A CRISPR View of Human Genome Editing in the 21st Century

by

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Dedication

This dissertation is dedicated to the memory of my father, William John Thiel (1941 – 2000), a promise that I have never forgotten, but wasn’t sure I would ever realize. That he never got to meet his grandchildren is a tragedy. Somewhat less tragic, but quite real for me though, is that he couldn’t be here to help see me through this. I’m pretty sure Bill would have enjoyed seeing me complete this damn thing.

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Abstract

Scientists, policymakers, and bioethicists agree that the public should weigh in on the ethical issues raised by genomics and biotechnology. But it’s not always clear what role non-experts can play in these debates, or how scholars should measure public opinion about complex scientific issues. The gene-editing technology CRISPR-cas9 offers an excellent case to consider how the public is invited into and excluded from debates about promising and controversial new technologies. This dissertation advances our understanding of social and ethical dimensions of gene-editing by asking how the news media present CRISPR to the public, analyzing the role laid out for the public in media discourse about CRISPR, and investigating U.S. public attitudes about gene-editing using data from a national survey.

Chapter 1 analyzes 304 articles from 8 ideologically diverse U.S. news sources to learn how CRISPR was framed in the news media in its early years (2012-2018). Most CRISPR coverage adopted a master frame I call “cautious optimism” consistently weighing both risks and benefits, but some veered into “boosterism,” framing that hypes possible benefits but ignores risks. Critical coverage of CRISPR was discernible though it was marginalized and under-represented. In general, coverage of CRISPR emphasized progress, profits and promises of cures, but generally steered clear of earlier decades’ worst tendencies (naïve genetic determinism, discrimination and perfectionism).

Chapter 2 uses the news corpus to investigate the role of the public in the media narratives of CRISPR. Drawing on theories of expertise and lay publics developed by scholars in

Science and Technology Studies (STS) and the Sociology of Scientific Knowledge, I argue that in the case of CRISPR, the hope for meaningful, policy-informing public engagement may be trapped in a temporal paradox wherein the time for the public to participate is always too soon, until it turns out to be too late. What appears as an earnest desire on the part of expert communities for the public to join in dialogue, discussion, or even consensus building about the future of CRISPR turns out to be illusory. A push and pull of inclusion and exclusion leaves the public no clear entry point to the discussion. Further, while some experts used public relations tactics to manage public opinion, others engaged in protective boundary work that had the effect of crowding publics out. The net effect of these dynamics is a public largely absent from the discourse and debates over gene-editing.

Chapter 3 draws on nationally representative survey data to understand U.S. lay public perspectives on the development of gene-editing. Prior survey research about gene-editing asks how the technology may impact the respondent individually. To expand on this framing, we ask about respondents' hopes and fears about the future of gene-editing for themselves, their families and society. We also go beyond asking simply whether respondents favor gene-editing by inquiring about their willingness to spend public money and contribute their own biospecimens to support gene-editing research. We find that public opinion is still somewhat underdeveloped, with most respondents neither strongly optimistic nor fearful and that trust in the healthcare system is an important predictor of attitudes about gene-editing.

With the gene-editing revolution underway, the future of media framing and public inclusion in shaping the direction of this technology is uncertain, but this research identifies pitfalls to avoid and insights to build on to improve engagement moving forward.

Introduction

"CRISPR can in theory cure any disease caused by one or a few mutations: not just sickle-cell but Huntington's disease, cystic fibrosis, muscular dystrophy or color blindness. We could cure AIDS patients by editing out the HIV viruses that hide in their DNA. By editing early embryos, we could reduce the incidence of genetically influenced diseases such as Alzheimer's and some types of breast cancer. We could make cosmetic changes in our children, altering their hair and eye color or even, in principle, their height, weight, body shape and intelligence. None of this has been tried in people, but since CRISPR works well in human cell cultures, it seems just a matter of time."
(Washington Post, 7/2/2017)

"I am absolutely confident that with CRISPR we are going to accelerate the rate at which we develop treatments that can control cancer, and cure some," said Phillip Sharp, an MIT biologist and Nobel laureate. "It's totally cool." (Washington Post, 5/4/2016)

"…people have to be concerned about not over-hyping. Don't over-promise, don't over-hype, don't lead people to think that cures are just around the corner. We can't underestimate — it's going to be a real struggle scientifically to make the kind of progress that's been stalled for so many years." (Huffington Post, 12/14/2015)

"I think that despite all the hype over gene editing, everybody but a few science fiction writers has underestimated the magnitude of the revolution they are ushering in," said Val Giddings, a senior fellow at the Information Technology and Innovation Foundation, a Washington-based think tank. "They will transform dramatically every aspect of the relationship between humans and our environment in overwhelmingly positive ways." (Washington Post, 8/12/2018)

"Most of the public does not appreciate what is coming."
Jennifer Doudna, UC Berkeley, CRISPR-cas9 Pioneer (Regalado, 2015)

Public understanding and acceptance of new biotechnologies is rarely a straightforward matter. And yet to the extent that the passages cited above are correct about the future of gene-editing, we face an urgent need for public deliberation about ethical and societal implications of this technology. At the same time, the passages above also illustrate the tendency (and concern) towards over-hyping new technologies. The conflicting messages and sentiments embedded in these passages, the prospect of radically altering life and evolution on the one hand, paired with warnings about the risks of over-hyping the promise of this revolution on the other, suggest that Jennifer Doudna could be right in a literal sense...the public has no idea what to think about this revolutionary technology. The way experts and media figures talk about tools like CRISPR has important consequences for public understanding, public opinion, public policy, regulation and the kind of science we pursue. The gene-editing technology CRISPR-cas9 offers an excellent case to consider how promising and controversial new technologies are presented to the public through media and how the public understands them. The CRISPR-cas9 system was first identified in 2012 as a gene-editing platform that has since become an essential tool in the kit of gene-editors around the world, lauded for its affordability, accessibility and efficacy. The CRISPR system has been used to edit the DNA of plants, animals and humans, offering the prospects of better health, better crops, disease eradication, among other advances. In a short time span CRISPR has accelerated the prospects for humans to transform not only living organisms, but to also direct the course of biological evolution. But the hopes around the potential gains CRISPR may bring us are matched by a revitalized host of societal and ethical concerns that extend back to the earliest days of the genomics revolution.

A sociological analysis can help us to understand how the terms of the debate over genomics and biotechnology take shape in public spaces such as the news media. Despite existing research on public debates about biotechnology, we lack a full understanding of how social, historical and contextual factors, such as evolving transformations in media, the expansion of genomics and genetics into everyday life or the scientific community's calls to engage the public may have impacted the discourse around CRISPR. This dissertation is guided by three broad questions. How was CRISPR framed and discussed in the U.S. news media between 2012 and 2018? Who is participating in public discussions about CRISPR and why is there so little room for public perspectives and involvement? What does the U.S. public really think about gene-editing? The three studies that comprise this dissertation advance our understanding of societal and ethical dimensions of the gene-editing technology CRISPR by first interrogating how news media presented and told the story of CRISPR in the critical early years (2012-2018), then by seeking to understand the role of the public in the media discourse and debates over this technology, and finally by investigating U.S. public attitudes and beliefs about CRISPR using data from a national survey.

