At present, there are few opportunities built into the research, public health, and health care infrastructures for negotiations regarding multiple data uses. And yet clear communication with the public is at the heart of what can be done to build or erode trust. Habermas' work (1996) provides a useful conceptual model for understanding the effect of dialogue on legitimacy and trust. Specifically, sufficient communication that the health system and its representatives (health care providers, public health officials, researchers) are acting in the public's best interests lays the groundwork for confidence in the health system's competency. Given the need for negotiation to establish clear communication, trust is an inherently relational phenomenon encompassing both emotive and rational beliefs. These cognitive and emotive bases for trust are evidenced by the relationship between system trust and psychosocial factors as well as cognitive beliefs about the health system (e.g., knowledge, beliefs about medical deception).

As health information flows expand in size and scope, and across a larger number of users, the system becomes more complex such that interpersonal conversation becomes more difficult (Luhmann, 2000). Governance that fails to engage the public stands to threaten trust insofar as it neglects the communicative demands of articulating how the individuals' best interests are being met. Absent clarity about the benefits and risks of health information sharing, the non-expert is left to imagine his own worst-case scenario. As shown by the statistical significance of beliefs about medical deception, these worst-case scenarios negatively and non-trivially affect system trust.

Niklas Luhmann has observed that "in the age of electronic data processing, […] trust can no longer be personalized, no longer implemented in social status; it is now only trust in the system" (2012). While it may be the fact that, as Luhmann notes, system trust is less grounded in social status and social hierarchy as compared to interpersonal trust relationships, systems are a composite of their constituent parts whose social reputation will affect beliefs in system trust. This is evidenced by the observed relationship between trust in data brokers and system trust as described in Chapter II. As to the personalization of trust, Luhmann had no way of anticipating the ability of electronic data processing to be able to personalize messaging and information flow according to sophisticated algorithms, online behavior, and stated preferences. Indeed, accommodating differences in personal beliefs, knowledge, and psychosocial factors will need to be achieved to enter into effective communication and negotiation to seamlessly use health information system-wide.

To date, informed consent has been the primary mechanism for communicating the terms and conditions for information use and the rights and responsibilities of the non-expert participant. Informed consent is widely recognized as a critical and exceptional moment of negotiation and trust building that is severely crippled by the complexity of the multiple regulatory requirements it seeks to fulfill (Burgess 2007; Federman, Hannam and Lyman Rodriguez 2003). For many types of research, asking for permission may be impracticable, overly burdensome, or even harmful to research if it introduces a new source of selection or participation bias. Assurances of data privacy and confidentiality can nonetheless be made clearly and consistently. Transparency may be an institutional ethic, but is only valuable if what is transparent is also visible and accessible.

Given some of the limitations of informed consent, community engagement is often proposed as a tool for building trust through relationship building. However, community engagement can contribute to a culture of mistrust if it fails to achieve its communications goals and will perpetually fall short if it fails to evolve with the information environment within and outside of health care. For example, community engagement often seeks public input on policy questions during a one-time event rather than as an ongoing, two-way communication mechanism (Harmon, Laurie and Haddow 2013; Yarborough et al. 2013). Single interactions with individuals and communities via informed consent or isolated public engagement events are unlikely to suffice when the nature of data use is open-ended. The ability for information to travel to and from the public via the Internet, social media, and mobile technologies makes failure to engage in dialogue increasingly unjustifiable.

Based on the findings of the trust survey elaborated in this dissertation, having an expectation of benefit or a positive view of data sharing generally is highly correlated with system trust. In other words, the willingness to accept vulnerability or risk is closely connected to the system's ability to demonstrate personal and social benefit. For example, if actors in the health system can openly trace the translation of research from bench to bedside, they are likely to build trust. Recommendations for assuring community benefit have been discussed in the literature and include improved communication of research findings, monetary sharing of royalties, or coverage of treatments. Winickoff and Winickoff (2003) propose a charitable trust model for biobanks that would include provisions for a return of benefits to participants. Return of research results to individuals is commonly proposed and increasingly an explicit part of longitudinal research, but this survey found a stronger correlation between system trust and confidence in the policy environment than between system trust and common individual-level control over health information sharing (personal autonomy).

Audit trails have been advocated for the UK's National Health Service to try to improve accountability and trust, but have proven counterproductive insofar as they add a bureaucratic layer that adds more inefficiency than transparency about how decisions are made. Rather, exposing existing policies and maximizing accessibility of electronic systems may prove as, if not more, useful to trust building. Measures might include publicizing already-existing safeguards, using and promoting patient portals to communicate how information is protected and used, and full disclosure about research and medical record use.

EVALUATING POLICY AND PRACTICE TO ASSURE TRUST IN THE HEALTH SYSTEM

The current policy environment lays a foundation for trust building between the general public and the experts who use health information. Similarly, any number of proposed interventions could build trust, as long as the concomitant communications regarding the trustworthiness of the health system and its information brokers are perceived as authentic and not deceptive. With a trusting relationship between the public and the brokers of health information comes the articulation of duties accompanying the freedom to share health information. As seen in the first two papers, belief in medical deception is both common (~40% believe in one or more of the deceptive practices queried), and negatively affects system trust – more so than privacy. While state and federal offices of health privacy are important to assure the safety and security of information, similar dedication to limiting deception, building confidence, and assuring trustworthiness could enable a more efficient health policy environment. For example, a survey examining preferences for broad (one-time) consent, which administratively is more cost-effective and less time-intensive than the alternative, study-by-study consent, found that having a positive view of research was highly correlated with a preference for broad consent in longitudinal studies (Platt et al., 2012).

The significance of identity theft as associated with system trust suggests a relationship between harm of data breaches outside of health care, and the trust of health information sharing within health care. As information becomes more ubiquitous and accessible, attitudes toward information-sharing, privacy, and even informed consent have shifted. For example, as Isaac Kohane, Director of the Children's Hospital Informatics Program and Henderson Professor of Pediatrics and Health Sciences and Technology at Harvard Medical School has noted anecdotally, techno-savvy Mac users are more likely than others to opt-in for personal genetic testing (Kohane 2011). Consumers are primed to regularly sign ‘terms and conditions’ agreements with or without reading them, waiving privacy concerns in exchange for perceived personal benefits. Analogously, and in this context, methods, such as gathering consent and conducting community engagement that usually seek to legitimize the sharing of health data and samples, may be reduced to ineffective formalities (Kohane et al. 2007). Trust building then, will require innovative strategies to avoid becoming a series of meaningless exercises that expend time and energy and fail to achieve their goal.

Table C.1 summarizes some of the ways health organizations and information brokers might evaluate their ability to fulfill the terms of public trust. The policies and practices proposed in this chapter should be examined not only in terms of their ability to achieve stated goals, but also in terms of how well they meet the expectations of the public. If the expectations of the public are unknown or untenable, frank and open dialogue should ensue. Active forms of trust building that are evaluated as such will provide the elasticity in the health system to discuss errors, complications, and uncertainty, without instilling fear of litigation or accusations of ethical misconduct. Furthermore, evaluating policies and practices to see whether and how they build trust will assure that trust building is not merely an exercise in expanding bureaucracy in the name of transparency as seen in the UK's audit requirements discussed above.

Table C.1 Public trust in health information sharing: Evaluating policy and practice

<table>
<tr><th></th><th></th><th>Health care providers</th><th>Health care organizations</th><th>Public health departments</th><th>Researchers</th></tr>
<tr><td rowspan="4">**Policies that promote trust**</td><td>**HIPAA**</td><td colspan="4" rowspan="10">***Evaluation of policy and practice to promote trust***
How well are benefits communicated?
Are communications bi-directional?
How well are expectations being managed?
Could policy and/or practice be streamlined to meet goals of multiple stakeholders?
How engaged are the trusted brokers – particularly health care providers and local researchers – in discussing information sharing with the public?
Are communications and options adaptive to diversity in the population?</td></tr>
<tr><td>**Common Rule**</td></tr>
<tr><td>**GINA**</td></tr>
<tr><td>**Meaningful use**</td></tr>
<tr><td rowspan="6">**Practices that promote trust**</td><td>**Communications**</td></tr>
<tr><td>**Patient portals/ Patient electronic access**</td></tr>
<tr><td>**De-identification**</td></tr>
<tr><td>**Return of research results**</td></tr>
<tr><td>**Informed consent**</td></tr>
<tr><td>**Audits**</td></tr>
</table>

THEORETICAL IMPLICATIONS

The strength of the relationship between system trust and having an expectation of benefit and a favorable view of data sharing suggest that the type of trust operant in the health system may be more of a political trust than is typically recognized in the health field. As health systems become larger and more abstract, political trust is likely to be increasingly operant as it accounts for expectation of benefit and not just a willingness to be vulnerable, a key driver of trust in interpersonal relationships and doctor-patient interactions. In the political context, failing to demonstrate individual or social benefits of welfare policies has had a crippling effect on their maintenance and on public trust. For example, Hetherington (2006) has shown that in the absence of direct benefits, beliefs in government incompetency coupled with mistrust of government have created a self-fulfilling prophecy in which assistance programs have failed to maintain public support not because they are ineffective but because the population believes they are ineffective. This belief weakens public support and thus public funding, creating programs that are in fact untrustworthy and ineffective at achieving their goals. Demonstrating the benefits of health information sharing would be a proactive way for data users to assure trust in the health system. Such demonstrations should seek out the large proportion of people who believe the health system actively deceives the public.

Taken together, the findings from the studies presented in this dissertation also suggest that trust can be quite high in the health system and, for now, is resilient to conflicting beliefs about deceptive behavior and confidence in the policy environment. However, the less significant impact of personal autonomy suggests that the operant type of trust in the context of health data systems may also be described as *dormant*. Dormant trust is a type of generalized trust based on a set of tacit expectations between trustor and trustee rather than clearly defined rules or a direct one-on-one relationship. When trust is broken the violation is clear and the relationship threatened. Dormant trust is relevant to the public-broker relationship in the health information context given that there are few opportunities for the public to interact with data brokers, and it is unclear under what conditions their relationship warrants direct interaction.

This kind of trust is much like the “dormant commerce clause” which precludes states from passing certain types of laws that would be in violation of Congress’ constitutional authority to regulate interstate commerce even if Congress has not acted (e.g., Internet regulations). In such cases, the Supreme Court has invoked the dormant commerce clause, enforcing the jurisdiction of Congress. While policy is limited in its ability to keep pace with the changes in the health data landscape, institutions can still be held accountable to responsible stewardship. At an equilibrium state, my theory of dormant trust would suggest that despite the public’s lack of awareness about how health and public health researchers and practitioners use and share health data, the public still maintains expectations of good governance, responsible stewardship, social benefit, and an acute awareness of what constitutes a violation of trust. Future studies to test this theory of dormant trust could help practitioners and policy makers identify flashpoints or tipping points in trust to develop plans of action that can proactively address breaches of trust when they occur.

Several key predictors of trust did not stand out as statistically significant as proposed in the postulated conceptual model that was tested in this dissertation. Privacy, for example, was not statistically significant as a predictor of system trust in any of the models evaluated in this dissertation. Similarly, one would expect experience to be clearly associated with system trust, but did not appear as statistically significant. This is not to say that these factors are irrelevant to understanding system trust. Rather, they are more likely to be part of underlying mechanisms that were not a part of this investigation. At the same time, the attention to privacy in the policy debates surrounding expanded health information sharing may be overshadowing factors that are a greater concern for assuring trust. For example, resources would be well spent by addressing communications issues highlighting the ways in which data sharing provides personal and social benefit as well as reducing perceived harm or deception. Communications need to address more than just informing the public, given the finding that knowledge is a double-edged tool in the trust-building enterprise. The presence of “smart skeptics” who are aware of how information is used are generally less trusting than those who know less.

FUTURE STUDIES

While variables measuring privacy and experience were not statistically significant in the analysis presented here, theoretical considerations warrant keeping them in future studies. Further studies should also evaluate potential non-linear and interaction effects in which these factors may play a part. Examination beyond the limited study of one direction of the two-way trust dynamic is also warranted. Qualitative and mixed methods approaches that further validate survey questions and findings would further inform areas in which policy and practice can better assure authenticity in institutional trustworthiness, transparency, and personalization. Survey research of the kind presented in this dissertation is nonetheless valuable for assessing a set of opinions and beliefs from a stakeholder group that is rarely heard from in research and development of large health data systems. The relatively large sample size of approximately one thousand, along with the probability-based sample, enhances the external validity of its findings and minimizes common sources of bias. While efforts were made to minimize satisficing and acquiescence bias through the use of reverse-coded items and the choice of scale, trust is a socially desirable trait that may have inflated the measure of trust in the health system and in information brokers.

The finding that individuals were more trusting of university researchers “in my state” than of university researchers generally suggests a high level of sensitivity to trust in specific rather than abstract trustees. Studies that are more specific in defining the trustee are more likely to report higher levels of trust than studies that frame trustees in more generic terms. This differentiation and the consequences should be further investigated. Using cognitive interviews and mixed methods approaches would help inform the identification for best practices in trust research. These studies should also investigate the additional dimensions of trust beyond fidelity, integrity, competency and global trust, as well as additional actors involved in data brokerage (e.g., insurance firms, pharmaceutical companies) that undoubtedly affect our understanding of system trust, but were beyond the scope of this dissertation.

Future research should push current ethical debates beyond theoretical considerations to better understand the public’s opinions and beliefs about specific policies in living institutional contexts. The disparity between the elaboration of ethical ideals of, for example, engagement, partnership, reciprocity, and transparency, and their empirical evaluation within existing and emergent models of data governance needs to be addressed through research. This might be accomplished using mixed methods approaches to investigate terms and conditions for trust in health information sharing that will provide a needed evidence-base for assuring the authentic application of these core principles. It can also begin to resolve the potential flashpoints raised by issues such as data, information, and knowledge ownership, identifiability, and whole genome sequencing of newborns. To investigate the multidimensionality of the trust fabric, future research should address: the current discontinuity between public expectations and current practices within health care systems, research enterprises and public health institutions; the state and consequences of the public's knowledge and misinformation (conspiracy theories) for health care, public health, and research data sharing practices; and, the implications of disruptive technologies such as whole genome sequencing of newborns on data sharing policies.

Policy has an important role in limiting deception, actual and perceived, and can help assure clarity of communication that can help manage expectations. Finding ways to build trust through negotiation and implementation of the values and beliefs of the general public into the governance of data brokerage promises to fortify the "strong trust fabric." This requires a better understanding of where and to what extent the public trusts or is skeptical of existing data arrangements as well as the perceived risks and benefits. Alan Westin, a prominent privacy lawyer and scholar, was recently remembered for recognizing that "the problems of protecting privacy are now so daunting that they can't be dealt with by law alone, but require a mix of legal, social and technological solutions" (Fox 2013). Assuring trust promises to be a key ingredient.

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APPENDIX A

Supplementary Tables and Figures

Table A.1 Correlation table of independent variables

	scoretotal	cons_index	privacy_in~x	expect_imp~	viewshare	esteem_inde	efficacy_i~x	altruism_i~x	optimism	trust_gen	hcp_indexre	ph_indexred	trust_resi~d	control_pol1	control_pol2
scoretotal	1														
cons_index	0.0699*	1													
privacy_in~x	0.1326*	0.4774*	1												
expect_imp~e	-0.0549	-0.3376*	-0.3414*	1											
viewshare	-0.1197*	-0.2997*	-0.3711*	0.5169*	1										
esteem_index	0.1008*	-0.1697*	-0.0908*	0.1599*	0.0962*	1									
efficacy_i~x	0.0679*	-0.0258	0.0629*	0.1567*	0.0996*	0.5184*	1								
altruism_i~x	-0.0081	0.1530*	0.1416*	0.1296*	0.1048*	0.1744*	0.2700*	1							
optimism	0.0681*	0.3626*	0.3015*	-0.2420*	-0.1567*	-0.1773*	0.0043	0.1604*	1						
trust_gen	-0.0666*	-0.1123*	-0.1065*	0.1957*	0.2270*	0.1649*	0.2609*	0.2211*	-0.1478*	1					
hcp_indexred	-0.0641*	-0.4706*	-0.3896*	0.4542*	0.3907*	0.2329*	0.1194*	-0.0254	-0.2819*	0.1681*	1				
ph_indexred	-0.0635*	-0.4323*	-0.3867*	0.4236*	0.4199*	0.1557*	0.044	0.043	-0.3139*	0.1599*	0.5531*	1			
trust_resi~d	-0.0745*	-0.4619*	-0.3806*	0.4041*	0.4026*	0.1958*	0.1119*	0.0247	-0.3027*	0.2095*	0.4963*	0.5971*	1		
control_pol1	-0.2571*	-0.1545*	-0.2565*	0.3409*	0.3594*	-0.0292	0.1105*	0.0929*	-0.0978*	0.2088*	0.2372*	0.2523*	0.2510*	1	
control_pol2	-0.2309*	-0.1147*	-0.1981*	0.2614*	0.2888*	0.0144	0.1091*	0.1068*	-0.0492	0.2288*	0.2160*	0.1777*	0.1841*	0.6028*	1
control_pol3	-0.0765*	0.1663*	0.1769*	-0.023	-0.0367	-0.0546	0.03	0.2320*	0.0756*	0.1182*	-0.1633*	-0.0842*	-0.0619*	0.0594	0.0739*
control_pol4	-0.2667*	-0.1740*	-0.2348*	0.3063*	0.3357*	-0.0174	0.0926*	0.1003*	-0.1203*	0.2187*	0.2142*	0.2093*	0.2630*	0.7406*	0.6197*
control_pol5	-0.2088*	-0.1687*	-0.1749*	0.3216*	0.3568*	0.0467	0.1397*	0.1967*	-0.0765*	0.2413*	0.2526*	0.2315*	0.3058*	0.5890*	0.5357*
control_pol6	-0.2814*	-0.2142*	-0.2982*	0.3673*	0.4056*	0.0271	0.1524*	0.1321*	-0.1289*	0.2843*	0.2952*	0.2921*	0.2953*	0.6802*	0.6219*
control_po~x	-0.2986*	-0.1463*	-0.2196*	0.3547*	0.3850*	-0.0052	0.1448*	0.2002*	-0.0898*	0.2971*	0.2354*	0.2431*	0.2798*	0.8310*	0.7827*
control_pe~1	-0.1779*	-0.1138*	-0.1835*	0.2510*	0.3060*	-0.0115	0.0993*	0.0549	-0.0658*	0.1901*	0.1828*	0.1518*	0.2062*	0.3868*	0.3424*
control_pe~2	-0.1192*	-0.0712*	-0.0392	0.1313*	0.1589*	0.0169	0.1229*	0.0771*	-0.052	0.1074*	0.0844*	0.0850*	0.2144*	0.2719*	0.2236*
control_pe~3	-0.0543	0.0458	0.0766*	0.0552	0.0666*	-0.0670*	0.0419	0.0472	0.0874*	0.1144*	-0.0757*	-0.0594	0.0009	0.1790*	0.1441*
control_pe~4	0.0660*	-0.3222*	-0.2496*	0.1847*	0.1573*	0.2636*	0.0143	-0.0387	-0.1742*	-0.017	0.3587*	0.2141*	0.2414*	-0.0346	-0.0417
control_pe~5	-0.0687*	-0.0993*	-0.06	0.2280*	0.1997*	0.1294*	0.2133*	0.1532*	-0.0116	0.1638*	0.1370*	0.1061*	0.1882*	0.2378*	0.2022*
control_pe~6	-0.0177	-0.0771*	0.0419	0.1633*	0.0943*	0.2921*	0.3207*	0.2094*	-0.0356	0.1035*	0.1291*	0.0552	0.1013*	0.1381*	0.1201*
control_pe~8	-0.2261*	-0.0831*	-0.1344*	0.1684*	0.2448*	-0.0914*	0.0555	0.0876*	-0.0242	0.1473*	0.0927*	0.1500*	0.1530*	0.4087*	0.3678*
control_pe~x	-0.1533*	-0.1630*	-0.1207*	0.2884*	0.3004*	0.1306*	0.2210*	0.1545*	-0.0634*	0.2045*	0.2093*	0.1668*	0.2667*	0.3986*	0.3384*
	***p<.05**	Shaded, p<.001													

Table A.1 Correlation table of independent variables (cont.)

	control_pol3	control_pol4	control_pol5	control_pol6	control_po~x	control_pe~1	control_pe~2	control_pe~3	control_pe~4	control_pe~5	control_pe~6	control_pe~8	control_pe~x
scoretotal													
cons_index													
privacy_in~x													
expect_imp~e													
viewshare													
esteem_index													
efficacy_i~x													
altruism_i~x													
optimism													
trust_gen													
hcp_indexred													
ph_indexred													
trust_resi~d													
control_pol1													
control_pol2													
control_pol3	1												
control_pol4	0.0848*	1											
control_pol5	0.1345*	0.5886*	1										
control_pol6	0.0749*	0.6751*	0.5463*	1									
control_po~x	0.3452*	0.8399*	0.7719*	0.8183*	1								
control_pe~1	0.0529	0.3830*	0.2906*	0.3939*	0.4205*	1							
control_pe~2	0.0883*	0.2579*	0.2706*	0.2423*	0.3092*	0.3084*	1						
control_pe~3	0.1019*	0.1409*	0.0969*	0.1404*	0.1838*	0.3552*	0.2363*	1					
control_pe~4	-0.1182*	-0.0527	-0.0117	0.0083	-0.0603	-0.0192	-0.0919*	-0.0731*	1				
control_pe~5	0.0804*	0.2251*	0.2095*	0.2438*	0.2735*	0.3518*	0.3343*	0.4748*	0.0781*	1			
control_pe~6	0.0998*	0.1306*	0.1663*	0.1374*	0.1816*	0.1894*	0.2334*	0.1543*	0.1080*	0.3228*	1		
control_pe~8	0.047	0.3980*	0.3243*	0.4152*	0.4469*	0.3707*	0.4054*	0.2747*	-0.1423*	0.3395*	0.1660*	1	
control_pe~x	0.1023*	0.3744*	0.3416*	0.3938*	0.4431*	0.6327*	0.6314*	0.6239*	0.1729*	0.7485*	0.5491*	0.6032*	1

Table A.2 Correlation table variable key

Variable abbreviation	**Variable**
scoretotal	Knowledge
cons_index	Belief in medical deception Index
privacy_in~x	Privacy Index
expect_imp~e	Expectation of Benefit: Improvement Index
viewshare	Expectation of Benefit: Favorable view of data sharing
esteem_index	Self-esteem index
efficacy_i~x	Self-efficacy index
altruism_i~x	Altruism index
optimism	Optimism
trust_gen	Generalized trust
hcp_indexred	Trust in Health Care Providers (Index)
ph_indexred	Trust in Public Health (Index)
trust_resi~d	Trust in Researchers (Index)
control_pol1	Access to electronic health information is adequately regulated (Pol 1)
control_pol2	As a whole, the health system is capable of self-monitoring policies that regulate information sharing
control_pol3	As a whole, the health system would be improved if it were monitored by a watchdog organization (Pol3)
control_pol4	Electronic health information is sufficiently protected by current law and regulation (Pol 4)
control_pol5	Health researchers are sufficiently accountable for conducting ethical research (Pol 5)
control_pol6	I am confident in the standards for keeping personal health information confidential (Pol 6)
control_po~x	*Policy Index (Chronbach's alpha = 0.82)*
control_pe~1	The health care system is easy to use (Pers 1)
control_pe~2	If wanted to withdraw from a research study, I would know how (Pers 2)
control_pe~3	It is easy to access my medical record online (Pers 3)
control_pe~4	It is difficult to learn about my health from my doctor (Pers 4) (Reverse coded)
control_pe~5	I could access my medical record if I wanted to (Pers5)
control_pe~6	I feel comfortable getting a second opinion when I am told something about my health (Pers 6)
control_pe~8	If I wanted to know how my health information had been shared, I would be able to (Pers 8)
control_pe~x	*Personal control index (Chronbach's alpha = 0.68)*