News Media and Public Engagement in Scientific Debates

For decades now, policymakers, scientists, and science funders have been calling for public engagement with science (Burall 2018; Degeling, Carter, and Rychetnik 2015; Editorial Board 2018; Fung 2015; Nisbet and Scheufele 2007; Rowe and Frewer 2005). Engagement is undertaken for a variety of goals including ethical reasons including social justice and respecting individuals, for political reasons such as enhancing democratic legitimacy, and for practical reasons such as responding to perceived threats of backlash (Abelson, Warren, and Forest 2012; Blacksher et al. 2012; Lehoux, Daudelin, and Abelson 2012; Solomon and Abelson 2012). These calls have created a need for better measures of public opinion, and an important new role for the news media as a site for experts to communicate with publics, and a place for publics to shape debates (Briggs and Hallin 2010, 2016; Geller, Bernhardt, and Holtzman 2002; Holtzman et al. 2005).

But skepticism about the value and purpose of public engagement in highly technical issues like gene-editing is supported by the common view that scientific expertise is the entry token to be a legitimate participant in any discussion worth having. For the skeptic, the most that expert communities can do is to offer "education" (the so-called "deficit model" of public ignorance) to the public and seek to hone the messaging around new and risky technologies so as to minimize fears and manage potential backlash. This project proceeds from the idea that the public has both a legitimate stake and a role to play in policy making around science, genomics, medicine, even though that role may vary depending on the context. Understanding what that role ought to be in the case of gene-editing can be aided by first understanding how public views and perspectives have already been captured in influential sites of discourse including the news media and in population-based surveys.

Framing Genomics and Biotechnology in News Media

Previous studies of media coverage of genomics and biotechnology suggest that there are shortcomings and biases in the ways that news media frames and discusses genetics and biotechnologies, including a consistent and pronounced positive bias in the tone and substance of coverage, dominance of expert and industry voices and tendencies towards hype and "thin" ethical debates. But these literatures are in need of updating, given transformations in the scientific and news media landscapes. Have these trends persisted into the second decade of the 21st century? Chapter 1 contributes to this literature by examining how U.S. news media framed and narrativized the emergence of CRISPR gene-editing in its early years (2012-2018).

A large body of multi-disciplinary empirical and theoretical studies has explored the complex relationship between medical science, health and the news media, including a particular emphasis on media portrayals of genomics and biotechnology. Scholars working in this space have used qualitative and quantitative analyses to understand how genetics and biotechnologies have been framed, characterized and narrativized in the news media, both in the present and over time, with a particular emphasis on the latter half of the 20th century (Condit 1999; Conrad 1997; ten Eyck and Williment 2003). This body of scholarship, built on how news media report on biotechnology, genetics and science, has interrogated such key questions as how we understand the meaning of genetics (Condit 1999, 2001; Conrad 1997, 1999c, 2001), the role of journalists and experts in shaping the narratives that are told about this science (Briggs & Hallin, 2016; Briggs & Hallin, 2010; Caulfield & Condit, 2012; Hallin et al., 2013), the significance and concerns about over-selling or hyping the benefits of biotech (Caulfield 2004, 2018; Caulfield et al. 2016; Caulfield and Condit 2012; van Lente, Spitters, and Peine 2013; Master and Resnik 2013; Musunuru 2017), and the ways that such media coverage both reflects and shapes public knowledge, attitudes and beliefs about these domains (Robert D. Benford and Snow 2000; Conrad 2001; Listerman 2010; Marks et al. 2007; Scheufele and Tewksbury 2007; de Vreese and Lecheler 2016). These studies have revealed that the story told in media about genomics and biotechnologies is an overwhelmingly positive story that centers progress, innovation, profit, overcoming obstacles and tales of heroic scientists and doctors (Eyck 2005; ten Eyck and Williment 2003; Marks et al. 2007; Nisbet, Nisbet, and Lewenstein 2002; Petersen 2001, 2005; Priest 2001; Priest and Eyck 2003). We also know that the media story of genetics and biotech changes over time and that the latter decades of the 20th century included an increased mindfulness of risks associated with genetic technologies, increased attention to ethical concerns, and evolving narratives around key concerns relating to genomics including reductionism, perfectionism and discrimination (Condit 1999; Priest and Eyck 2003). However, although ethical issues are increasingly raised in the news media, the depth and quality of the ethical discourse has been called into serious question (Evans 2002, 2020).

Since most of the previous work relied on data from the late 20th century, we don't know whether and how past trends in news media framing of genomics and biotechnology have continued. The U.S. news media landscape has changed in recent decades, both through the growth and availability in the number of national news sources (cable, web and print) and in the increasingly ideological identification of sources across the left-right political spectrum (Jurkowitz et al. 2020). This evolution in the media landscape raises the possibility that the discourse on gene-editing might likewise have taken on a more pronounced ideological caste across the spectrum of sources. Furthermore, most previous studies in this area focus on the field of genetics or biotechnology as a whole, rather than a specific technology, application or context. This project set out to focus on a single part of the genomics revolution, namely the emergence of the gene-editing technology CRISPR, in order to sharpen the context and attend to particularities of the debate raised by this technology. Chapter 1 updates our understanding of the role of media in shaping debates around biotechnology in general and attunes us to the specifics of the issues surrounding CRISPR and the unfolding revolution in gene-editing.

Where is the Public?

While many scientists claim to welcome public engagement with science, the meaning of "engagement" is complex and slippery, and there are a number of pressures causing scientists to defend the boundaries of their expertise and to limit the scope and purpose of engagements with the public (Goold et al. 2012; Marris 2015; Rowe and Frewer 2005). On first blush, it appears that the scientists and institutions engaged in the CRISPR revolution have been eager and open to engage the public. In Chapter 2, I investigate the role of the public in the media narratives of

CRISPR. What appears as an earnest desire on the part of expert communities for the public to join in dialogue, discussion or even consensus building, turns out to be far from a clear invitation. Chapter 2 draws on theories of expertise developed by scholars in Science and Technology Studies (STS) and the Sociology of Scientific Knowledge to argue that in the case of CRISPR, the hope for meaningful, policy-informing public engagement may be trapped in a temporal paradox wherein the time for the public to participate is always too soon, until it turns out to be too late.