Figure A. 1 Histogram of System Trust

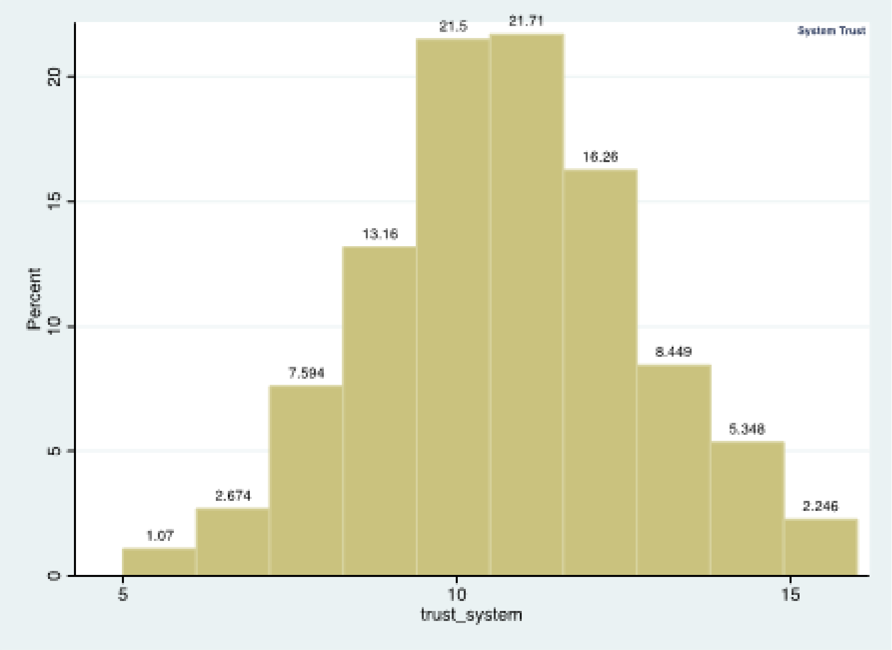


Figure A. 2 Histograms of Expectations of Data Sharing

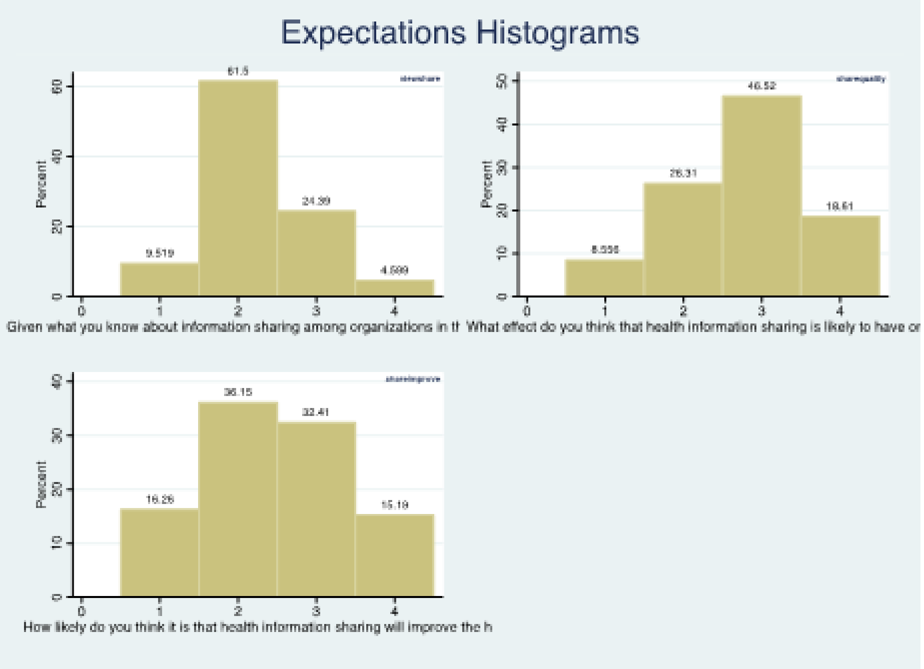


Figure A. 3 Histogram of Knowledge

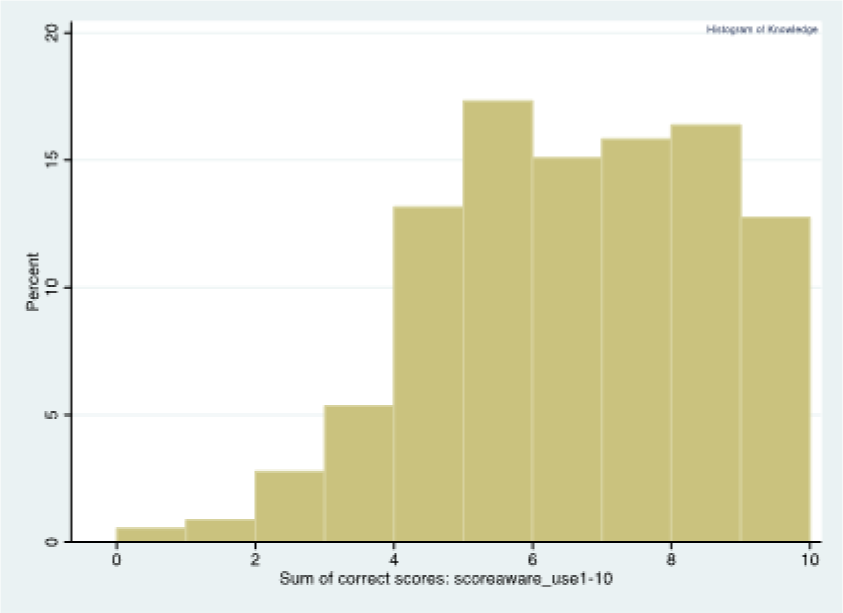


Figure A. 4 Histogram of Support for Affordable Care Act

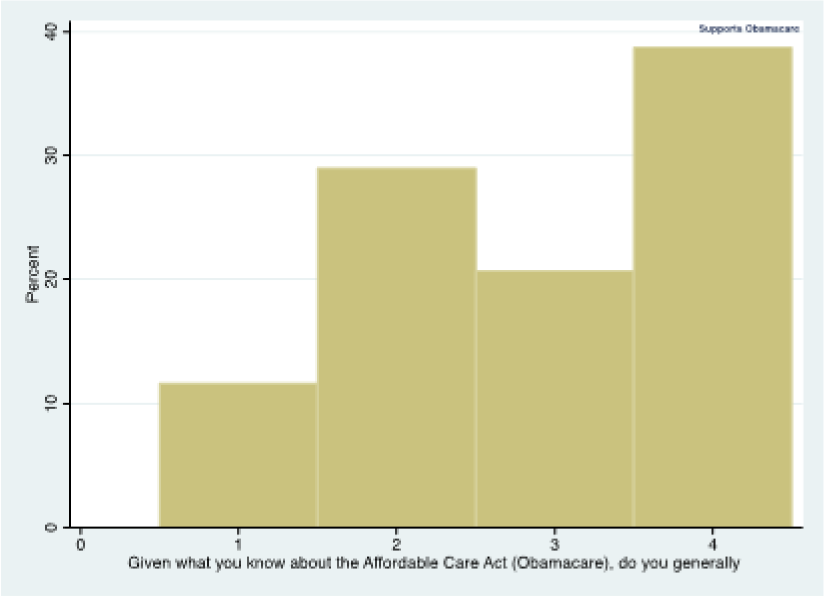


Figure A. 5 Histograms of Psychosocial Factors

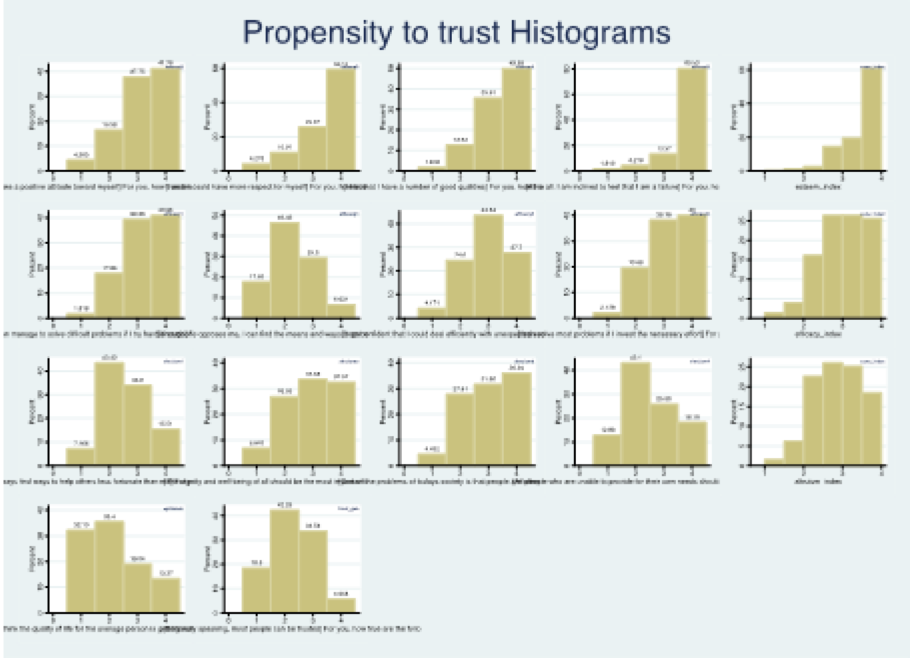


Figure A. 6 Histograms of Privacy Variables

Figure A. 7 Histograms of Beliefs about Medical Deception

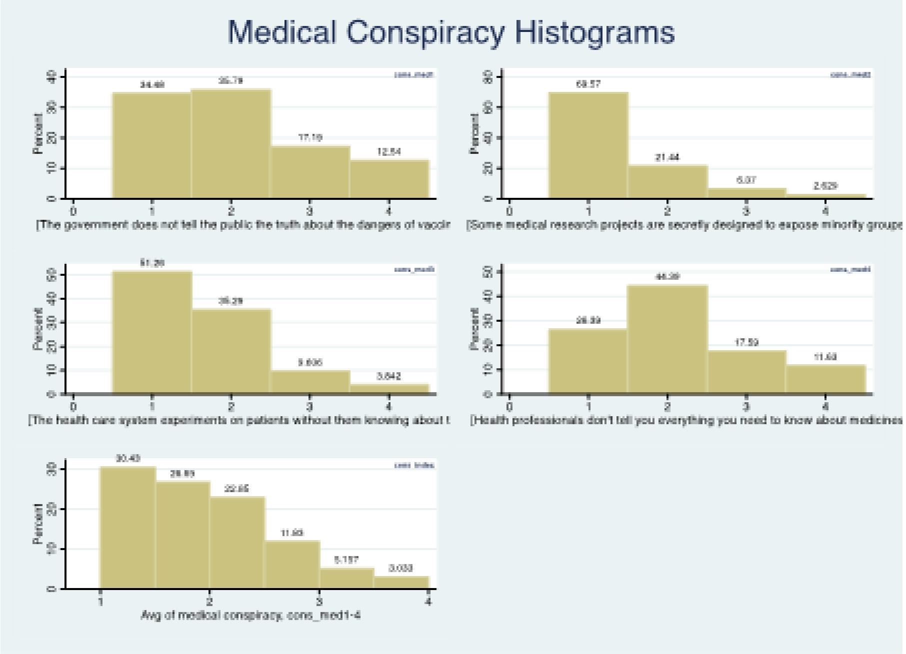


Figure A. 8 Histograms of Trust in Information Brokers (Indices)

Figure A. 9 Histograms of Trust in University Researchers (Generally)

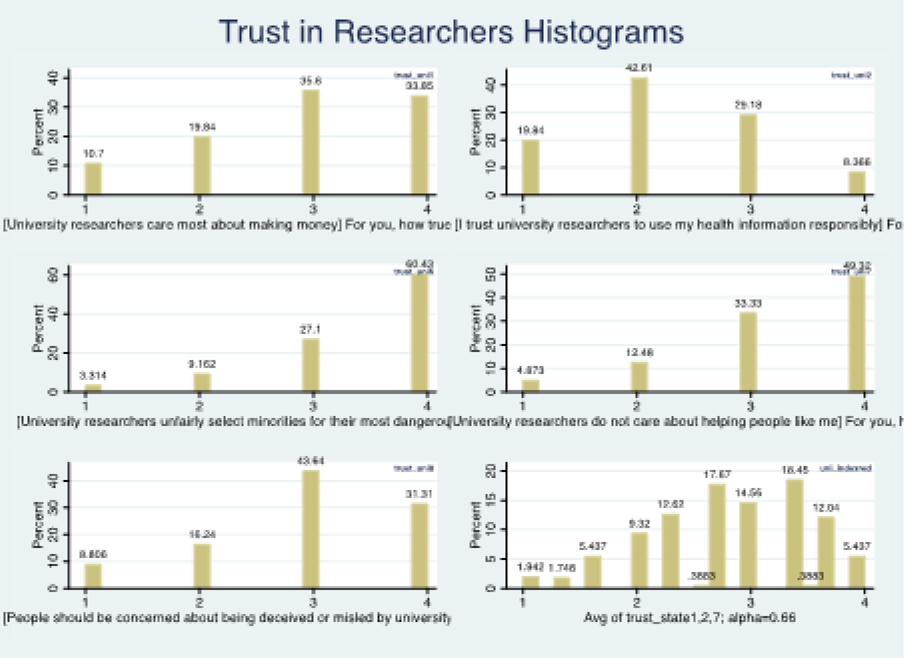


Figure A. 10 Histograms of Trust in University Researchers "in my state"

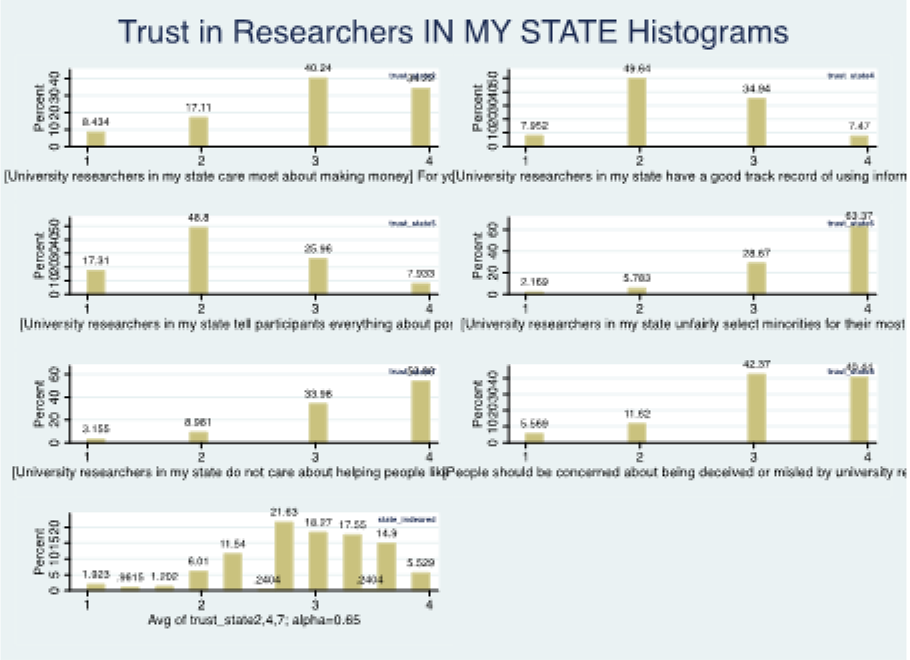


Figure A. 11 Histograms of Trust in Public Health Departments

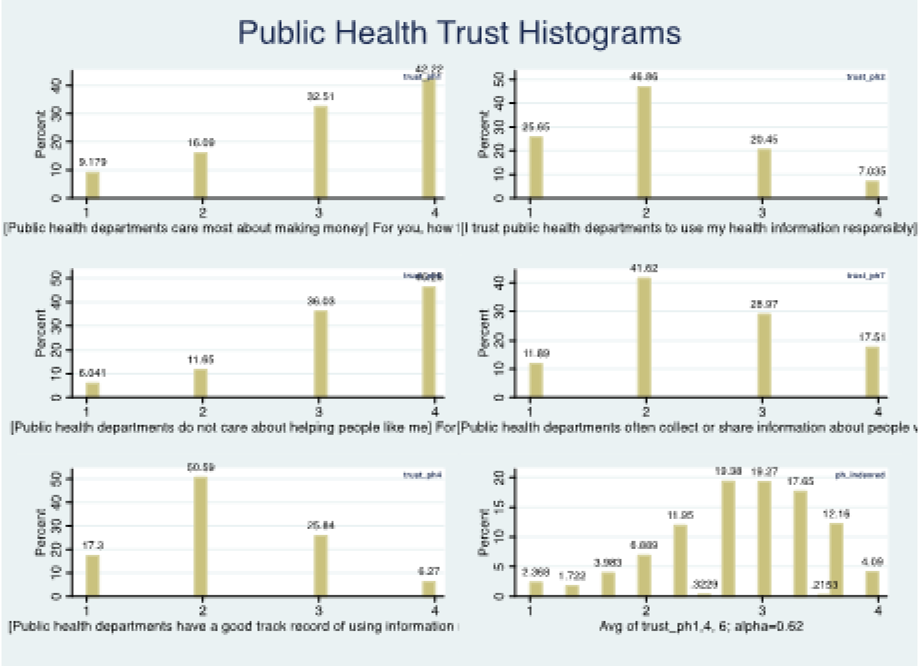
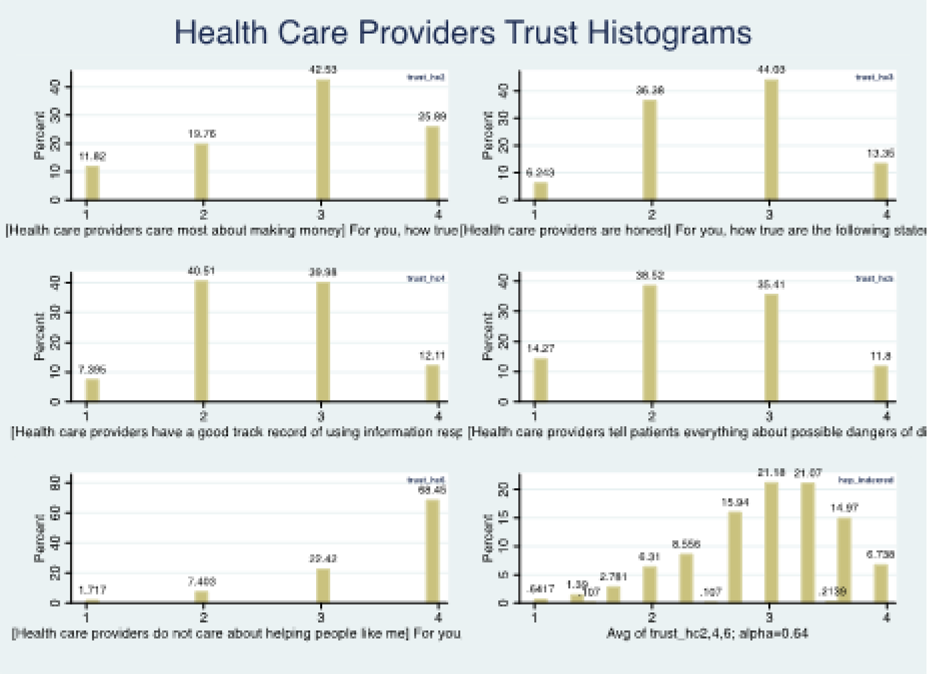


Figure A. 12 Histograms of Trust in Health Care Providers



APPENDIX B

Survey Design and Documentation

INTRODUCTION

The goal of this dissertation is to identify key factors associated with public trust in a health system that shares data across organizations for various purposes such as research, payment, quality improvement, and health care and public health practice. I conducted a survey of the general public to evaluate the trustor characteristics, trust in information brokers (health care providers, public health departments, and university researchers), and perceived policy environment and personal autonomy of individuals that might predict trust in today's complex health system. This appendix provides additional details about the survey development, validation, pilot results, and final survey implementation that lay outside the scope of discussion in previous chapters.

SURVEY DEVELOPMENT AND INITIAL DESIGN

I developed a 117-item survey to evaluate predictors of trust in the health system (i.e., System Trust, Y_{trust}), broadly defined as a web of relationships among health care providers, departments of health, insurance systems, and researchers. In the complete postulated conceptual model (See Figure 3.1), predictors of System Trust included trustor characteristics, trust in information brokers (health care providers, researchers, and public health), and beliefs about personal autonomy and the policy environment for health information sharing.

Measures of the dependent variable – System Trust – and the independent variables used in this paper were adapted from prior studies and contextualized for the health system as needed (Hall et al. 2002, 2001, 2002). Sources included the California Health Foundation's 2005

National Consumer Health Privacy survey(Bishop, Holmes and Kelley 2005) and methods used in risk analysis literature {\See e.g., \Visschers 2011; (Siegrist, Connor and Keller 2012) to develop measures of knowledge, experience, and expectations. Questions from the Medical Mistrust Index(Boulware et al. 2003; LaVeist, Isaac and Williams 2009), and related studies of privacy of health information were adapted to assess privacy concerns and beliefs about deceptive behavior in the health field (Anderson and Agarwal 2011; Bishop, Holmes and Kelley 2005) . The Health Privacy Survey also informed questions about expectation of benefit and knowledge. Questions from the General Social Survey (Smith et al. n.d.), National Election Survey(Feldman and Steenbergen 2001), the General Self-efficacy Scale(Schwarzer and Jerusalem 1995) and the Rosenberg Self Esteem scale (Rosenberg et al. 1995) were used to survey psychosocial factors. Questions developed by the Federal Trade Commission (2003) about identity were also included in the survey (*Identity Theft Survey Report* 2003).

The market research institute GfK, which fielded the survey used in this dissertation, provided basic demographic information as well as additional profile data on Internet banking, political views (i.e., liberal, conservative) civic engagement and self-rated health. Questions adapted from existing surveys or developed anew were done so in collaboration with a research team (Kardia, Platt, Thiel) and in light of principles of survey question design to reduce common forms of bias such as satisficing and acquiescence bias (Krosnick 1991; Krosnick and Presser 2010; Groves 2009; Couper 2008). Table B.1 lists the constructs hypothesized in the proposed conceptual model, survey questions, and their original source.

Table B.1 Survey questions and sources

Construct	Survey questions	Sources/ Notes
System trust: Fidelity	Do not care about helping people like me Value my needs Would not knowingly do anything to harm me Care most about research Care most about what is convenient for its practitioners Care most about holding costs down	((Thompson et al. 2004)) (Egede and Ellis 2008) (Colquitt, Scott and LePine 2007) (Hall et al. 2001) (Abigail et al. 2004)
System trust: Integrity	Try hard to be fair in dealing with others Would try to hide a serious mistake Tell me how my health information is used Would never mislead me about how my health information is used	(Colquitt, Scott and LePine 2007) (Armstrong et al. 2013) (LaVeist, Isaac and Williams 2009) (Hall et al. 2001) (, 2002) (Dugan, Trachtenberg and Hall 2005)
System trust: Competency	Are very good at conducting research Have a good track record of using information responsibly Have specialized capabilities that can promote innovation and discovery in health and wellness Should be more careful than they are in sharing health information Are not good at their jobs Make a lot of mistakes	(Hall et al. 2001) (Earle 2010) (Colquitt, Scott and LePine 2007) (LaVeist, Isaac and Williams 2009)
System trust: Global Trust	Can be trusted to keep my health information secure Can be trusted to use my health information responsibly Think about what is best for me Act in an ethical manner	(Egede and Ellis 2008) (Hall et al. 2001)
Privacy	Keeping my electronic personal health information private is very important to me I believe the privacy of my electronic personal health information is seriously threatened I worry that private information about my health could be used against me There are some things I would not tell my healthcare providers because I can’t trust them with the information	(Kaufman et al. 2009) (Anderson and Agarwal 2011) (Hall et al. 2001; Kaufman et al. 2009) (Hall et al. 2002)