The fields of Science and Technology Studies and the Sociology of Scientific Knowledge have developed theories of expertise that help account for the genesis and functioning of the dynamics around experts and expertise. Expertise is essential to understanding contemporary scientific practice and the way science (as an organizing idea in society) figures in our social imagination (Jasanoff 2005; Jasanoff and Kim 2016; Wynne 1992b, 1992a; Wynne, Peterson, and Pinch 1995). For scholars in this tradition, the issue of expertise (and related concepts of trust, risk and legitimacy) is central to understanding contemporary society and the place of highly specialized science in structuring markets, policy, national aspirations and international competition (Eyal 2019; Jasanoff 2005; Sideri 2018). A key issue in this work is understanding how scientific experts achieve and maintain legitimation in society, particularly in the face of challenges whether they be on epistemic grounds, ethical grounds or motivated by private or financial interests (Collins and Evans 2002; Eyal 2019; Gieryn 1983, 1995). In Chapter 2 of this project, I employ Gieryn's notion of "boundary work" to help account for the response of the scientific community to the rupture caused by a "rogue actor" and argue that the efforts to expel the rogue actor had additional implications for the role of the public.

STS scholarship emphasizes the philosophical and practical implications of the gap between experts and lay publics (Latour 1999). Furthermore, they have theorized how experts and publics negotiate the means and ends of scientific advancements. Such divides have had impacts on the course of scientific development, the advance of markets and the trust relationship between the scientific community and lay publics. Genomics and biotechnology have been the site for a number of such ruptures between expert and lay publics (e.g. stem cells, cloning, GMOs). In this project, the question of expertise is analyzed in terms of the role of experts who contribute to and dominate the news media discourse in the narratives surrounding CRISPR. In Chapters 1 and 2, experts are counterpoised to "publics," or various non-expert constituencies, who either appear in the media discourse or who are conspicuous by their absence. In Paper 1, experts are seen contributing to the shaping of the master-frames of 'cautious optimism' and 'boosterism.' In Paper 2, I unpack the role of experts and journalists in configuring publics, whether as a force to be managed, a source of potential legitimacy for future science or as a wholly ignorable mass that lacks the requisite knowledge or credentials to engage in the debates and discourse unfolding about CRISPR.

Historians, ethnographers and legal scholars, looking at the evolution of contemporary biotechnology have helped to theorize the relationship between the evolution of the science and the driving forces of the market, identifying key relationships among stakeholders in government, academia, business and the public sphere (Hogarth 2017; Hughes 2011; Parthasarathy 2017b, 2017a; Reardon 2017; Rose 2007; Sunder Rajan 2006). This body of work informs my understanding of the influence of market actors, market-focused media and issues that have been central to the story of CRISPR in its early years, particularly the patent dispute between UC Berkeley and Harvard. The entwinement of scientific and market aspirations for this technology infuses my understanding and interpretation of the narratives of CRISPR (Chapter 1), the approach of market actors in proactively managing the public's impressions of CRISPR (Chapter 2) and the question of how publics tie support for CRISPR to support for public financing of research (Chapter 3).

What does the public really think?

Calls for public engagement have also been met with attempts to measure public opinion about biotech and genomics using survey research. But this body of work tends to limit itself to simple measures of approval or disapproval, without contextualizing the issue or using statistical modeling to help understand the sources of variation in attitudes. Chapter 3 of this dissertation improves on this research by using nationally representative survey data to understand U.S. lay public perspectives on the development of gene-editing and connects it to pressing issues relating to health research infrastructure and finance needs. Additionally, most survey research asks the question of support or dissent for gene-editing only in terms of how the technology may impact the respondent individually. To expand on this framing, we inquire how respondents' hopes and fears about the future of gene-editing varies between themselves, their families and society overall.

A Brief Overview of CRISPR-cas9

CRISPR is an acronym, short for clustered regularly interspaced short palindromic repeats, and it describes a feature of how DNA contains regular and predictable patterns of the nucleic acids (the A, C, G and T) that make up DNA. CRISPR-cas9 refers to the gene-editing system, first described by Jennifer Doudna and Emmanuelle Charpentier in 2012 (Jinek et al.

2012) that has revolutionized contemporary biology and for which they were recently awarded the Nobel Prize in chemistry[1]. The CRISPR-cas9 platform is comprised of the cas9 enzyme (or another similar enzyme such as cas13) and a guide RNA programmed to match a specific pallidromic repeat in the DNA. Once the guide RNA locates the target region, the cas9 enzyme initiate a double strand break of the DNA which is subsequently repaired by the cells own repair mechanisms. It furthermore allows the insertion or deletion of segments of DNA, and has recently been modified to allow single point mutations (CRISPR Prime) and to make alterations in the epigenome (CRISPRon/off). In under a decade, CRISPR has become an essential tool for bench scientists in a vast array of fields and the prospects of turning bench-side innovations into clinical and commercial applications have only accelerated.

The latest in a trio of gene editing approaches that include zinc fingers (ZNF) and TALENs, CRISPR-cas9 offered the most precise, effective and accessible (inexpensive) means so far to make modifications to genomes. This breakthrough in molecular genetics dovetails with the current efforts to build an infrastructure of "precision medicine" and is viewed as a technology that will have profound implications for how we treat human health in the 21st century (Razzouk 2018) and is an important component of the aspiration to develop personalized/precision medicine. By 2015, CRISPR was already being heralded as the "breakthrough of the year" by the prominent journal *Science*. The breadth of disease and disability states addressed by this ongoing research reflects the ambitions tied to CRISPR-cas9 including: various cancers, HIV, blood disorders (e.g. Sickle Cell, Thalassemia, hemophilia),

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[1] For an accessible introduction to CRISPR, see esp. (Doudna and Sternberg 2017). A number of volumes have since been published that describe the science, history, ethics and personalities involved in the creation of CRISPR-cas9 including (Baylis, Greely, Isaacson, Evans, Davies, Metzl), not to mention reams of journal articles, magazine and news journalism, multi-media content etc.

Alzheimer's disease, amyotrophic lateral sclerosis (ALS), deafness, cystic fibrosis, Huntington's disease, retinitis pigmentosa, Duchenne muscular dystrophy (Razzouk 2018).

In addition to the proliferation of basic and applied science, CRISPR-cas9's early years were notable for a number of people, institutions and events that propelled the technology into greater visibility beyond the confines of the lab bench. First, a prominent patent battle was waged in the courts between two major academic institutions (UC Berkeley and the Broad Institute) over which institution (and which scientists) could lay claim to the most important advancements in CRISPR-cas9 technology (Achenbach and Johnson 2017; Johnson 2016; Sherkow 2018). Second, related to the patent battle, a controversy over how the history of the technology should be told was sparked when a prominent Harvard scientist published a history of CRISPR-cas9 that (critics claimed) over-emphasized the contributions of the Harvard-Broad Institute and de-emphasized the contributions of the Berkeley-based team (Eisen 2016; Lander 2016; Vence 2016). Third, owing largely to the accessibility and relative ease of use, CRISPR-cas9 attracted the early and avid interest of members of the biohacking community, individuals pursuing scientific experimentation and research outside the confines of the traditional cites of scientific activity (universities, corporations, government) (Arbesman 2018; McLean and Furloni 2018; Pearlman 2017; Zhang 2018).

Along with patent battles, debates over CRISPR's history and the biohacker movement, CRISPR-cas9 was brought out into public prominence by the steady pace of scientific work that increasingly pushed up against the ethical, social and policy quandaries provoked by gene editing. Decades-old debates about whether we should pursue something just because we can do it resurfaced. A sampling of such issues includes: Should we allow editing of human embryos? Is it permissible to experiment on human embryos with gene modification? How do we decide if something should count as an enhancement or not? How can we regulate non-governmentally funded research? Who is included and who is excluded in the imagined future of gene-editing? Two notable moments of controversy include the 2017 experiment conducted by scientists in Oregon that involved the first known attempt to use CRISPR on human embryos in the United States to modify a gene that would confer protection against developing heart disease and Chinese scientist He Jiankui's use of CRISPR to modify twin embryos that lead to an international uproar.

The prospects of abuses of the technology or applications that might be viewed as unethical became apparent to the creators or the technology, who took early steps to get out ahead of potential societal backlash, calling for a moratorium on the most controversial applications including so-called heritable or germline genome modification of humans. It became quickly apparent that the debates about gene-editing and CRISPR were not only about the science, but about what society will approve or sanction and CRISPR-cas9, for all of its promise to potentially cure congenital diseases, transform agriculture or possibly eliminate vector borne illnesses, found itself enmeshed in the controversies that unfold in the space between science and society.

On November 25, 2018, news broke about the birth of a pair of Chinese twins. The world soon learned about these twins (and later a third child) that a Chinese scientist named He Jiankui had used CRISPR-cas9 on while in embryo stage (Regalado 2018). He's goal with these experiments was to use CRISPR to modify the CCR5 gene so that the children might have protection from future risk of contracting HIV, a modification that, if it worked, would be passed on to subsequent generations. The general sentiment of the scientific community was that this experiment contravened what they *thought* was a broadly held consensus view: that CRISPRcas9 should not be used to make germ-line (heritable) modifications of human DNA. The firestorm that this announcement created triggered an abundance of commentary, official statements of condemnation from notable figures, professional and political bodies, and debate over how many different violations (ethical, scientific, legal etc.) this experiment represented (e.g. Cohen, 2018; Hurlbut, Jasanoff, & Saha, 2018; Schaefer, 2018; Schrank, 2018). He Jiankui was eventually shunned from the scientific community and jailed by Chinese authorities, but the ramifications of his actions continue to impact the debates over this technology. The reaction of the scientific community to this experiment features in the argument of Paper 2 in this dissertation.

Yet, the debates over CRISPR-cas9 technology didn't start with He Jiankui's experiment. Rather, it began to unfold among scientists, bioethicists, policy makers, media pundits and interested lay publics when CRISPR first emerged in the national consciousness (circa 2012-14). The emergence of CRISPR, unlike other gene-editing technologies such as TALENS or Zinc Fingers, brought renewed urgency and attention to the unresolved scientific, social and ethical questions that have existed since the inception of the genomics era in the 20th century. Can we use genome-editing technology to alter the DNA of individuals to not only cure them of disease, but to confer future immunity or protection against illness, or even perhaps to promote enhancements of human capacity and cognition that might make us "better than well"? If we can do this, should we? If we do, what are the consequences for individuals, families and societies? How do we decide what counts as a treatment, prevention or enhancement? What kind of oversight or regulation do we need, what kind do we desire and what kind of regulation can we reasonably expect? The way scientists, policymakers, and the public answer these questions will shape the development of CRISPR technology.

After a tumultuous period following He Jinakui's experiments, and a relative pause in the amount of coverage of CRISPR in the media, some good news for the gene-editing community started to accumulate. For example, a recent NPR series has carefully followed the early success of an experimental use of CRISPR to treat Sickle Cell Disease and in 2020, the Nobel prize was awarded to Doudna and Charpentier for their pioneering work (Jinek et al. 2012) in discovering and characterizing the CRISPR-cas9 platform. In addition, CRISPR has received favorable news coverage as it has been employed in the development of diagnostic tests for COVID-19. Nonetheless, the underlying ethical and societal challenges remain. I now turn to brief summaries of each Chapter of the dissertation.

Framing Gene-Editing: CRISPR in the U.S. News Media, 2012-2018 (Paper 1)

In the first chapter of this dissertation, I draw on a news media corpus of eight U.S. news sources spanning 2012-2018 to examine the question of how the discourse and debates around CRISPR were framed in these early years in influential public spaces. The news media sample was selected to encompass mainstream, prestige news outlets (*New York Times*, *Washington Post*), business-oriented news media (*Wall Street Journal*), ideologically conservative (*Foxnews.com*, *Breitbart*), ideologically liberal (Huffington Post, *Mother Jones*) and a middle of the road outlet with the largest distribution of any news source (*USA Today*). Previous studies depicted an overly optimistic media narrative about biotech. I find that most CRISPR coverage adopts a measured framing of cautious optimism, with an overwhelmingly positive tone that pairs a story of progress toward scientific and/or medical benefits with a consideration of risks and ethical concerns. This master-frame is supported throughout by the dominant voices of scientists, commercial company representatives and some members of the bioethics community who are eager to take societal concerns about gene-editing seriously, but also are eager to allay concerns and fears that they view as misguided or misplaced.

In addition, some coverage slips into “boosterism:” it leaves the discussion of risks behind, amplifying progress and an array of actual or potential benefits, especially scientific and economic benefits. The boosterism narrative turns the ethical challenges typically associated with gene-editing on their head, asking instead why, if we can safely use this technology, it wouldn’t become normative and even a duty for parents to employ to assure the best possible physical and mental health of their future children.

Finally, a third master-frame is present in the articles that adopted a critical tone and emphasized risks and the potential for early successes to lead society down a slippery slope towards more controversial and potentially divisive applications of CRISPR. Notably, the critical narrative appeared most often in the more ideologically aligned sources, and this finding accords with previous work that holds that the discourse overall is thinner and less robust as a result. The relative absence of the critical master frame in prestige news sources means that the reading public is less equipped to engage with the full array of concerns and perspectives that could be taken in relation to CRISPR.

U.S. news media discourse about CRISPR evinced a broad spectrum of complexity, from sophisticated scientific reporting to overly simplified and sensationalist coverage. In general, I find that while the discourse managed to avoid previous eras worst tendencies tying genomics to naïve determinism, discrimination and perfectionism, these concepts still resonate in the discourse as the emergence of CRISPR brought urgency to the ethical questions around gene-editing.

Always Too Soon, Until It's Too Late: Excluding the Public from Debates about Gene Editing (Paper 2)

In the second chapter of this project, I draw on the same media sample used in Paper One to address two related questions:

1. What roles have there been for the "general public" to play in the media discourse surrounding CRISPR?
2. What can the news media discourse about CRISPR tell us about why the voice of the "public" has been relatively silent so far in the CRISPR debates?