	Doctors could share embarrassing information about me with people who have no business knowing it	(Bishop, Holmes and Kelley 2005) (Dinev and Hart 2006)
Medical deception	The government does not tell the public the truth about the dangers of vaccines Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS The health care system experiments on patients without them knowing about the experiments Health professionals don't tell you everything you need to know about medicines.	(Cooper, Larson and Katz 2008) (Mainous et al. 2006) (Abigail et al. 2004) (Armstrong et al. 2013)
Knowledge	State and local health departments collect information from physicians and clinics to monitor the health of communities Your physician determines all uses of information in your medical record Researchers always need to obtain permission from you to access your medical record Health insurance companies are prohibited from using your health information to deny your coverage Institutions may charge money to researchers to access health information You own your health information Your health information may be used in multiple studies without your permission or knowledge A person's permission is required for all health research Permission is NOT required for research using your health information if your identity (name, address) has been removed All forms of discrimination based on genetic information are prohibited by law	Study team; topics covered and general method of testing knowledge derived from: (Damschroder et al. 2007) (Bishop, Holmes and Kelley 2005) (Gross et al. 2012) (Siegrist and Cvetkovich 2000)
Expectations of benefit	What is your personal opinion? What effect do you think that health information sharing is likely to have on the quality of health care that you receive? What is your personal opinion? How likely do you think it is that health information sharing will improve the health of people living in the United States?	Study team (Ancker et al. 2013)
Identity theft	Has your personal information (social security number, credit or debit cards, bank account) been misused or stolen within the last five years? Is the misuse of your personal information still causing you problems? For example, are you still spending time clearing up credit accounts or your credit report? Or, have you	(*Identity Theft Survey Report* 2003)

	managed to resolve all of the problems caused by the misuse of your information?	
View of data sharing	Given what you know about information sharing among organizations in the health system, do you generally have a favorable or unfavorable opinion of it?	Study team
Broker trust: Health care	Health care providers care most about making money Health care providers are honest Health care providers have a good track record of using information responsibly Health care providers tell patients everything about possible dangers of different treatments Health care providers do not care about helping people like me	(LaVeist, Isaac and Williams 2009) (Hall et al. 2001) (Earle 2010)
Broker trust: Public health	Public health departments care most about making money I trust public health departments to use my health information responsibly Public health departments do not care about helping people like me Public health departments often collect or share information about people without telling them about it Public health departments have a good track record of using information responsibly	(LaVeist, Isaac and Williams 2009) (Earle 2010)
Broker trust: Research	University researchers [in my state] care most about making money I trust university researchers [in my state] to use my health information responsibly University researchers [in my state] unfairly select minorities for their most dangerous research studies University researchers [in my state] do not care about helping people like me People should be concerned about being deceived or misled by university researchers [in my state]	(LaVeist, Isaac and Williams 2009) (Mainous et al. 2006)
Policy environment	Access to electronic health information is adequately regulated As a whole, the health system is capable of self-monitoring policies that regulate information sharing As a whole, the health system would be improved if it were monitored by a “watchdog” organization Electronic health information is sufficiently protected by current law and regulation Health researchers are sufficiently accountable for conducting ethical research I am confident in the standards for keeping personal health information confidential	("Consumers and Health Information Technology: A National Survey ," 2010) (Poortinga and Pidgeon 2003) (Damschroder et al. 2007) (Vance, Elie-Dit-Cosaque and Straub 2008)

Personal autonomy	The health care system is easy to use If wanted to withdraw from a research study, I would know how It is easy to access my medical record online It is difficult to learn about my health from my doctor I could access my medical record if I wanted to I feel comfortable getting a second opinion when I am told something about my health If I wanted to know how my health information had been shared, I would be able to find out	(Hall et al. 2001)
Self-efficacy	I can manage to solve difficult problems if I try hard enough If someone opposes me, I can find the means and ways to get what I want I am confident that I could deal efficiently with unexpected events I can solve most problems if I invest the necessary effort	(Schwarzer and Jerusalem 1995)
Self-esteem	I take a positive attitude toward myself I wish I could have more respect for myself I feel that I have a number of good qualities All in all, I am inclined to feel that I am a failure	(Rosenberg et al. 1995)
Altruism	I always find ways to help others less fortunate than me The dignity and well-being of all should be the most important concern in any society One of the problems of today’s society is that people are often not kind enough to All people who are unable to provide for their own needs should be helped by others	(Feldman and Steenbergen 2001)
Optimism	I think the quality of life for the average person is getting worse, not better	(Smith et al. n.d.)
Generalized trust	Generally speaking, most people can be trusted	(Smith et al. n.d.)
Demographic questions	Basic demographics (See Appendix BXX), health, political spectrum, health information sources, community and civic engagement, financial transactions Affordable Care Act: Given what you know about the Affordable Care Act (Obamacare), do you generally have a favorable or unfavorable opinion of it?	GfK KnoweldgePanel©, ACA question adapted from (*Health Tracking Poll: Exploring the Public’s Views on the Affordable Care Act (ACA) | the Henry J. Kaiser Family Foundation* n.d.)

VALIDATING THE INSTRUMENT

Instrument validation underwent three stages of review and revision. First, three experts in survey methodology to informally reviewed the content and style of the questions. I discussed in-person, or over email, the strengths and weaknesses of the instrument generally, timing, and clear areas for improvement. Review of specific questions and engaging individuals as "experts" has limited utility given the inevitability of imperfect questions and that experts are not those ultimately taking the survey, however, they were able to identify areas for clear improvement in survey design (e.g., whether or not to include a "% complete" indicator, use of video in the introduction rather than long text) (Groves 2009). The survey was then put into the online survey platform Qualtrics. An additional 11 individuals – doctoral students, University of Michigan staff, and other colleagues – piloted the survey in August 2013. These individuals helped to identify technical problems as well as questions that required additional clarification.

In September 2013, I conducted an online Qualtrix survey of the general public (n=447) using Amazon's Mechanical Turk (MTurk) system. MTurk is an online Internet crowdsourcing marketplace that is increasingly being used for survey research and is a good source for efficiently gathering high-quality data (Buhrmester, Kwang and Gosling 2011). While not a random sample of the population, MTurk workers are demographically at least if not more representative of the U.S. population as compared to traditional subject pools taken from college undergraduate and Internet samples in terms of gender, race, age and education (Paolacci, Chandler and Ipeirotis 2010). As compared to typical Internet convenience samples, non-response error seems to be less of a concern in MTurk samples.

KEY PILOT SURVEY RESULTS

The descriptive statistics for the MTurk sample are displayed in Table B.2. The participants were 51% male and 89.3% were under the age of 55 years old. The majority were non-Hispanic white (76.1%) but all major racial/ethnic groups were represented in the sample. Approximately 45% of participants had 4-years or college or more. Most of the survey participants rented or lived with family rather than owning their own home (62.4% v. 37.6%). In terms of self-rated health, 40.7% reported being in excellent or very good health and only 13.0% reported being in fair or poor health. For general comparison, Table B.2 also includes the values for these demographic variables that were available from the U.S. Census 2012. While I did not perform formal statistical tests of comparison, it is clear to see that the MTurk sample is younger, less diverse, and more educated than the U.S. population.

The MTurk pilot test of the survey instrument provided informed key decision points for the final draft of the survey. First, the pilot enabled comparison of bi-polar versus uni-polar scales to capture opinions and beliefs. Second, it provided comparison of general versus specific framing for questions about trustees. Third, the validity of indices was evaluated using Chronbach's alpha and principal component analysis. This analysis also provided information on how to reduce the length and redundancy of the questionnaire.

Uni-polar versus bi-polar scales

Anticipating that most individuals are unaware of many data use practices and given the propensity for individuals to answer "Don't Know" or neutral to knowledge- or experience-based questions, an even-numbered (4-point) scale was used (Mondak 2001) . This provided the opportunity to evaluate intuitive responses among a non-expert public. Many surveys of trust have used Agree/Disagree Likert scales though, across studies, surveys are inconsistent with respect to the scales they use and it is unclear that any scales have been tested *per se*. To estimate and control for potential bias in participant responses due to the type of scale, I measured beliefs about privacy, medical deception, psychosocial factors, trust in information brokers, and System Trust using two scales. Half of the participants were asked questions on a four-point bi-polar Agree/Disagree scale (Strongly Agree, Somewhat Agree, Somewhat Disagree, and Strongly Disagree). The other half responded to these questions using a four-point uni-polar scale based on the prompt: "How true are the following statements." The value labels that followed were: Not at all true, Somewhat true, Fairly true, and Very true.

While there were some significant mean differences in the responses depending upon which scale was utilized, there was no difference in any of the regression relationships with

System Trust (results not shown). Uniformly, the four-point unipolar scale had slightly better statistical properties in terms of its centering in the four point scale, including less skewness and kurtosis than the bi-polar scale and was thus used in the final survey fielded by GfK.

Table B.2 Descriptive statistics of survey participants (N=447) and Univariate regression relationship with system trust

Demographic factor	*Sample (%)*	*US population[29] (%)*	*b(univariate)*
Sex			
Male	51.5%	49.0%	Ref
Female	48.5%	51.0%	-0.16
Age			
18-25	21.3%	20.0%	Ref
26-34	40.0%	20.0%	-0.28
35-54	27.9%	30.0%	-0.27
55-64	8.05%	10.0%	-0.20
65+	2.68%	10.0%	0.30
Race/ Ethnicity			
White Non-Hispanic	76.1%	63.2%	Ref
Black Non-Hispanic	7.16%	12.9%	0.37
Asian Non-Hispanic	8.05%	5.2%	- 0.06
Hispanic	4.70%	17.0%	- 0.12
Other	3.13%	27.2%	0.17
Education			
High School diploma or less	12.5%	43.2%	Ref
Some college or 2-year college	42.1%	28.6%	-0.48
4-year college	36.9%	18.4%	-0.16
Masters or above	8.50%	9.8%	-0.21
Owns home	37.6%		Ref
Does not own home	62.4%		-0.28
Self-rated health			-0.29**
Excellent	17.6%		
Very good	40.7%		
Good	28.6%		
Fair	11.4%		
Poor	1.57%		

**p<0.05

Question framing: General versus specific

To evaluate the effect on system trust (Y_{trust}) of asking about general versus specific framing for trusted brokers, survey respondents were asked either about trust in university researchers generally or about trust in University of Michigan researchers. A variable indicating which set of variables respondents were given was generated (i.e., researcher-type: University of Michigan, I=1 or Researchers generally, I=0). The trust in university researchers index (X_{res}) included all responses. The dependent variable system trust was then regressed on the trust in university researchers index, the researcher-type indicator variable, and the interaction of the two variables $I*X_{res}$. In cases where trust in university researchers did not have an effect on system trust, none of the regression coefficients would be significant; if trust in University of Michigan researchers were significant, the indicator and interaction term would be significant; if trust in university researchers generally were significant, then the trust in researchers variable and indicator would be significant; and if both were significant predictors of system trust, all three variables would be significant.

The MTurk data suggested that there was a statistically significant difference in trust of University of Michigan researchers versus university researchers generally, and that University of Michigan researchers seemed to be more trusted that university researchers generally. To further investigate the nuances of the difference between the two types of researchers, the GfK survey asked respondents either about university researchers generally versus university researchers “in my state.”

Validity of scales and indices

For the main outcomes of System Trust as well as four trustor characteristics (privacy, self-esteem, altruism, and self-efficacy), and trust in information brokers, Chronbach’s alpha was calculated to assess the internal validity of measures within a single construct (e.g., fidelity, competency, trust in health care providers). I then used data from the “How True” scale (n=243) to conduct principal component analysis to identify the most parsimonious set of survey questions that explained the most multivariate variation in that dimension. Specifically, examining the principal components that cumulatively explained at least 75% of the observed variation within a single construct, I examined which variables contributed most to these principal components (eigenvectors).

For example, the variables measuring fidelity, I had used eight questions. Five of the components explained 84% of the variation in those eight dimensions. Identifying the variables that contributed least to the five principal components, I eliminated two variables from the final questionnaire, while still retaining >80% of the variability in that dimension of system trust. After removal of the variable, new Chronbach's alpha and principal components were estimated to confirm the reliability of the group of variables. Table B.3 shows the Chronbach's alpha estimations for the four dimensions of trust with the original set of variables and with the more parsimonious set derived from the principal component analysis. Figures B.1-B.4 show the principal components and Eigenvectors for the variables in each of the four trust dimensions (fidelity, integrity, competency, and global trust). Figures B.1-B.4 also show the results of the PCA after variable removal. While the results of analysis from other indices are not shown, the same process was applied.

Table B.3 Chronbach's Alpha for system trust dimensions (Pilot Study)

	All variables		**Reduced set of variables**	
Trust Dimension	**No. of items**	**Chronbach's α**	**No. of items**	**Chronbach's α**
Fidelity	8	0.792	6	0.665
Competency	9	0.816	6	0.699
Integrity	5	0.818	4	0.753
Global trust	4	0.915	4	0.915

Indices were generated for four System Trust dimensions, trustor characteristics of privacy, belief in medical conspiracy, and psychosocial factors (self-esteem, altruism, and self-efficacy), as well as trust in brokers. The indices were calculated as the sum of the participant's responses to those survey questions divided by the number of questions. The measure of system trust used in this dissertation is equal to the sum of the four trust dimension indices.

FINAL IMPLEMENTATION

GfK, Inc. conducted the final implementation of the survey, including sampling and data collection. This firm was chosen because it is the only probability-based Internet panel in the U.S.; all the other panels are based on volunteers. Participants in GfK studies are randomly recruited by mail and telephone and provided with access to the Internet, avoiding many forms of self-selection bias. In Appendix C, I include GfK's report and documentation of their methodology. The final survey is included as Appendix D.

Figure B.1 Principle Component Analysis, Fidelity

FIDELTY					
All variables			**Reduced set of variables**		
Component	**Eigenvalue**	**Cumulative Proportion**	**Component**	**Eigenvalue**	**Cumulative Proportion**
Comp1	3.411	0.426	Comp1	2.293	0.382
Comp2	1.152	0.571	Comp2	1.145	0.573
Comp3	0.872	0.680	Comp3	0.865	0.717
Comp4	0.710	0.768	Comp4	0.679	0.830
Comp5	0.601	0.843	Comp5	0.590	0.929
Comp6	0.462	0.901	Comp6	0.428	1.000
Comp7	0.433	0.955			
Comp8	0.359	1.000			

Fidelity: All variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**	**Comp5**	**Comp6**	**Comp7**	**Comp8**
~~trust_fid1~~	~~0.420~~	~~0.084~~	~~-0.073~~	~~0.197~~	~~-0.128~~	~~-0.856~~	~~0.049~~	~~-0.145~~
trust_fid2	0.386	0.025	-0.060	-0.603	-0.472	0.063	0.209	0.463
trust_fid3	0.370	-0.450	0.180	0.087	0.223	0.008	-0.656	0.375
trust_fid4	0.349	-0.487	0.138	0.185	0.307	0.151	0.686	-0.023
trust_fid5	0.332	0.343	-0.053	0.676	-0.374	0.388	-0.010	0.149
trust_fid6	0.175	0.505	0.794	-0.138	0.254	0.001	0.033	-0.007
~~trust_fid7~~	~~0.442~~	~~-0.066~~	~~-0.059~~	~~-0.256~~	~~-0.118~~	~~0.291~~	~~-0.228~~	~~-0.762~~
trust_fid8	0.282	0.419	-0.551	-0.123	0.632	0.080	0.002	0.143

Fidelity: Reduced set of variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**	**Comp5**	**Comp6**
trust_fid2	0.468	0.042	-0.085	0.627	-0.613	0.065
trust_fid3	0.471	-0.448	0.138	-0.044	0.188	-0.722
trust_fid4	0.454	-0.487	0.089	-0.124	0.247	0.687
trust_fid5	0.417	0.336	-0.097	-0.737	-0.400	-0.014
trust_fid6	0.239	0.516	0.771	0.132	0.251	0.041
trust_fid8	0.349	0.426	-0.602	0.172	0.552	-0.018

Figure B.2 Principle Component Analysis, Integrity

INTEGRITY					
All variables			**Reduced set of variables**		
Component	**Eigenvalue**	**Cumulative Proportion**	**Component**	**Eigenvalue**	**Cumulative Proportion**
Comp1	2.964	0.593	Comp1	2.335	0.584
Comp2	0.728	0.738	Comp2	0.723	0.765
Comp3	0.499	0.838	Comp3	0.492	0.887
Comp4	0.455	0.929	Comp4	0.450	1.000
Comp5	0.355	1.000			

Integrity: All variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**	**Comp5**
trust_int2	0.4688	-0.004	-0.563	0.5113	0.4492
~~trust_int3~~	~~0.4952~~	~~-0.0449~~	~~-0.1466~~	~~0.1271~~	~~-0.8456~~
trust_int4	0.373	0.8359	0.3884	-0.0014	0.1065
trust_int5	0.4242	-0.53	0.6828	0.1943	0.1874
trust_int6	0.4647	-0.1353	-0.2108	-0.8274	0.1915