I find that the actual voice of the public (whether as patients, consumers, advocates, citizens or broadly construed members of society) was largely excluded from the media coverage of CRISPR, particularly as compared with the scientific, bioethics and commercial experts who contributed to telling the story and reflecting on its meaning in the media. While members of the public were rarely quoted in the media, news articles still constructed various roles for them to play. In coverage of the agricultural implications of CRISPR, commercial and scientific actors engaged in a "public relations" effort to manage fears, convince skeptics that gene-editing was different from the technologies employed with GMOs, and avoid the kinds of acrimonious and divisive debates that typified the GMO era in the U.S. and Europe.

In contrast, calls for public inclusion in debates over the use of CRISPR in humans emerged early, but in ways marked by underlying confusion. Discussions of public inclusion in debates about CRISPR were marked by vacillation between urgent calls for debate and public involvement and efforts to diminish the sense of urgency and the closing down of pathways where the public might find their way into the debate, creating uncertainty around when, how and whether the public ought to be engaged in this discourse. Experts' boundary work to defend the field against the actions of a rogue scientist crowded out the public further, reinforcing the alienating distance between experts and publics. I argue that the net result of the tactics of public relations, the confusion around when the public can or should become part of the discussion, and the intense crowding out of the public when controversies emerge leave us with an implicit arrangement where it is always too early for public participation, until it becomes too late. The desire to include the public in debates over gene-editing in the U.S. continually conflicts with longer standing dispositions among expert communities to keep the public at arms length, to manage the terms of debates and to shore up the legitimacy and standing of scientific practice.

Gene-editing in the eyes of the American Public: Evidence From a national survey (Paper 3)

(Co-authors: Jodyn E. Platt, Sharon L. R. Kardia)

Why do some people view gene-editing technology more favorably than others? Existing survey research on public attitudes towards CRISPR tends to construct the dependent variables of interest (support/lack of support for genome editing technology) in the abstract, without provoking respondents to consider their own personal connections to this technology. For the final chapter of this dissertation, we constructed three dependent variables that raise the personal stakes of CRISPR and gene-editing for respondents by first asking about respondents' willingness to donate biospecimens for gene-editing research, second about their comfort with tax dollars being spent on gene-editing research and third about their levels of anxiety and optimism about the future of this technology. These questions prompted respondents to consider the extent to which they are prepared and comfortable with making contributions towards a CRISPR-mediated future.

We use OLS regression models to examine predictors of support and dissent from gene-editing. We find that majorities of respondents show support for gene-editing across multiple demographic, experiential and attitudinal factors, but that this support is somewhat ambivalent overall. Furthermore, we find that attitudes towards gene-editing are associated with demographics (sex, education) and respondents' commitments including ideology and religious adherence. Respondents' degree of trust in the health care system had the most explanatory power in accounting for the variation in attitudes towards gene-editing. These findings suggest that future efforts to engage the public on CRISPR should consider how factors like institutional trust (and mistrust) relate to acceptance or rejection of new and controversial technologies such as CRISPR.

Not yet a decade old, the CRISPR technology has ignited a scientific renaissance, with the possibility of dramatic advances in areas of medicine that have been otherwise stagnant for decades (e.g. Sickle Cell Disease and Beta Thalassemia). The public is still awakening to the possibilities CRISPR represents and the societal and ethical questions that are provoked with each new application. The 2020 awarding of the Nobel prize for the discovery of CRISPR-cas9 suggests how excited and committed the scientific community is about a CRISPR-mediated future. There is an urgent need for research on how the public is coming to understand the ethical and societal implications of CRISPR and its applications. This project contributes to this end by assessing the ways that CRISPR was discussed in the media, examining the role of the public in the early years discourse about CRISPR and by using survey research to develop more nuanced understanding of the U.S. public's views of gene-editing. Future work should employ a variety of methods (interviews, focus groups, deliberative democracy) to engage various publics directly in deeper reflection and consideration of what this technology means for all of us.

CHAPTER 1 – Framing Gene-Editing: CRISPR In U.S. News Media, 2012-2018

1.1 Introduction

The emergence of CRISPR-cas9 as a gene-editing platform in 2012 reignited decades old debates around genetic engineering, now referred to by the term "gene-editing," a phrase that connotes the familiarity and ease of use of a word processor. The debates over the potential applications of gene-editing across multiple sectors (health, agriculture, pest control, climate change mitigation etc.) have a familiar ring for many attentive participants, but a renewed urgency given the seemingly astonishing pace of development of CRISPR, especially in light of the common refrain that CRISPR is cheap, accessible and highly efficacious (in spite of off-target effects and the potential for mosaicism).

Given the highly contentious debates in the early 2000s over stem cells, cloning and chimeras, one might expect that a revived debate over gene-editing would rekindle familiar and hardened views among various segments of the American public. For example, the conservative movement's moral objections that stem from their views of the moral status of embryos, might be expected to reemerge in this context to voice strong objections and seek to steer the debates towards moratoriums on research, with the force of policy behind them. According to Gabel and Moreno (2019) however, the reality of the political context in the U.S. had shifted significantly by 2012 (the year that scientists first report using CRISPR-cas9 to edit a genome), such that the conservative movement had moved on to other concerns and that the rise of Donald Trump's particular brand of conservatism lead many of the leading bioconservative voices active in the stem cell debates to focus on their critiques of Trumpian conservatism and economics. This retreat, according to Gabel and Moreno meant that with the exception of the notable furor that was sparked by He Jiankui's use of CRISPR in China in 2018 to modify embryos that were later implanted and brought to term, the debate over CRISPR has been comparatively sedate and under the radar.

If this theory is true on the whole, we might wonder if the media coverage of CRISPR in the United States is a story of a relatively calm, under the radar discourse. A comparatively low-key debate over gene-editing would be beneficial to scientists and companies scarred by the contentious and confusing debates of the stem cell and GMO eras. A closer look at the ways that the debate has played out in various venues would give us a clearer understanding of the status of the contentious issues that surround this technology, which still call for interrogation, debate, public reckoning and the guidance of policy.

This study turns to the news media to assess how the discourse around CRISPR unfolded across eight U.S. news sources from 2012-2018. Specifically, this study describes the tone and framing of the debate to help specify the extent to which the discourse around CRISPR is a continuation of ongoing debates in American life around the role of biotechnology and the potential to reshape life in all of its forms, and the extent to which the old debates are taking on a new character.

In contemporary democracies, media is both a mirror of public discourse and a vehicle for influential actors to shape the discourse and influence the policy agenda (Bennett and Entman 2001). Understanding how debates over biotechnology have been framed in the news media is thus a crucial step in making connections between the public sphere, experts, interest group actors and the policy community. Prior analysis of media coverage of biotechnology discovered that over the last three decades of the 20th century, the salience of biotechnology issues has increased in the U.S. public and policy spheres (Condit 1999; Nisbet et al. 2002). Such analyses have tended to assess the fields of biotechnology or genetics as a whole, taking in the full gamut of issues, stakeholders and contexts, however, as (Nisbet et al. 2002) note, a more focused look at a specific dimension or technology would enable a more contextually rich assessment of the dynamics observed of the field writ large. The present study, focused on the gene-editing technology CRISPR-cas9, makes this contribution.

Studies of media framing of genetics and biotechnology during the 1990s and early 2000s found that this coverage was predominantly positive, dominated by scientists, commercial and government experts with an increasing role for discussion of ethical issues. Since then, the media landscape has broadened and the political landscape has changed. The change is marked by a proliferation of news media sources with national reach and more pronounced ideological leanings. The sources in my sample were chosen to try to capture how this variation in the media landscape impacts the overall discourse. In addition to mainstream, prestige news sources, this study includes a sampling of business/finance news to provide variation in perspectives and framing of the economic prospects of CRISPR and gene-editing, offering a more complete view of the place of CRISPR in the biotech economy than coverage in traditional media alone. In addition, the news media sample includes partisan identified outlets on the left and right edges of the ideological spectrum. This broad sampling reveals the dominant narrative framing of CRISPR and two contrasting alternative framings.

Does the framing of CRISPR in the news media represent a break from previous eras of genomic discourse, or does it carry forward the shortcomings of previous eras' framing of genetics and biotechnology? To answer this question, I assess how CRISPR was framed in the news media discourse in the United States between 2012 and 2018. The relative dominance of a "cautious optimism" narrative suggests that the coverage of CRISPR continues many of the characteristics of the preceding eras of genomics, including the generalized positive coverage, optimism around future benefits and the capacity for science to self-regulate, and a growing role for ethical discussion in the media. The strength of the "boosterism" narrative suggests the importance of looking outside of prestige mews media (a common approach in earlier eras) and reveals how the dominant narrative of "cautious optimism" can be aided by the enthusiasm of "boosterism" while also seeking to maintain a responsible distance from that narratives excesses. Finally, the relative scarcity of the "critical" narrative across the corpus suggests that while some in the bioethics and scientific community are mindful of the critical point of view, challenges to the dominant optimistic narrative have struggled to find a foothold.

1.1.1 Prior Studies of Biotechnology In The Media

Prior research on media coverage of genomics and biotechnology reveals an optimistic media discourse that emphasizes health benefits and economic gains and with little discussion of risks or dissenting voices. The earliest studies focus on the 1970s debates over recombinant DNA (rDNA) (Pfund and Hofstadter 1981). Although *risks* (often unknown and unquantified) were a salient concern, particularly with agricultural uses of recombinant DNA, media coverage during this period was found to be largely *more positive than negative* in tone about the technology, with *industry* experts (as compared to academic or government interests) setting the terms of the discussion (Marks et al. 2007). The dominance of industry voices in this early reporting gave way over time to greater presence of *academic scientists* and *government* *representatives* (Conrad 1999a; Nisbet and Lewenstein 2002; Priest 1994), but industry has maintained a consistent presence in news media-based discourse around biotechnology.

Media coverage of biotechnology during the rest of the twentieth century emphasized *scientific progress* frames and adopted a generally *uncritical perspective*, particularly when it came to medical applications (Durant, Bauer, and Gaskell 1998; Eyck 2005; ten Eyck and Williment 2003; Nisbet and Lewenstein 2002; Nisbet and Scheufele 2009; Priest and Eyck 2003). This framing continued throughout the first decade of the Human Genome Project, where media discourse around numerous genetics issues was predominantly *positive in tone* and characterized by "cautious optimism" (Condit 2001), trends that have been noted in studies addressing a variety of issues including the framing of genes and mental illness in news media (Conrad 2001), the genetics of behavioral traits (Conrad 1997), cancer genetics (Henderson and Kitzinger 1999), or genetics and medicine broadly conceived (Petersen 2001). This work revealed a heavy preference for "*progress*" framing of biotechnology in media, with a secondary emphasis on "*economic*" and "*public accountability*" framing. The positive framing, veneration of scientific experts and emphasis on benefits and progress is notable when contrasted with media coverage of agricultural biotechnology, which was found to be more likely to be focused on risk, controversy and the influence of commercial interests, particularly in the 1990s when GMOs were subject to intense scrutiny in Europe (Durant et al. 1998; ten Eyck and Williment 2003; Marks et al. 2007).

In addition to their focus on positive framings around progress, cures and economic potential, these late twentieth-century media discourses often has *under-emphasized* critical points of view, skewed towards *omitting debate and dissention* from its coverage of biotechnology, left critical or dissenting expert or lay voices out of the discourse, or marginalized dissenters through the delegitimation of their perspectives (Caulfield 2018; Condit 2001; Nisbet et al. 2002; Priest and Eyck 2003).

In seeking to account for the particular character of media framing of biotechnology, scholars have identified *factors related to the media* and *factors related to science*. The collaboration between reporters and scientists that is required to assure accurate coverage of complex or technical issues has been identified as a biasing factor impacting coverage (Conrad, 1999b). Reporters often view the institutions of science, such as peer review, as license to let science reporting be "source driven" and "source framed" (Nisbet et al. 2002; Petersen 2001). Still others point to a shared culture between media and science that is driven by market logic, which can incline towards biotech "boosterism" around "investment opportunities" and "potential social benefits" (Priest and Eyck 2003).

One key explanatory dimension in this body of work is the role of experts and expertise in shaping the media narratives. Several types of experts are typically employed by news journalists to "make sense of the genetic revolution," including industry and industry scientists, university scientists, doctors, government officials, activist groups, and financial advisers (Ten Eyck, 2005; Priest and Ten Eyck, 2003). Ten Eyck (2005) describes the role of experts in these contexts as "agents of legitimation" (p.306), whose task is to either support or discredit the specific biotechnology at issue in a given article. In an analysis of ten years of biotechnology articles from the *New York Times* and *Washington Post*, Ten Eyck (2005) found that among the sixteen categories of experts, *industry representatives*, *university scientists* and *federal government representatives* (legislators and agency reps) were the top three types of experts cited by journalists (Ten Eyck, 2005). Given the significant impact of *who* is asked to speak on matters of biotechnology and genetics on *what* gets said, the analysis of media discourse on

CRISPR in this study looks both to the work of specific experts in shaping the discourse as well as general trends of which categories of voices are dominant, subordinate or absent.

If the primary explanatory accounts for media framing of biotechnology look to the media and experts, a second major explanatory pathway looks further upstream to the context of knowledge production to identify structural or contextual factors surrounding the contemporary research university, the funding and realities of "big science" and the entwinement of market logic and scientific discovery (Berman 2012; Hess 2007). For example, (Caulfield, 2004, 2018) traces the hype around biotechnology and genetics to the professional and institutional pressures on *researchers* and *institutions* who are the origination points of the production of research findings. Researchers thus hold a dual role in the propagation of hype, both as progenitors of hype (through, for example, overly sensationalized press releases) and as expert legitimators of the hype coming from their colleagues in their media appearances.

Since most studies focus on earlier debates, it remains unclear whether these trends have continued in the twenty-first century. Contemporary coverage of genomics may have shifted, given the emergence of new media, social media and a more pervasive presence of commercial biotechnology and genomics in social life (e.g. direct to consumer genetic testing). Further, prior studies have tended to ignore media sources targeted towards the business/investment sector as significant sites of discourse around biotechnology. This project is designed to take these evolutions in the news media landscape into account.