Integrity: Reduced set of variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**
trust_int2	0.533	-0.012	-0.571	0.624
trust_int4	0.438	0.819	0.370	-0.020
trust_int5	0.488	-0.552	0.654	0.170
trust_int6	0.535	-0.155	-0.331	-0.762

Figure B.3 Principle Component Analysis, Competency

COMPETENCY					
All variables			**Reduced set of variables**		
Component	**Eigenvalue**	**Cumulative Proportion**	**Component**	**Eigenvalue**	**Cumulative Proportion**
Comp1	3.708	0.412	Comp1	2.439	0.407
Comp2	1.637	0.594	Comp2	1.100	0.590
Comp3	1.036	0.709	Comp3	0.927	0.744
Comp4	0.737	0.791	Comp4	0.615	0.847
Comp5	0.565	0.854	Comp5	0.528	0.935
Comp6	0.533	0.913	Comp6	0.392	1.000
Comp7	0.337	0.950			
Comp8	0.271	0.980			
Comp9	0.177	1.000			

Competency: All variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**	**Comp5**	**Comp6**	**Comp7**	**Comp8**	**Comp9**
~~trust_comp1~~	~~0.4036~~	~~0.0174~~	~~-0.2979~~	~~-0.2727~~	~~-0.2123~~	~~0.4502~~	~~0.0134~~	~~0.6515~~	~~-0.036~~
trust_comp2	0.3504	-0.3958	-0.0319	0.1796	-0.2751	-0.2754	0.7285	-0.0579	0.0403
trust_comp3	0.4227	-0.0189	-0.2062	-0.3316	-0.2026	0.2508	-0.182	-0.7285	0.0279
~~trust_comp4~~	~~0.3617~~	~~-0.3451~~	~~0.0913~~	~~0.0305~~	~~-0.1459~~	~~-0.5484~~	~~-0.6161~~	~~0.1872~~	~~0.0643~~
trust_comp5	0.2976	-0.3007	-0.2467	0.4632	0.6857	0.2518	-0.0778	-0.0475	-0.061
trust_comp6	0.3137	0.5334	0.005	0.2843	-0.0893	-0.1834	0.0026	-0.0286	-0.7027
~~trust_comp7~~	~~0.2926~~	~~0.5653~~	~~-0.0313~~	~~0.3012~~	~~0.0048~~	~~-0.0885~~	~~0.0215~~	~~0.0166~~	~~0.7033~~
trust_comp8	0.1862	-0.1078	0.8135	0.2345	-0.1672	0.4526	-0.0633	-0.0079	0.0052
trust_comp9	0.3124	0.1322	0.3683	-0.5843	0.5575	-0.2194	0.2142	0.0552	-0.009

Competency: Reduced set of variables

Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**	**Comp5**	**Comp6**
trust_comp2	0.457	-0.447	0.101	0.001	-0.496	0.579
trust_comp3	0.509	0.000	-0.302	-0.195	-0.386	-0.680
trust_comp5	0.396	-0.542	-0.103	0.170	0.706	-0.108
trust_comp6	0.347	0.524	-0.374	0.644	0.032	0.223
trust_comp8	0.288	0.178	0.862	0.286	-0.006	-0.246
trust_comp9	0.415	0.447	0.072	-0.661	0.324	0.284

Figure B.4 Principle Component Analysis, Global Trust

GLOBAL TRUST					
All variables			Reduced set of variables (NO CHANGE)		
Component	Eigenvalue	Cumulative Proportion	Component	Eigenvalue	Cumulative Proportion
Comp1	3.203	0.801	Comp1	3.203	0.801
Comp2	0.356	0.890	Comp2	0.356	0.890
Comp3	0.293	0.963	Comp3	0.293	0.963
Comp4	0.147	1.000	Comp4	0.147	1.000

Global trust: All variables				
Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**
trust_glob1	0.5134	-0.015	-0.5683	0.6428
trust_glob2	0.5194	-0.2018	-0.3676	-0.7446
trust_glob3	0.4786	0.8043	0.3479	-0.0559
trust_glob4	0.4875	-0.5588	0.6487	0.1712
trust_glob1	0.5134	-0.015	-0.5683	0.6428
Global trust: Reduced set of variables				
Variable	**Comp1**	**Comp2**	**Comp3**	**Comp4**
trust_glob1	0.5134	-0.015	-0.5683	0.6428
trust_glob2	0.5194	-0.2018	-0.3676	-0.7446
trust_glob3	0.4786	0.8043	0.3479	-0.0559
trust_glob4	0.4875	-0.5588	0.6487	0.1712

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APPENDIX C

GfK Documentation

The GfK Group Project Report
for the
Public Trust in "Big (Health) Data" Projects Project

Submitted to:
Jodyn Platt, MPH
University of Michigan

Date submitted: March 10, 2014

GfK PROJECT DIRECTOR:	Poom Nukulkij
GfK ACCOUNT EXECUTIVE:	Wendy Mansfield
GfK PROJECT NUMBER:	310.111.00166.1

GfK Deliverable Authorization

Printed Name	Signature	Date	Title
J. Michael Dennis, Ph.D.	Mike Dennis	3/10/2014	Managing Director, Government and Academic Research

Table of Contents

Study Design & Documentation

Introduction

The GfK Group (GfK) conducted the Public Trust in "Big (Health) Data" Projects Project on behalf of the University of Michigan. Specifically, the study examined people's experiences and perceptions of how their health information (e.g., medical or insurance records, test samples, immunization history) is treated by medical professionals and organizations such as doctor's offices, hospitals, public health departments, insurance companies, and university researchers. The survey was conducted using sample from KnowledgePanel®.

Sample Definition, Data Collection Field Period & Survey Length

The study was conducted on KnowledgePanel®, a probability-based web panel designed to be representative of the United States. The sample for this survey consisted of non-institutionalized general population adults (18+ year olds) residing in the United States.

The survey was fielded in English in two stages: The Pretest and the Main. For each survey, GfK sampled randomly age eligible adults. Selected panel members for each survey received an email invitation to complete the survey and were asked to do so at their earliest convenience.

The Pretest survey was designed to test the functionality and length of the instrument in a small sample of approximately 25 panel members. The median completion time of the Pretest survey was 23 minutes. Upon completion, minor changes were made to the Pretest survey for the Main. The median completion time of the Main survey was 21 minutes.

Upon completion of the survey, members who joined KnowledgePanel and had existing PCs and internet access received the standard cash-equivalent post-survey incentive, an amount equivalent to $1 to $1.50 depending on when they joined the panel. Members who did not have PCs and internet access prior to joining KnowledgePanel received laptop PCs and internet access upon joining the panel. Because both surveys were longer than the 15 minute weekly survey experience that panel members receive, everyone who completed the Pretest and Main survey received an entry into the KnowledgePanel sweepstakes as compensation.

The final programmed Main survey instrument is shown in Appendix A.

The field periods, completion and qualification rates for the surveys are presented below.

	Field Start	Field End	N Fielded	N Completed	Completion Rate	N Qualified*	Qualification Rate

Pretest	1/22/2014	1/24/2014	63	25	39.7%	25	100%
Main	2/5/2014	2/24/2014	2,082	1,103	52.9%	1,062	96.3%

* Of the 1,103 Main interviews collected, 41 were cleaned out for constant refusals, leaving a total of 1,062 delivered in the final Main survey dataset.

Survey Cooperation Enhancements

Besides the standard measures taken by GfK to enhance survey cooperation, the following steps were also taken: Email reminders to non-responders were sent on day three of the field period.

Data File Deliverables and Descriptions

GfK prepared and delivered fully-formatted Stata datasets containing the survey and demographic data with the appropriate variable and value labels as described below.

The table below shows the final Pretest and Main survey files delivered:

Delivery Date	File Type	File Name	File Size	N Records	Inclusion of Standard Background Demographics
1/28/2014	Stata	Univ of Michigan_Public Trust_Pretest_Client.dta	104kB	25	Yes
3/6/2014	Stata	Univ of Michigan_Public Trust_main_Client.dta	2.6MB	1,062	Yes

In addition to the survey variables from the main interview, GfK's standard profile variables, a set of additional profile variables, and a series of data processing variables created by GfK were provided in the data file. The following table shows the name and description of all variables included in the Main survey dataset.

Name	Label
CaseID	Case ID
tm_start	Interview start time (GMT)
tm_finish	Interview finish time (GMT)
duration	Interview duration in minutes
weight	Post-Stratification weight
QFLAG	DATA ONLY: Qualification Flag
D2_1	Were you able to see and hear the video?

Trust_fid2	[Do not care about helping people like me] The organizations that have my health information and share it...
Trust_fid3	[Value my needs] The organizations that have my health information and share it...
Trust_fid4	[Would not knowingly do anything to harm me] The organizations that have my health information and share it...
Trust_fid6	[Care most about research] The organizations that have my health information and share it...
Trust_fid5	[Care most about what is convenient for its practitioners] The organizations that have my health information and share it...
Trust_fid8	[Care most about holding costs down] The organizations that have my health information and share it...
Trust_int2	[Try hard to be fair in dealing with others] The organizations that have my health information and share it...
Trust_int4	[Would try to hide a serious mistake] The organizations that have my health information and share it...
Trust_int5	[Tell me how my health information is used] The organizations that have my health information and share it...
Trust_int6	[Would never mislead me about how my health information is used] The organizations that have my health information and share it...
Trust_comp2	[Are very good at conducting research] The organizations that have my health information and share it...
Trust_comp3	[Have a good track record of using information responsibly] The organizations that have my health information and share it...
Trust_comp5	[Have specialized capabilities that can promote innovation and discovery in health and wellness] The organizations that have my health information and share it...
Trust_comp6	[Should be more careful than they are in sharing health information] The organizations that have my health information and share it...

Trust_comp8	[Are not good at their jobs] The organizations that have my health information and share it...
Trust_comp9	[Make a lot of mistakes] The organizations that have my health information and share it...
Trust_glob1	[Can be trusted to keep my health information secure] The organizations that have my health information and share it...
Trust_glob2	[Can be trusted to use my health information responsibly] The organizations that have my health information and share it...
Trust_glob3	[Think about what is best for me] The organizations that have my health information and share it...
Trust_glob4	[Act in an ethical manner] The organizations that have my health information and share it...
Trustorgs_hcp	[Health care providers] How much do you trust the following organizations to manage how your health information is shared within the health system?
Trustorgs_ins	[Insurance companies] How much do you trust the following organizations to manage how your health information is shared within the health system?
Trustorgs_res	[University researchers] How much do you trust the following organizations to manage how your health information is shared within the health system?
Trustorgs_hos	[Hospitals] How much do you trust the following organizations to manage how your health information is shared within the health system?
Trustorgs_phd	[Public health departments] How much do you trust the following organizations to manage how your health information is shared within the health system?
Viewshare	Given what you know about information sharing among organizations in the health system, do you generally have a favorable or unfavorable opinion of it?
Sharequality	What effect do you think that health information sharing is likely to have on the quality of health care that you receive?
Shareimprove	How likely do you think it is that health information sharing will improve the health of people living in the United States?
Decisions	How would you prefer to make decisions about how your health information is shared?

Q29_1	[Personal doctor] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_2	[Nurse] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_3	[Therapist] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_4	[University researcher] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_5	[Insurance agent] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_6	[Public health official] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_7	[Other (please specify)] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_8	[None of these] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_Refused	[Refused] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q29_Other	[Open end response] Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?
Q30_1	[My doctor or primary care provider] Which of the following would you feel comfortable assigning to make decisions about how your health information is

	shared?
Q30_2	[Other health care professional] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_3	[My spouse or partner] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_4	[Other family member] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_5	[My insurance company] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_6	[Public health department] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_7	[University researcher] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_8	[Other (please specify)] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_Refused	[Refused] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Q30_Other	[Open end response] Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?
Trust_hc2	[Health care providers care most about making money] For you, how true are the following statements about how health care providers share your health information?
Trust_hc3	[Health care providers are honest] For you, how true are the following statements about how health care providers share your health information?

Trust_hc4	[Health care providers have a good track record of using information responsibly] For you, how true are the following statements about how health care providers share your health information?
Trust_hc5	[Health care providers tell patients everything about possible dangers of different treatments] For you, how true are the following statements about how health care providers share your health information?
Trust_hc6	[Health care providers do not care about helping people like me] For you, how true are the following statements about how health care providers share your health information?
Trust_ph1	[Public health departments care most about making money] For you, how true are the following statements about how state and local public health departments share your health information?
Trust_ph2	[I trust public health departments to use my health information responsibly] For you, how true are the following statements about how state and local public health departments share your health information?
Trust_ph6	[Public health departments do not care about helping people like me] For you, how true are the following statements about how state and local public health departments share your health information?
Trust_ph7	[Public health departments often collect or share information about people without telling them about it] For you, how true are the following statements about how state and local public health departments share your health information?
Trust_ph4	[Public health departments have a good track record of using information responsibly] For you, how true are the following statements about how state and local public health departments share your health information?
dov_split	Random assignment for Trust_uni and Trust_um
Trust_uni1	[University researchers care most about making money] For you, how true are the following statements about how university researchers share your health information?

Trust_uni2	[I trust university researchers to use my health information responsibly] For you, how true are the following statements about how university researchers share your health information?
Trust_uni6	[University researchers unfairly select minorities for their most dangerous research studies] For you, how true are the following statements about how university researchers share your health information?
Trust_uni7	[University researchers do not care about helping people like me] For you, how true are the following statements about how university researchers share your health information?
Trust_uni8	[People should be concerned about being deceived or misled by university researchers] For you, how true are the following statements about how university researchers share your health information?
Trust_um2	[University researchers in my state care most about making money] For you, how true are the following statements about how researchers at the major research university in your state share your health information?
Trust_um4	[University researchers in my state have a good track record of using information responsibly] For you, how true are the following statements about how researchers at the major research university in your state share your health information?
Trust_um5	[University researchers in my state tell participants everything about possible dangers] For you, how true are the following statements about how researchers at the major research university in your state share your health information?
Trust_um6	[University researchers in my state unfairly select minorities for their most dangerous research studies] For you, how true are the following statements about how researchers at the major research university in your state share your health information?
Trust_um7	[University researchers in my state do not care about helping people like me] For you, how true are the following statements about how researchers at the major research university in your state share your

	health information?
Trust_um8	[People should be concerned about being deceived or misled by university researchers in my state] For you, how true are the following statements about how researchers at the major research university in your state share your health information?
Optimism	[I think the quality of life for the average person is getting worse, not better] For you, how true are the following statements?
Efficacy1	[I can manage to solve difficult problems if I try hard enough] For you, how true are the following statements?
Efficacy4	[If someone opposes me, I can find the means and ways to get what I want] For you, how true are the following statements?
Efficacy5	[I am confident that I could deal efficiently with unexpected events] For you, how true are the following statements?
Efficacy6	[I can solve most problems if I invest the necessary effort] For you, how true are the following statements?
Esteem2	[I take a positive attitude toward myself] For you, how true are the following statements?
Esteem3	[I wish I could have more respect for myself] For you, how true are the following statements?
Esteem4	[I feel that I have a number of good qualities] For you, how true are the following statements?
Esteem5	[All in all, I am inclined to feel that I am a failure] For you, how true are the following statements?
Trust_gen	[Generally speaking, most people can be trusted] For you, how true are the following statements?
Altruism1	[I always find ways to help others less fortunate than me] For you, how true are the following statements?
Altruism2	[The dignity and well-being of all should be the most important concern in any society] For you, how true are the following statements?
Altruism3	[One of the problems of todays society is that people are often not kind enough to others] For you, how true are the following statements?