1.1.2 Determinism, Discrimination and Perfectionism

In addition to identifying a news media discourse that is predominantly positive and optimistic about the scientific, medical and economics benefits of genomics, heavily shaped by the perspective of scientists, other scholars have focused on key thematic issues specific to the context of genomics. For example, Celeste Condit's (Condit 1999) landmark study of U.S. news media coverage of genetics over the course of the 20th century focuses on three key themes that shape the discourse: biological determinism, discrimination and perfectionism. Condit traced the evolution and salience of these concepts over time and found that there was an ebb and flow to the relative predominance of each of these ways that the meaning of genetic science and findings are expressed in media reporting and understood by society.

In the present study I examine the role of deterministic thinking in the media discourse around CRISPR by exploring the role that polygenicity plays in the descriptions and explanations of gene-editing. I show how coverage of CRISPR has largely eschewed simple deterministic conceptions of genetics, but that the concept of polygenicity itself occupies a rhetorical role in the discourse around CRISPR as a means to quell anxieties about "runaway" abuses of gene-editing.

Over the course of the 20th century, there was a diminishing tendency for media discussions of genetics to reflect or reinforce discriminatory attitudes or perfectionist (or eugenic) ideas about how to apply genetic knowledge and technologies (esp. in the context of reproduction) (Condit 1999). Condit does, however, raise a concern that the growing popularity of the genetic testing market at the start of the 21st century would revive some of the discriminatory and perfectionist strains of thinking and discourse around genetics. With the potential capacity to make changes to the genomes of future individuals at will, gene-editing technologies must confront their potential to revive and reinforce discriminatory and perfectionist attitudes about which genotypes are "natural" "normal" or "healthy" (Benjamin 2016; Garland-Thomson 2020). CRISPR is a technology that is primed to place questions of discrimination and perfectionism back into the heart of discourse and debate. Have these issues reemerged as salient characteristics of media discourse and what changes to how these concepts are invoked can be identified?

Another feature of media coverage of genomics, beyond its positive or critical stance, is the extent to which it engages deeply with ethical questions. John Evans argues that late twentieth-century debates about gene-editing tended to be "thin"—that is, they focused on *means* (how and when to use gene-editing) and not the *ends* (why and whether to use gene-editing at all) (Evans 2002). Evans attributes the thinning of debate to the professionalization and ascendance of the field of bioethics, and the creation of government bodies that were largely guided by its emphasis on autonomy, beneficence, nonmaleficence and justice[2]. We don't know if the media discourse around CRISPR has had a "thin" focus on means or if a thicker discourse that weighs the implications of such uses for society, equity, and the future of humanity as well has emerged. This study tracks both the presence and use of ethical frames in the news media coverage of CRISPR and the presence and impact of bioethicists in the media coverage of CRISPR.

1.2 Methods

I use thematic and frame analysis as primary methods to assess the discourse around CRISPR in the assembled text corpus. This encompassed three main phases: data collection and preparation, coding and memo writing, data analysis and interpretation.

1.2.1 Data: Building a News Media Corpus Beyond the Mainstream

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[2] Beauchamp & Childress's *Principles of Biomedical Ethics*, from 1979 is the locus classicus of this framework, now in it's 7th edition, the meta-debates about how influential this approach has been continue.

One major shortcoming of the existing body of work that analyzes biotechnology discourse is the tendency to focus exclusively on mainstream media outlets (Marcon et al., 2019) as the site of discourse. This study expands this traditional focus to encompass partisan news outlets and business and investment-focused sources. Existing studies of media framing of biotechnology have not generally explored the influence of the partisan political identification of news sources, which we know shapes news framing (Bennett and Entman 2001; Wagner and Gruszczynski 2016). Scholars have found that partisan identification significantly predicts attitudes towards biotechnology and a broad decades long trend of conservative skepticism and diminishing trust in science (Gauchat 2011). However, as noted above, compared with previous eras of biotechnology coverage (esp. cloning and stem cells) the CRISPR era has appeared to be notably less marked by deep public rancor among political partisans (Gabel and Moreno 2019). A close comparative look at ideologically aligned media outlets enables me to elucidate the how to what extent the discourse and debates over CRISPR reflect the ideological divides of this era.

In addition to looking at prestige and mainstream news media across the ideological spectrum, this study includes a source that is primarily pitched to an audience of investors and those more explicitly focused on the market activities and potential of biotechnologies (*The Wall Street Journal*). I hypothesized that this source would be primarily characterized by economic and scientific progress framing and somewhat more prone to "hype" and "disillusionment" cycles than other news sources. The exceptions to the tendency for media studies to ignore financial-oriented publications (Briggs and Hallin 2016; Nelkin 1987) suggest that the salience of the commercialization theme, and the influence of commercial actors in shaping the discourse, make including finance-oriented media an essential component of media studies moving forward.

I searched eight news sources (The *New York Times*, The *Washington Post*, *USA Today*, The *Wall Street Journal*, *Foxnews.com*, *Breitbart*, Huffington Post, *Mother Jones*) spanning the dates January 1, 2013 - December 31, 2018, which encompasses the period from the first media reporting on CRISPR up to approximately two months after the public revelation of the birth of twins born in China who had their DNA edited during in-vitro fertilization by the scientist He Jiankui. Given the reliance on the prestige press in most of the previous work in this vein, I included the *New York Times* and *Washington Post* in my sample. To capture news at the edges of the ideological spectrum, I included sources with a pronounced ideological identity, including *Foxnews.com* and *Breitbart* News as exemplars of ideologically right-wing outlets. *Foxnews.com* I viewed as more a mainstream conservative news outlet, while *Breitbart* News reflects a much more hard-line right-wing ideology. For left-leaning outlets I chose Huffington Post as the avatar of a mainstream left-wing news outlet, while *Mother Jones*, a news magazine with a strong left-leaning tilt was included to weigh against the presence of *Breitbart*. Finally, I also included *USA Today* as it is the newspaper with the widest distribution in the country, characterized by a steadfastly “middle-of-the-road,” and easy to digest reporting style.

To complete my article searches, I used a combination of news source databases (e.g. ProQuest, Factiva) and the source websites. Given the unique acronym that is ‘CRISPR,’ I was able to readily search for all articles in each source for the term “CRISPR*” (asterisk was added to include all forms of the word, e.g. CRISPR-cas9). In several cases, the source’s own website search engine was the best way to obtain the articles. All articles were converted to ‘.pdf’ files, serialized into a database and entered into MAXQDA 2020 qualitative data analysis software for coding.

The original search yielded a total of 403 articles. Upon review, 95 of the articles from this search (~25%) were dropped from the analytic sample either because the term CRISPR only appeared incidentally and the article was insufficiently focused on the topic or the article was a duplicate. Table 1-1 summarizes the sources and the number of articles that were fully coded after excluding dropped items and the source or database used to identify articles.