Altruism4	[All people who are unable to provide for their own needs should be helped by others] For you, how true are the following statements?
Experience_pcp1	Do you have a primary care doctor?
Experience_pcp2	In the past year, how many times have you seen your primary care doctor?
Experience_pcp3	On balance, would you say your experience with your primary care doctor has been positive, neutral or negative?
Experience_phd1a_a	[Received public health services (e.g., WIC)] In the past year, have you done any of the following?
Experience_phd1a_b	[Had a child that received newborn screening (heel prick test)] In the past year, have you done any of the following?
Experience_phd1a_c	[Been to a Community Health Center] In the past year, have you done any of the following?
Experience_phd1a_d	[Contacted my state or local public health department for information (e.g., rabies exposure, environmental hazard)] In the past year, have you done any of the following?
Experience_phd1a_e	[Contacted my state or local public health department to report a health concern (e.g., food poisoning)] In the past year, have you done any of the following?
Experience_phd1a_f	[Been in contact with my state or local public health department for other reasons] In the past year, have you done any of the following?
Experience_phd1a_g	[None of these] In the past year, have you done any of the following?
Experience_phd1a_Refused	[Refused] In the past year, have you done any of the following?
Experience_phd2_a	[Received public health services (e.g., WIC)] On balance, how was your experience with each of the following?
Experience_phd2_b	[Had a child that received newborn screening (heel prick test)] On balance, how was your experience with each of the following?
Experience_phd2_c	[Been to a Community Health Center] On balance, how was your experience with each of the following?
Experience_phd2_d	[Contacted my state or local public health department for information (e.g., rabies exposure, environmental

	hazard)] On balance, how was your experience with each of the following?
Experience_phd2_e	[Contacted my state or local public health department to report a health concern (e.g., food poisoning)] On balance, how was your experience with each of the following?
Experience_phd2_f	[Been in contact with my state or local public health department for other reasons] On balance, how was your experience with each of the following?
Experience_ins1	Do you have health insurance coverage?
Experience_ins2	Have you had a gap in health insurance coverage in the past year?
Experience_ins3	On balance, would you say your experience with your health insurance company has been positive, neutral or negative?
Experience_ins4	[My health insurer could use my private health information against me] For you, how true are the following statements?
Experience_ins5	[My insurer could share personal information about me with people who have no business knowing it] For you, how true are the following statements?
Q37	Has your personal information (social security number, credit or debit cards, bank account) been misused or stolen within the last five years?
Q38	Is the misuse of your personal information still causing you problems?
Privacy1	[Keeping my electronic personal health information private is very important to me] For you, how true are the following statements?
Privacy3	[I believe the privacy of my electronic personal health information is seriously threatened] For you, how true are the following statements?
Privacy4	[I worry that private information about my health could be used against me] For you, how true are the following statements?
Privacy5	[There are some things I would not tell my healthcare providers because I can't trust them with the information] For you, how true are the following statements?

Privacy6	[Doctors could share embarrassing information about me with people who have no business knowing it] For you, how true are the following statements?
Pub_priv1	[Innovation from PRIVATE sector] For you, how true are the following statements?
Pub_priv2	[Innovation from FED GOVT] For you, how true are the following statements?
Pub_priv3	[Innovation from NIH] For you, how true are the following statements?
Pub_priv4	[Thanks to regular government quality control, I trust my doctor and his/her treatments'] For you, how true are the following statements?
Cons_med1	[The government does not tell the public the truth about the dangers of vaccines] For you, how true are the following statements?
Cons_med2	[Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS] For you, how true are the following statements?
Cons_med3	[The health care system experiments on patients without them knowing about the experiments] For you, how true are the following statements?
Cons_med4	[Health professionals don't tell you everything you need to know about medicines.] For you, how true are the following statements?
Aware_use1	[State and local health departments collect information from physicians and clinics to monitor the health of communities] What do you think of the following statements, true or false?
Aware_use2	[Your physician determines all uses of information in your medical record] What do you think of the following statements, true or false?
Aware_use3	[Researchers always need to obtain permission from you to access your medical record] What do you think of the following statements, true or false?
Aware_use4	[Health insurance companies are prohibited from using your health information to deny your coverage] What do you think of the following statements, true or false?
Aware_use5	[Institutions may charge money to researchers to access health information] What do you think of the following statements, true or false?

Aware_use6	[You own your health information] What do you think of the following statements, true or false?
Aware_use7	[Your health information may be used in multiple studies without your permission or knowledge] What do you think of the following statements, true or false?
Aware_use8	[A person's permission is required for all health research] What do you think of the following statements, true or false?
Aware_use9	[Permission is NOT required for research using your health information if your identity (name, address) has been removed'] What do you think of the following statements, true or false?
Aware_use10	[All forms of discrimination based on genetic information are prohibited by law] What do you think of the following statements, true or false?
Control_pol1	[Access to electronic health information is adequately regulated] For you, how true are the following statements?
Control_pol2	[As a whole, the health system is capable of self-monitoring policies that regulate information sharing] For you, how true are the following statements?
Control_pol3	[As a whole, the health system would be improved if it were monitored by a watchdog organization] For you, how true are the following statements?
Control_pol4	[Electronic health information is sufficiently protected by current law and regulation] For you, how true are the following statements?
Control_pol5	[Health researchers are sufficiently accountable for conducting ethical research] For you, how true are the following statements?
Control_pol6	[I am confident in the standards for keeping personal health information confidential] For you, how true are the following statements?
Control_pers1	[The health care system is easy to use] For you, how true are the following statements?
Control_pers2	[If wanted to withdraw from a research study, I would know how] For you, how true are the following statements?
Control_pers3	[It is easy to access my medical record online] For you, how true are the following statements?

Control_pers4	[It is difficult to learn about my health from my doctor] For you, how true are the following statements?
Control_pers5	[I could access my medical record if I wanted to] For you, how true are the following statements?
Control_pers6	[I feel comfortable getting a second opinion when I am told something about my health] For you, how true are the following statements?
Control_pers8	[If I wanted to know how my health information had been shared, I would be able to find out] For you, how true are the following statements?
Obamacare	Given what you know about the Affordable Care Act (Obamacare), do you generally have a favorable or unfavorable opinion of it?
Close	In thinking about health information sharing, do you have any comments you would like to share?
PPAGE	Age
ppagecat	Age - 7 Categories
ppagect4	Age - 4 Categories
PPEDUC	Education (Highest Degree Received)
PPEDUCAT	Education (Categorical)
PPETHM	Race / Ethnicity
PPGENDER	Gender
PPHHHEAD	Household Head
PPHHSIZE	Household Size
PPHOUSE	Housing Type
PPINCIMP	Household Income
PPMARIT	Marital Status
PPMSACAT	MSA Status
PPREG4	Region 4 - Based on State of Residence
ppreg9	Region 9 - Based on State of Residence
PPRENT	Ownership Status of Living Quarters
PPSTATEN	State
PPT01	Presence of Household Members - Children 0-1
PPT25	Presence of Household Members - Children 2-5
PPT612	Presence of Household Members - Children 6-12
PPT1317	Presence of Household Members - Children 13-17
PPT18OV	Presence of Household Members - Adults 18+
PPWORK	Current Employment Status
PPNET	HH Internet Access
pph10001	In general, would you say your physical health is. . .?

ppp10012	In general, do you think of yourself as...
pph20032	[Doctor] Have you used any of the following sources for health information?
pph20033	[Pharmacist] Have you used any of the following sources for health information?
pph20034	[Nurse, nurse practitioner, or physician's assistant] Have you used any of the following sources for health information?
pph20035	[Relative, friend, or co-worker] Have you used any of the following sources for health information?
pph20036	[Someone you know who has a particular medical condition] Have you used any of the following sources for health information?
pph20037	[Disease association or patient support group] Have you used any of the following sources for health information?
pph20038	[Educational forum at a local clinic, hospital, community center] Have you used any of the following sources for health information?
pph20039	[Pharmaceutical company] Have you used any of the following sources for health information?
pph20040	[Health insurance company] Have you used any of the following sources for health information?
pph20041	[Newspapers or magazines] Have you used any of the following sources for health information?
pph20042	[Television] Have you used any of the following sources for health information?
pph20043	[The Internet] Have you used any of the following sources for health information?
pph20107	[Social Media] Have you used any of the following sources for health information?
pph20108	[Health Care App] Have you used any of the following sources for health information?
pph20044	[Something else] Have you used any of the following sources for health information?
pph20045	[Have not looked for health information in the past 12 months] Have you used any of the following sources for health information?
ppp10086	[Attended a PTA/school group meeting] In the past 12 months, have you…

ppp10087	[Attended a community group meeting] In the past 12 months, have you…
ppp10088	[Donated blood] In the past 12 months, have you…
ppp10089	[Given money to a charity] In the past 12 months, have you…
ppp10090	[Worked for a charity or your church] In the past 12 months, have you…
ppp10091	[None of these] In the past 12 months, have you…
ppp10092	[Attended a political protest or rally] In the past 12 months, have you...
ppp10093	[Contacted a government official] In the past 12 months, have you...
ppp10094	[Volunteered or worked for a Presidential campaign] In the past 12 months, have you…
ppp10095	[Volunteered or worked for another political candidate, issue, or cause] In the past 12 months, have you…
ppp10096	[Given money to a Presidential campaign] In the past 12 months, have you…
ppp10097	[Given money to another political candidate, issue, or cause] In the past 12 months, have you…
ppp10098	[Worked with others in your community to solve a problem] In the past 12 months, have you…
ppp10099	[Served on a community board] In the past 12 months, have you…
ppp10100	[Written a letter to the editor] In the past 12 months, have you…
ppp10101	[Written a 'letter to the editor'] In the past 12 months, have you…
ppp10102	[Held a publicly elected office] In the past 12 months, have you…
ppp10103	[None of these] In the past 12 months, have you…
ppfs0538	[By telephone] Which of the following ways do you handle your financial transactions?
ppfs0539	[By mail] Which of the following ways do you handle your financial transactions?
ppfs0540	[Online, not smartphone] Which of the following ways do you handle your financial transactions?
ppfs0541	[Face-to-face] Which of the following ways do you handle your financial transactions?

ppfs0542	[None of the above] Which of the following ways do you handle your financial transactions?

Key Personnel

Key personnel on the study include:

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GfK Methodology

Introduction

The GfK Group (formerly Knowledge Networks) is passionate about research in marketing, media, health, and social policy. We collaborate closely with client teams throughout the research process, while applying rigor in everything we do. We specialize in innovative online research that consistently gives leaders in business, government, and academia the confidence to make important decisions. GfK delivers affordable, statistically valid online research through KnowledgePanel® and leverages a variety of other assets, such as world-class advanced analytics, an industry-leading physician panel, an innovative platform for measuring online ad effectiveness, and a research-ready behavioral database of frequent supermarket and drug store shoppers.

GfK has recruited the first online research panel that is representative of the entire U.S. population. Panel members are randomly recruited through probability-based sampling, and households are provided with access to the Internet and hardware if needed.

GfK recruits panel members by using address-based sampling methods [formerly GfK relied on random-digit dialing methods]. Once household members are recruited for the panel and assigned to a study sample, they are notified by email for survey taking, or panelists can visit their online member page for survey taking (instead of being contacted by telephone or postal mail). This allows surveys to be fielded very quickly and economically. In addition, this approach reduces the burden placed on respondents, since email notification is less intrusive than telephone calls, and most respondents find answering Web questionnaires more interesting and engaging than being questioned by a telephone interviewer. Furthermore, respondents have the freedom to choose what time of day to complete their assigned survey.

Documentation regarding KnowledgePanel sampling, data collection procedures, weighting, and IRB-bearing issues are available at the below online resources.

- http://www.knowledgenetworks.com/ganp/reviewer-info.html
- http://www.knowledgenetworks.com/knpanel/index.html
- http://www.knowledgenetworks.com/ganp/irbsupport/

The GfK Group

The GfK Group has a strong tradition in working with sophisticated academic, government, and commercial researchers to provide high quality research, samples, and analyses. The larger GfK Group offers the fundamental knowledge for governmental agencies, academics, industries, industry, retailers, services companies and the media need to provide exceptional quality in research to make effective decisions. It delivers a comprehensive range of information and consultancy services. GfK is one of the leading survey research organizations worldwide, operating in more than 100 countries with over 11,000 research staff. In 2010, the GfK Group's sales amounted to EUR 1.29 billion.

For further information, visit our website: www.gfk.com.

Panel Recruitment Methodology

When GfK began recruiting in 1999 as Knowledge Networks, the company established the first online research panel (now called KnowledgePanel®) based on probability sampling covering both the online and offline populations in the U.S. Panel members are recruited through national random samples, originally by telephone and now almost entirely by postal mail. Households are provided with access to the Internet and a netbook computer, if needed. Unlike Internet convenience panels, also known as "opt-in" panels, that include only individuals with Internet access who volunteer themselves for research, KnowledgePanel recruitment has used dual sample frames to construct the existing panel. As a result, panel members come from listed and unlisted telephone numbers, telephone and non-telephone households, and cell phone only households, as well as households with and without Internet access, which creates a representative sample. Only persons sampled through these probability-based techniques are eligible to participate on KnowledgePanel. Unless invited to do so as part of these national samples, no one on their own can volunteer to be on the panel.

RDD and ABS Sample Frames

KnowledgePanel members today may have been recruited by either the former random digit dialing (RDD) sampling or the current address-based sampling (ABS) methodologies. In this section, we will describe the RDD-based methodology; the ABS methodology is described in a separate section below. To offset attrition, multiple recruitment samples are fielded evenly throughout the calendar year.

KnowledgePanel recruitment methodology has used the quality standards established by selected RDD surveys conducted for the Federal government (such as the CDC-sponsored National Immunization Survey).

GfK employed list-assisted RDD sampling techniques based on a sample frame of the U.S. residential landline telephone universe. For purposes of efficiency, GfK excluded only those banks of telephone numbers (a bank consists of 100 numbers) that had fewer than two directory listings. Additionally, an oversampling was conducted within a stratum of telephone exchanges that had high concentrations of African American and Hispanic households based on

Census data. Note that recruitment sampling was done without replacement, thus numbers attempted in earlier waves were excluded from subsequent recruitment waves.

A telephone number for which a valid postal address can be matched occurred in about 67-70% of each sample at the time RDD was being used for recruitment. These address-matched cases were all mailed an advance letter informing them that they had been selected to participate in the KnowledgePanel. For purposes of efficiency, the numbers without a matched-physical address were under-sampled at a rate of 0.75 relative to the address-matched numbers. Both the minority oversampling mentioned above and this under-sampling of non-address households are accounted for appropriately in the in the panel’s weighting procedures.

Following the mailings, telephone recruitment by professional interviewers/recruiters began for all sampled telephone numbers. Telephone numbers for cases sent to recruiters were dialed for up to 90 days, with at least 14 dial attempts for cases in which no one answers the phone, and for numbers known to be associated with households. As occurs for most telephone interviews, for those participants who were hesitant or expressed a soft refusal, extensive refusal conversion was also performed. The recruitment interview, about 10 minutes in length, begins with informing the household member that the household had been selected to join KnowledgePanel. If the household did not have a computer and access to the Internet, the household member is told that, as reward for completing a short survey weekly, the household will be provided with free monthly Internet access and a laptop computer (in the past, the household was provided with a WebTV device, currently, netbooks are provided). All members of the household were enumerated, and some initial demographic and background information on prior computer and Internet use was collected.

Households that informed recruiters that they had a home computer and Internet access were asked to take GfK surveys using their own equipment and Internet connection. Incentive points per survey, redeemable for cash, are given to these “PC” (personal computer) respondents for completing their surveys. Panel members provided with a laptop computer and free Internet access do not participate in this per-survey points-incentive program. However, all panel members receive special incentive points for selected surveys to improve response rates and/or for all longer surveys as a modest compensation for the extra burden of their time and participation.

For those panel members receiving a laptop or netbook computer, each unit is custom-configured prior to shipment with individual email accounts so that it is ready for immediate use by the household. Most households are able to install the hardware without additional assistance, although GfK maintains a toll-free telephone line for technical support. The GfK Call Center contacts household members who do not respond to email and attempts to restore both contact and participation. PC panel members provide their own email addresses, and we send their weekly survey invitations to that email account.

All new panel members receive an initial survey for the dual purpose of welcoming them as new panel members and introducing them to how online survey questionnaires work. New panel members also complete a separate profile survey that collects essential demographic information such as gender, age, race, income, and education to create a personal member profile. This information can be used to determine eligibility for specific studies and is factored in for weighting purposes. Operationally, once the profile information is stored, it does not need to be re-collected as a part of each and every survey. This information is also updated annually for all panel members. Once new members have completed their profile surveys, they are designated as "active," and considered ready to be sampled for client studies. [Note: Parental or legal guardian consent is also collected for the purpose of conducting surveys with teenage panel members, aged 13 to17.]

Once a household is recruited and each household member's email address is either obtained or provided, panel members are sent survey invitations linked through a personalized email message (instead of by phone or postal mail). This contact method permits surveys to be fielded quickly and economically, and also facilitates longitudinal research. In addition, this approach reduces the burden placed on respondents, since email notification is less intrusive than telephone calls and allows research subjects to participate in research when it is convenient for them.

Address-Based Sampling (ABS) Methodology

When GfK first started panel recruitment in 1999, the conventional opinion among survey experts was that probability-based sampling could be carried out cost effectively through the use of national RDD samples. The RDD landline frame at the time allowed access to 96% of U.S. households. Due to the rapid rise of cell phone-only households, this is no longer the case. In 2009, GfK first used address-based sampling for panel recruitment to reflect the changes in society and telephony over recent years. Some of the factors that have reduced the long-term scientific viability of landline RDD sampling methodology are as follows: declining respondent cooperation in telephone surveys, the development of "do not call" lists to reduce unsolicited commercial calls, call screening with caller-ID devices, increased use of answering machines; dilution of the RDD sample frame as measured by the working telephone number rate (more fax lines and lines dedicated to other functions), and finally, the emergence of cell phone only households (CPOHH), since these households are typically excluded from the RDD frame because they have no landline telephone.

According to the Centers for Disease Control and Prevention (January-June 2011), approximately 33.6% of all U.S. households cannot be contacted through RDD sampling—31.6% as a result of CPOHH status and 2% because they have no telephone service whatsoever.

Among some age segments, the RDD non-coverage would be substantial: 47% of young adults, ages 18–24, reside in CPOHHs, 58% of those 25–29 years old, and 46% of those who are 30–34.[1]

After conducting an extensive pilot project in 2008, GfK made the decision to move to use an address-based sample (ABS) frame in response to the growing number of cell phone only households that are outside the RDD frame. Before conducting the ABS pilot, we also experimented with supplementing RDD samples with cell phone samples. However, this approach was found to be much more costly, and raised a number of other operational, data quality, and liability issues (for example, calling cell phones while respondents were driving).

The key advantage of the ABS sample frame is that it allows sampling of almost all U.S. households. An estimated 97% of households are "covered" in sampling nomenclature. Regardless of household telephone status, those households can be reached and contacted through postal mail. Second, the GfK ABS pilot project revealed several additional advantages beyond expected improvement in recruiting adults from CPOHHs:

- Improved sample representativeness for minority racial and ethnic groups
- Improved inclusion of lower educated and lower income households
- Exclusive inclusion of the fraction of CPOHHs that have neither a landline telephone nor Internet access (approximately four to six percent of US households).

ABS involves probability-based sampling of addresses from the U.S. Postal Service's Delivery Sequence File. Randomly sampled addresses are invited to join KnowledgePanel through a series of mailings and, in some cases, telephone follow-up calls to non-responders when a telephone number can be matched to the sampled address. Operationally, invited households have the option to join the panel by one of several ways:

- Completing and returning a paper form in a postage-paid envelope,
- Calling a toll-free hotline maintained by GfK, or
- Going to a dedicated GfK web site and completing an online recruitment form.

After initially accepting the invitation to join the panel, respondents are then "profiled" online by answering key demographic questions about themselves. This profile is maintained through the same procedures that were previously established for RDD-recruited panel members.

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[1] Blumberg SJ, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, January–June 2011. National Center for Health Statistics. December 2011. Available from: http://www.cdc.gov/nchs/nhis.htm.

Respondents not having an Internet connection are provided a laptop or netbook computer and free Internet service. Respondents sampled from the ABS frame, like those sampled from the RDD frame, are offered the same privacy terms and confidentiality protections that we have developed over the years and that have been reviewed and approved by dozens of Institutional Review Boards.

Large-scale ABS sampling for KnowledgePanel recruitment began in April 2009. As a result, sample coverage on KnowledgePanel of CPOHHs, young adults, and minority population groups has been increasing steadily since that time.

Because current KnowledgePanel members have been recruited over time from two different sample frames, RDD and ABS, GfK implemented several technical processes to merge samples sourced from these frames. KN's approach preserves the representative structure of the overall panel for the selection of individual client study samples. An advantage of mixing ABS frame panel members in any KnowledgePanel sample is a reduction in the variance of the weights. ABS-sourced samples tend to align more closely to the overall demographic distributions in the population, and thus the associated adjustment weights are somewhat more uniform and less varied. This variance reduction efficaciously attenuates the sample's design effect and confirms a real advantage for study samples drawn from KnowledgePanel with its dual frame construction.

Survey Sampling from KnowledgePanel

Once panel members are recruited and profiled, they become eligible for selection for client surveys. In most cases, the specific survey sample represents a simple random sample from the panel, for example, a general population survey. Customized stratified random sampling based on profile data can also be conducted as required by the study design.

The general sampling rule is to assign no more than one survey per week to individual members. Allowing for rare exceptions during some weeks, this limits a member's total assignments per month to four or six surveys. In certain cases, a survey sample calls for pre-screening, that is, members are drawn from a subsample of the panel (such as females, Republicans, grocery shoppers, etc.). In such cases, care is taken to ensure that all subsequent survey samples drawn that week are selected in such a way as to result in a sample that remains representative of the panel distributions.

Survey Administration

Once assigned to a survey, members receive a notification email letting them know there is a new survey available for them to take. This email notification contains a link that sends them to the survey questionnaire. No login name or password is required. The field period depends on the client's needs and can range anywhere from a few hours to several weeks.

After three days, automatic email reminders are sent to all non-responding panel members in the sample. If email reminders do not generate a sufficient response, an automated telephone reminder call can be initiated. The usual protocol is to wait at least three to four days after the email reminder before calling. To assist panel members with their survey taking, each individual has a personalized "home page" that lists all the surveys that were assigned to that member and have yet to be completed.

GfK also operates an ongoing modest incentive program to encourage participation and create member loyalty. Members can enter special raffles or can be entered into special sweepstakes with both cash rewards and other prizes to be won.

The typical survey commitment for panel members is one survey per week or four per month with duration of 10 to 15 minutes per survey. In the case of longer surveys, an additional incentive is typically provided.

Sample Weighting

The design for KnowledgePanel® recruitment begins as an equal probability sample with several enhancements incorporated to improve efficiency. Since any alteration in the selection process is a deviation from a pure equal probability sample design, statistical weighting adjustments are made to the data to offset known selection deviations. These adjustments are incorporated in the sample's **base weight**.

There are also several sources of survey error that are an inherent part of any survey process, such as non-coverage and non-response due to panel recruitment methods and to inevitable panel attrition. We address these sources of sampling and non-sampling error by using a **panel demographic post-stratification weight** as an additional adjustment.

All the above weighting is done before the study sample is drawn. Once a study sample is finalized (all data collected and a final data set made), a set of **study-specific post-stratification weights** are constructed so that the study data can be adjusted for the study's sample design and for survey non-response.

A description of these types of weights follows.

The Base Weight

In a KnowledgePanel sample there are eight known sources of deviation from an equal probability of selection design. These are corrected in the Base Weight and are described below.

1. Under-sampling of telephone numbers unmatched to a valid mailing address

   An address match is attempted on all the Random Digit Dial (RDD)-generated telephone numbers in the sample after the sample has been purged of business and institutional numbers and screened for non-working numbers. The success rate for address matching is in the 60 to 70% range. Households having telephone numbers with valid addresses are sent an advance letter, notifying them that they will be contacted by phone to join KnowledgePanel. The remaining, unmatched numbers are under-sampled as a recruitment efficiency strategy. Advance letters improve recruitment success rates. Under-sampling was suspended between July 2005 and April 2007. It was resumed in May 2007, using a sampling rate of 0.75. RDD recruitment ended in July 2009.

2. RDD selection proportional to the number of telephone landlines reaching the household

   As part of the field data collection operation, information is collected on the number of separate telephone landlines in each selected household. The probability of selecting a multiple-line household is down-weighted by the inverse of the number of landlines. RDD recruitment ended in July 2009.

3. Some minor oversampling of Chicago and Los Angeles in early pilot surveys

   Two pilot surveys carried out in Chicago and Los Angeles when the panel was initially being built increased the relative size of the sample from these two cities. With natural attrition and growth in size of the overall panel, that impact has declined over time. It remains part of our base adjustment weighting because of a small number of extant panel members from that initial panel cohort.

4. Early oversampling the four largest states and central region states

   At the time when the panel was first being built, survey demand in the four largest states (California, New York, Florida, and Texas) necessitated oversampling during January–October 2000. Similarly, the central region states were oversampled for a brief period of time. These now diminishing effects still remain in the panel membership and thus weighting adjustments are required for these geographic areas.

5. Under-sampling of households not covered by the MSN® TV service network

   Certain small areas of the U.S. are not serviced by MSN®, thus the MSN®TV units (Web-TV) distributed to non-Internet households prior to January 2009 could not be used for those recruited non-Internet households. Overall, the result is a small residual under-sample in those geographic areas which requires a minor weighting adjustment for those locations. Since January 2010, laptop computers with dial-up access are being distributed to non-Internet households, thus eliminating this under-coverage component.

6. RDD oversampling of African American and Hispanic telephone exchanges

   As of October 2001, oversampling of telephone exchanges with a higher density of minority households (specifically, African American and Hispanic) was implemented to increase panel membership for those groups. These exchanges were oversampled at approximately twice the rate of other exchanges. This oversampling is corrected in the base weight. RDD recruitment ended in July 2009.

7. Address-based sample phone match adjustment

   Toward the end of 2008, GfK began recruiting panel members by using an address-based sample (ABS) frame in addition to RDD recruitment. Once recruitment through the mail, including follow-up mailings to ABS non-respondents was completed, telephone recruitment was added. Non-responding ABS households where a landline telephone number could be matched to an address were subsequently called and telephone recruitment was initiated. This effort resulted in a slight overall disproportionate number of landline households being recruited in a given ABS sample. A base weight adjustment is applied to return the ABS recruitment panel members to the sample's correct national proportion of phone-match and no phone-match households.

8. ABS oversample stratification adjustment

   In late 2009 the ABS sample began incorporating a geographic stratification design. Census blocks with high density minority communities were oversampled (Stratum 1) and the balance of the census blocks (Stratum 2) were relatively under-sampled. The definition of high density and minority community and the relative proportion between strata differed among specific ABS samples. In 2010, the two strata were redefined to target high density Hispanic areas in Stratum 1 and all else in Stratum 2. In 2011, pre-identified ancillary information and not census block data were used to construct and target four strata as follows: Hispanic ages 18-24, Non-Hispanic ages 18-24, Hispanic ages 25+ and Non-Hispanic ages 25+. An appropriate base weight adjustment is applied to each relevant sample to correct for these stratified designs. Also in 2011, a separate sample targeting only persons ages 18-24 was fielded across the year also using predictive ancillary information. Combined with the four-stratum sample, the base weight adjustment compensates for cases from this unique young adult over-sample. In 2012, a similar four-stratum design is used but the ages have been changed to 18-29 and 30+ for both the Hispanic and Non-Hispanic strata.

The Panel Demographic Post-stratification Weight

To reduce the effects of any non-response and non-coverage bias in the overall panel membership (before the study sample is drawn), a post-stratification adjustment is applied based on demographic distributions from the most recent data from the Current Population Survey (CPS). The benchmark distributions for Internet access among the U.S. population of adults are obtained from the most recent special CPS supplemental survey measuring Internet access (October 2010).

The overall panel post-stratification variables include:

- Gender (Male/Female)
- Age (18–29, 30–44, 45–59, and 60+)
- Race/Hispanic ethnicity (White/Non-Hispanic, Black/Non-Hispanic, Other/Non-Hispanic, 2+ Races/Non-Hispanic, Hispanic)
- Education (Less than High School, High School, Some College, Bachelor and beyond)
- Census Region (Northeast, Midwest, South, West)
- Household income (under $10k, $10K to <$25k, $25K to <$50k, $50K to <$75k, $75K to <$100k, $100K+)
- Home ownership status (Own, Rent/Other)
- Metropolitan Area (Yes, No)
- Internet Access (Yes, No)

The Panel Demographic Post-stratification weight is applied prior to a probability proportional to size (PPS) selection of a study sample from KnowledgePanel. This weight is designed for sample selection purposes.

Study-Specific Post-Stratification Weights

Once the sample has been selected and fielded, and all the study data are collected and made final, a post-stratification weight is computed to adjust for any survey non-response as well as any non-coverage or under- and over-sampling resulting from the study-specific sample design.

Demographic and geographic distributions for the non-institutionalized, civilian population ages 18+ from the most recent CPS are used as benchmarks in this adjustment. The Spanish language proficiency distributions are from the most currently available Pew Hispanic Center Survey (2007).

The following benchmark distributions are utilized for this post-stratification adjustment **[THIS MAY BE DIFFERENT FOR DIFFERENT STUDIES]:**

- Gender (Male/Female) by Age (18–29, 30–44, 45–59, and 60+)
- Race/Hispanic ethnicity (White/Non-Hispanic, Black/Non-Hispanic, Other/Non-Hispanic, 2+ Races/Non-Hispanic, Hispanic)
- Education (Less than High School, High School, Some College, Bachelors and higher)
- Household Income (under <$25k, $25K to <$50k, $50K to <$75k, $75K+)
- Census Region (Northeast, Midwest, South, West) by Metropolitan Area (Yes, No)
- Internet Access (Yes, No)

Comparable distributions are calculated by using all completed cases from the field data (n = 1,062). Since study sample sizes are typically too small to accommodate a complete cross-tabulation of all the survey variables with the benchmark variables, a raking procedure is used for the post-stratification weighting adjustment. Using the base weight as the starting weight, this procedure adjusts the sample data back to the selected benchmark proportions. Through an iterative convergence process, the weighted sample data are optimally fitted to the marginal distributions.

After this final post-stratification adjustment, the distribution of the calculated weights are examined to identify and, if necessary, trim outliers at the extreme upper and lower tails of the weight distribution. The post-stratified and trimmed weights are then scaled to the sum of the total sample size of all eligible respondents (this is the WEIGHT variable in the final dataset).

APPENDIX D

Survey Instrument

December, 2013
- Study Details -

Note: This page may be removed when the questionnaire is sent to the client. However, it must exist in the version sent to OSD.

SNO	**S18373**
Survey Name	**Public Trust Survey**
Client Name	**University of Michigan**
Great Plains Project Number	**C526714577**
Project Director Name	**Poom Nukulkij**
Team/Area Name	**G&A**

Samvar (Include name, type and response values. "None" means none. Blank means standard demos. This must match SurveyMan.)	
Specified Pre-coding Required	
Timing Template Required (y/n)	**Enabled by default**
Multi-Media	**Video**

Important: **Do not change Question numbers after Version 1; to add a new question, use alpha characters (e.g., 3a, 3b, 3c.) Changing question numbers will cause delays and potentially errors in the program.**

Public Trust Survey
December, 2013
- Questionnaire -

[DISPLAY]
D1. Welcome!

Thank you for taking this survey about health information sharing. Before you start answering questions, we would like you to watch a two-minute video. In total, we expect the survey to take about 20 minutes to complete.

Please answer all the questions; if you are unsure about how to respond, that's OK. Answer the best you can.

We would also appreciate it if you took notes as you go along. There will be an opportunity at the end to tell us what you think in general about health information sharing.

Click on the "Next" button at the bottom of every screen to advance to the next page.

[DISPLAY]
D2. When you have finished watching the video, scroll down and click "Next" to begin answering questions.

[INSERT VIDEO]

[SP; PROMPT ONCE]
D2_1. Were you able to see and hear the video?

Yes 1
No 2

[SHOW ONLY IF D2_1=1]
[DISPLAY; HAVE THE WORD "HERE" LINKED TO AN HTML COPY OF THE TRANSCRIPT TEXT WITH A "CONTINUE" BUTTON AT THE BOTTOM OF THE SCREEN]
Click here if you would like to view a copy of the transcript.

[IF D2_1=2 OR REFUSED AFTER PROMPT]
[DISPLAY]
D3. *Survey*
Introductory Video Transcript

Most of us have gone to the doctor’s office at some point in our lives. We fill out some forms, we have our blood pressure checked, and maybe we get immunized, diagnosed, tested, treated, or referred to somebody else. In this process we meet with people, like nurses or doctors, surgeons or therapists, who are expected to respect our privacy.

You may or may not be aware of the extent to which your health information is shared. Your treatment at a hospital might call for a team approach requiring dozens of health professionals to look at your chart. Your public health department might alert you when your child needs a booster shot because they keep a record of the immunizations she’s had at her pediatrician’s office. Your insurance company may track your progress in physical therapy to find out whether it’s helping.

In the age of the Internet, health information can be shared quickly and broadly. Increasingly, entire networks of people, including health care professionals, public health officials, insurers, or researchers, are able to access your health information.

There are laws designed to protect your privacy, but information about you can still be shared. Some health information sharing is permitted only after personal “identifiers,” like your name and address, are removed. For example, your doctor may report the number of flu cases she sees during flu season, without sharing the names of people who have had the flu. You may or may not know that even biospecimens, like blood left over from a cholesterol test or tissues left over from surgery, might be set aside to be used for research.

You are part of a large health system that includes doctor’s offices, hospitals, public health departments, insurance companies and researchers.

We’re interested in hearing what you think about health information sharing. *Thank you for taking the time to tell us.*

[DISPLAY]
D4. As you take this survey, please keep in mind that “health information” can come in many forms, including records from your doctor’s office or hospital stay, information derived from blood test samples, insurance records, your immunization history, or information you provide when you participate in a research study.

When we ask about “organizations” we mean the organizations and groups such as doctor’s offices, hospitals, public health departments, insurance companies, and university researchers, which work together as a health system.

[GRID, SP ACROSS]

[RANDOMIZE]

[DISPLAY; HAVE THE WORD "HERE" LINKED TO D5 WITH A "CONTINUE" BUTTON AT THE BOTTOM OF THE SCREEN TO GET BACK TO FID2_8]

fid2_8. Please click here to review the definitions of "health information" and "organizations."

To begin, we'd like to learn your personal opinions.

For you, how true are the following statements about the organizations that have your health information and share it? (If you are unsure, please make your best guess.)

The organizations that have my health information and share it...

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

fid2. Do not care about helping people like me
fid3. Value my needs
fid4. Would not knowingly do anything to harm me
fid6. Care most about research
fid5. Care most about what is convenient for its practitioners
fid8. Care most about holding costs down

[IF FID2_8="HERE" OR INT2_INT6="HERE" OR COMP2_COMP8="HERE" OR COMP9_GLOB4="HERE" DISPLAY]

D5. Remember that "health information" can come in many forms, including records from your doctor's office or hospital stay, information derived from blood test samples, insurance records, your immunization history, or information you provide when you participate in a research study.

When we ask about "organizations" we mean the organizations and groups such as doctor's offices, hospitals, public health departments, insurance companies, and university researchers, which work together as a health system.

[GRID, SP ACROSS]

[RANDOMIZE]

[DISPLAY; HAVE THE WORD "HERE" LINKED TO D5 WITH A "CONTINUE" BUTTON AT THE BOTTOM OF THE SCREEN TO GET BACK TO INT2_INT6]

int2_int6. Please click here to review the definitions of "health information" and "organizations."

For you, how true are the following statements about the organizations that have your health information and share it? (If you are unsure, please make your best guess.)

The organizations that have my health information and share it...

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

int2. Try hard to be fair in dealing with others
int4. Would try to hide a serious mistake
int5. Tell me how my health information is used
int6. Would never mislead me about how my health information is used

[GRID, SP ACROSS]
[RANDOMIZE]
[DISPLAY; HAVE THE WORD "HERE" LINKED TO D5 WITH A "CONTINUE" BUTTON AT THE BOTTOM OF THE SCREEN TO GET BACK TO COMP2_COMP8]

comp2_comp8. Please click here to review the definitions of "health information" and "organizations."

For you, how true are the following statements about the organizations that have your health information and share it? (If you are unsure, please make your best guess.)

The organizations that have my health information and share it...

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

comp2. Are very good at conducting research
comp3. Have a good track record of using information responsibly
comp5. Have specialized capabilities that can promote innovation and discovery in health and wellness
comp6. Should be more careful than they are in sharing health information
comp8. Are not good at their jobs

[GRID, SP ACROSS]

[RANDOMIZE]

[DISPLAY; HAVE THE WORD "HERE" LINKED TO D5 WITH A "CONTINUE" BUTTON AT THE BOTTOM OF THE SCREEN TO GET BACK TO COMP2_COMP8]

comp9_glob4. Please click here to review the definitions of "health information" and "organizations."

For you, how true are the following statements about the organizations that have your health information and share it? (If you are unsure, please make your best guess.)

The organizations that have my health information and share it...

Not at all	Somewhat well	Fairly well	Very well
1	2	3	4

comp9. Make a lot of mistakes
glob1. Can be trusted to keep my health information secure
glob2. Can be trusted to use my health information responsibly
glob3. Think about what is best for me
glob4. Act in an ethical manner

[GRID, SP ACROSS]

[RANDOMIZE]

Trustorgs. How much do you trust the following organizations to manage how your health information is shared within the health system?

Do not trust at all	Somewhat trust	Fairly trust	Trust a lot
1	2	3	4

hcp. Health care providers
ins. Insurance companies
res. University researchers
hos. Hospitals
phd. Public health departments

[SP]

Viewshare. Given what you know about information sharing among organizations in the health system, do you generally have a favorable or unfavorable opinion of it?

Very favorable	1
Somewhat favorable	2
Somewhat unfavorable	3
Very unfavorable	4

[SP]

sharequality. What is your personal opinion? What effect do you think that health information sharing is likely to have on the quality of health care that you receive?

Health information sharing is likely to *decrease* the quality of my health care	1
Health information sharing is likely to have *no effect* on the quality of my health care	2
Health information sharing is likely to benefit somewhat the quality of my health care	3
Health information sharing is likely to *improve* the quality of my health care a lot	4

[SP]

Shareimprove. What is your personal opinion? How likely do you think it is that health information sharing will improve the health of people living in the United States?

Not likely to improve the health of people living in the United States	1
Somewhat likely to improve the health of people living in the United States	2
Fairly likely to improve the health of people living in the United States	3
Very likely to improve the health of people living in the United States	4

[SP]

decisions. How would you prefer to make decisions about how your health information is shared?

I would like to be the only person making decisions about how my health information is shared 1
I would like to consult with a health care professional to help make decisions about how my health information is shared 2
I would prefer to delegate decision making about how my health information is shared to someone I trust 3
I have no opinion about how decisions are made regarding my health information..........4

[IF DECISIONS= 2]
[MP]

Q29. Which health care professionals would you feel comfortable consulting to help you make decisions about how your health information is shared?

1. Personal doctor
2. Nurse
3. Therapist
4. University researcher
5. Insurance agent
6. Public health official
7. Other (please specify)**[TEXTBOX]**
8. None of these**[sp]**

[IF DECISIONS= 3]
[MP]

Q30. Which of the following would you feel comfortable assigning to make decisions about how your health information is shared?

1. My doctor or primary care provider
2. Other health care professional
3. My spouse or partner
4. Other family member
5. My insurance company
6. Public health department
7. University researcher
8. Other (please specify)**[TEXTBOX]**

[GRID, SP ACROSS]

[RANDOMIZE]

hc4_hc6. Health care providers are people such as doctors and nurses who provide medical treatment.

For you, how true are the following statements about how *health care providers* share your health information?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

hc2. Health care providers care most about making money
hc3. Health care providers are honest
hc4. Health care providers have a good track record of using information responsibly
hc5. Health care providers tell patients everything about possible dangers of different treatments
hc6. Health care providers do not care about helping people like me

[GRID, SP ACROSS]

[RANDOMIZE]

ph1_ph7. For you, how true are the following statements about how *state and local public health departments* share your health information?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

ph1. Public health departments care most about making money
ph2. I trust public health departments to use my health information responsibly
ph6. Public health departments do not care about helping people like me
ph7. Public health departments often collect or share information about people without telling them about it
ph4. Public health departments have a good track record of using information responsibly

[PROGRAMMING NOTE: PLEASE RANDOMLY ASSIGN RESPONDENT INTO 2 DOV_SPLIT GROUP, DOV_SPLIT=1 WILL ANSWER UNI1_UNI8 QUESTIONS, AND DOV_SPLIT=2 WILL ANSWER UM2_UM8 QUESTIONS]

dov_split **[SP]**

uni1_uni8	1
um2_um8	2

[IF DOV_SPLIT=1]
[GRID, SP ACROSS]

[RANDOMIZE]

uni1_uni8. For you, how true are the following statements about how ***university researchers*** share your health information?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

uni1. University researchers care most about making money
uni2. I trust university researchers to use my health information responsibly
uni6. University researchers unfairly select minorities for their most dangerous research studies
uni7. University researchers do not care about helping people like me
uni8. People should be concerned about being deceived or misled by university researchers

[IF DOV_SPLIT=2]
[GRID, SP ACROSS]

[RANDOMIZE]

um2_um8. For you, how true are the following statements about how ***researchers at the major research university in your state*** share your health information?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

UM2. University researchers in my state care most about making money
UM4. University researchers in my state have a good track record of using information responsibly
UM5. University researchers in my state tell participants everything about possible dangers
UM6. University researchers in my state unfairly select minorities for their most dangerous research studies
UM7. University researchers in my state do not care about helping people like me
UM8. People should be concerned about being deceived or misled by university researchers in my state

[GRID, SP ACROSS]

[RANDOMIZE]

Opt_est5. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true

1	2	3	4

Optimism.	I think the quality of life for the average person is getting worse, not better
efficacy1.	I can manage to solve difficult problems if I try hard enough
efficacy4.	If someone opposes me, I can find the means and ways to get what I want
efficacy5.	I am confident that I could deal efficiently with unexpected events
efficacy6.	I can solve most problems if I invest the necessary effort
esteem2.	I take a positive attitude toward myself
esteem3.	I wish I could have more respect for myself
esteem4.	I feel that I have a number of good qualities
esteem5.	All in all, I am inclined to feel that I am a failure

[GRID, SP ACROSS]
[RANDOMIZE]
Trust_alt4. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

trust_gen.	Generally speaking, most people can be trusted
altruism1.	I always find ways to help others less fortunate than me
altruism2.	The dignity and well-being of all should be the most important concern in any society
altruism3.	One of the problems of today’s society is that people are often not kind enough to others
altruism4.	All people who are unable to provide for their own needs should be helped by others

[SP]
experience_PCP1. Do you have a primary care doctor?

Yes 1
No..2
Not sure 3

[IF EXPERIENCE_PCP1=1]

[SP]

experience_pcp2. In the past year, how many times have you seen your primary care doctor?

Not at all	1
Once	2
Twice	3
Three times or more	4

[IF EXPERIENCE_PCP1=1]
[SP]

experience_pcp3. On balance, would you say your experience with your primary care doctor has been positive, neutral or negative?

Positive	1
Neutral	2
Negative	3

[MP]

experience_phd1a. In the past year, have you done any of the following?

a. Received public health services (e.g., WIC)
b. Had a child that received newborn screening (heel prick test)
c. Been to a Community Health Center
d. Contacted my state or local public health department for information (e.g., rabies exposure, environmental hazard)
e. Contacted my state or local public health department to report a health concern (e.g., food poisoning)
f. Been in contact with my state or local public health department for other reasons
g. None of these**[SP]**

[IF EXPERIENCE_PHD1A_A=1 OR EXPERIENCE_PHD1A_B=1 OR EXPERIENCE_PHD1A_C=1 OR EXPERIENCE_PHD1A_D=1 OR EXPERIENCE_PHD1A_E=1 OR EXPERIENCE_PHD1A_F=1]
[GRID, SP ACROSS]

experience_phd2. On balance, how was your experience with each of the following?

Positive	Neutral	Negative
1	2	3

a. **[IF EXPERIENCE_PHD1A_A=1]**Received public health services (e.g., WIC)
b. **[IF EXPERIENCE_PHD1A_B=1]**Had a child that received newborn screening (heel prick test)

c. **[IF EXPERIENCE_PHD1A_C=1]**Been to a Community Health Center
d. **[IF EXPERIENCE_PHD1A_D=1]**Contacted my state or local public health department for information (e.g., rabies exposure, environmental hazard)
e. **[IF EXPERIENCE_PHD1A_E=1]**Contacted my state or local public health department to report a health concern (e.g., food poisoning)
f. **[IF EXPERIENCE_PHD1A_F=1]**Been in contact with my state or local public health department for other reasons

[SP]
experience_ins1. Do you have health insurance coverage?

Yes	1
No	2
Not sure	3

[IF EXPERIENCE_INS1=1]
[SP]
experience_ins2. Have you had a gap in health insurance coverage in the past year?

Yes	1
No	2
Not sure	3

[IF EXPERIENCE_INS1=1]
[SP]
experience_ins3. On balance, would you say your experience with your health insurance company has been positive, neutral or negative?

Positive	1
Neutral	2
Negative	3

[IF EXPERIENCE_INS1=1]
[GRID, SP ACROSS]
[RANDOMIZE]

experience. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

ins4. My health insurer could use my private health information against me

ins5. My insurer could share personal information about me with people who have no business knowing it

[SP]

Q37. Has your personal information (social security number, credit or debit cards, bank account) been misused or stolen within the last five years?

Yes 1
No...2
Not sure 3

[IF Q37=1]
[SP]

Q38. Is the misuse of your personal information still causing you problems? For example, are you still spending time clearing up credit accounts or your credit report? Or, have you managed to resolve all of the problems caused by the misuse of your information?

Still experiencing problems 1
All problems are resolved..................................2
Did not experience any problems......................3

[GRID, SP ACROSS]

[RANDOMIZE]

Privacy. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

1. Keeping my electronic personal health information private is very important to me

3. I believe the privacy of my electronic personal health information is seriously threatened

4. I worry that private information about my health could be used against me

5. There are some things I would not tell my healthcare providers because I can’t trust them with the information

6. Doctors could share embarrassing information about me with people who have no business knowing it

[GRID, SP ACROSS]

[RANDOMIZE]

pub. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

priv1. Most of the innovation that has occurred in health care has been from research in the private sector

priv2. Most of the innovation that has occurred in health care has been from research funded by the federal government

priv3. Most of the innovation that has occurred in health care has been from research funded by that National Institutes of Health (NIH)

priv4. Thanks to regular government quality control, I trust my doctor and his/her treatments

[GRID, SP ACROSS]

[RANDOMIZE]

cons. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

med1. The government does not tell the public the truth about the dangers of vaccines

med2. Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS

med3. The health care system experiments on patients without them knowing about the experiments

med4. Health professionals don’t tell you everything you need to know about medicines.

[GRID, SP ACROSS]

[RANDOMIZE]

aware. What do you think of the following statements, true or false?

True	False
1	2

use1. State and local health departments collect information from physicians and clinics to monitor the health of communities

use2. Your physician determines all uses of information in your medical record

use3. Researchers always need to obtain permission from you to access your medical record

use4. Health insurance companies are prohibited from using your health information to deny your coverage
use5. Institutions may charge money to researchers to access health information
use6. You own your health information
use7. Your health information may be used in multiple studies without your permission or knowledge
use8. A person's permission is required for all health research
use9. Permission is NOT required for research using your health information if your identity (name, address) has been removed
use10. All forms of discrimination based on genetic information are prohibited by law

[GRID, SP ACROSS]

[RANDOMIZE]

pol1_pol6. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

pol1. Access to electronic health information is adequately regulated
pol2. As a whole, the health system is capable of self-monitoring policies that regulate information sharing
pol3. As a whole, the health system would be improved if it were monitored by a "watchdog" organization
pol4. Electronic health information is sufficiently protected by current law and regulation
pol5. Health researchers are sufficiently accountable for conducting ethical research
pol6. I am confident in the standards for keeping personal health information confidential

[GRID, SP ACROSS]

[RANDOMIZE]

pers1_pers8. For you, how true are the following statements?

Not true	Somewhat true	Fairly true	Very true
1	2	3	4

pers1. The health care system is easy to use
pers2. If wanted to withdraw from a research study, I would know how

pers3. It is easy to access my medical record online
pers4. It is difficult to learn about my health from my doctor
pers5. I could access my medical record if I wanted to
pers6. I feel comfortable getting a second opinion when I am told something about my health
pers8. If I wanted to know how my health information had been shared, I would be able to find out

[SP]

obamacare. Given what you know about the Affordable Care Act (Obamacare), do you generally have a favorable or unfavorable opinion of it?

Very favorable	1
Somewhat favorable	2
Somewhat unfavorable	3
Very unfavorable	4

[LARGE TEXT BOX]

Close. In thinking about health information sharing, do you have any comments you would like to share?