Table 1-1. Sampled Articles by Source

Source	Number of Articles
Left partisan lean	
Huffington Post	18
Mother Jones	8
Prestige press (Left partisan lean)	
New York Times	48
Washington Post	47
"Middle of the road"	
USA Today	21
Economic reporting (Right partisan lean)	
WSJ	86
Right partisan lean	
Foxnews.com	51
Breitbart	25
Total	**304**

1.2.2 Frame Analysis

Frame analysis offers a powerful tool to decode the embedded frames in discursive spaces, explore the relationship between interests and frames and connect domains of expertise to frames. By examining frame activity around a specific issue (a) over time, (b) in multiple discursive spaces, (c) by various actors and communities of expertise, it is thus possible to ascertain the multiple (often competing) logics that shape and define the terms of the discussion for the public as they attempt to come to terms with the potential risks and benefits, hope and hype and trade-offs intrinsic to the development and adoption of controversial emerging technology.

Gitlin (1980) defines media frames as “persistent patterns of cognition, interpretation, and presentation, of selection, emphasis, and exclusion, by which symbol handlers routinely organize discourse, whether visual or verbal” (p. 7). This study draws both methodologically and substantively on bodies of work on framing in health policy (e.g. Barry, Brescoll, and Gollust 2013; Rahn, Gollust, and Tang 2017), sociology (Benford & Snow, 2000; Campbell, 2002; Conrad, 2001; Gamson & Modigliani, 1989; Nisbet & Lewenstein, 2002; Scheufele, 2011), political science (e.g. Grogan, Singer, & Jones, 2017; Jerit, 2008) and communications (Entman 2007; Priest and Eyck 2003; Scheufele 2011; Zhou and Moy 2007) and proposes to identify and analyze frames that are embedded in media discourse around CRISPR-cas9.

The foregoing work on media framing of biotechnology and genomics offers a number of helpful starting points for considering the framing of CRISPR in my study. First, I adapted the framing typology used by Nisbet & Lewenstein (2002), which they adapted from prior work (Durant et al., 1998; Gamson & Modigliani, 1989; Nisbet & Scheufele, 2007) (TABLE 1-2). In addition to starting from this framing typology, I accommodated novel frames that emerged inductively through the process of qualitative analysis following the strategies described by (Deterding and Waters, 2018). Thus my framing typology directly builds on the findings of the prior literature and sharpens the view of what makes the terms of the debate around CRISPR distinctive or continuous with previous eras.

Table 1-2. Framing Typology for Biotechnology

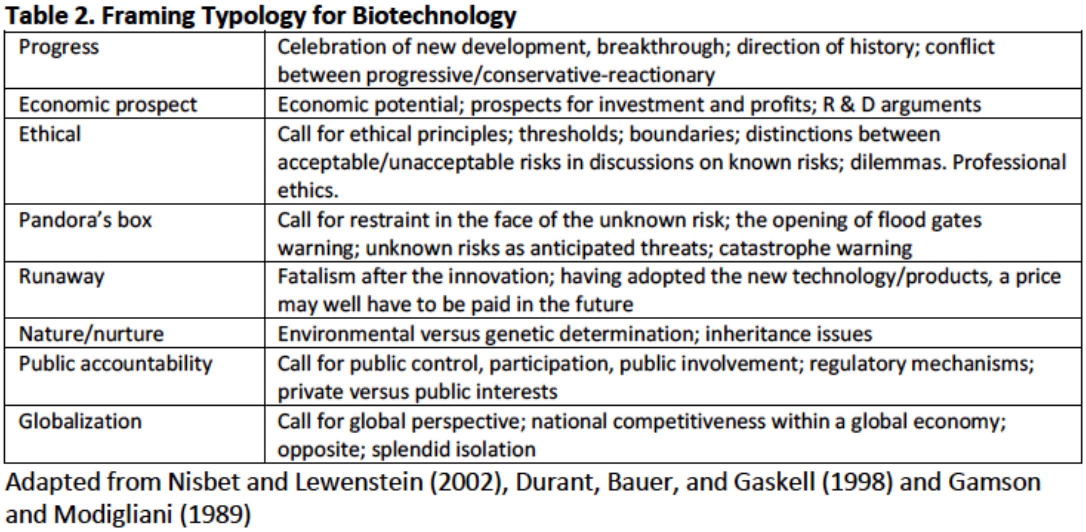

Table 2. Framing Typology for Biotechnology

Progress	Celebration of new development, breakthrough; direction of history; conflict between progressive/conservative-reactionary
Economic prospect	Economic potential; prospects for investment and profits; R & D arguments
Ethical	Call for ethical principles; thresholds; boundaries; distinctions between acceptable/unacceptable risks in discussions on known risks; dilemmas. Professional ethics.
Pandora's box	Call for restraint in the face of the unknown risk; the opening of flood gates warning; unknown risks as anticipated threats; catastrophe warning
Runaway	Fatalism after the innovation; having adopted the new technology/products, a price may well have to be paid in the future
Nature/nurture	Environmental versus genetic determination; inheritance issues
Public accountability	Call for public control, participation, public involvement; regulatory mechanisms; private versus public interests
Globalization	Call for global perspective; national competitiveness within a global economy; opposite; splendid isolation

Adapted from Nisbet and Lewenstein (2002), Durant, Bauer, and Gaskell (1998) and Gamson and Modigliani (1989)

1.2.3 Coding and Analysis

For the analysis of my coded text corpus, I use both quantitative content analysis and qualitative analysis built off both a set of *a priori* codes and emergent themes. My approach to coding the text corpus draws on a recent innovation in qualitative analysis (Deterding and Waters 2018) that the creators call "flexible coding". In contrast to the commonly cited, but less commonly achieved, strongly inductive approach of Grounded Theory, flexible coding allows for a combination of both substantive codes that are derived from extant theory and prior literature *as well as* emergent codes that are discovered in the process of coding. Flexible coding is an adaptation of a top-down approach (Urquhart 2013) which is intended (among other goals) to facilitate the use of qualitative data sets for multiple studies. While Deterding and Waters developed flexible coding with large sets of interview data in mind, this approach was adaptable to the news media corpus in my study.

Flexible coding divides the coding schema into three key dimensions: attributes, index codes, analytic codes. The first step was to code for attributes which can be thought of as the structural independent variables attributable to each document. For newspaper articles this "metadata" includes such information as the publication, date, author, section of paper article appears in and word length (where discernible). In addition, I coded each article for geographic focus (USA, China, UK, Japan, South Korea, Europe, Global, Other), focus of article (human health, agriculture, animals, basic science, gene drive, climate) and "focusing event" (identifying what precipitated the writing of the article, e.g. report on a new study involving CRISPR, the Chinese twins story etc.).

Once the attributes were identified for all the articles, the next step was to apply index codes to the data while generating research memos at the document or document group level (i.e. a memo covering all NYT articles from 2015). Indexing is coding for broad topics (for example the presence/absence of the frame elements adopted from prior literature) that are key to the research questions, in the case of this study, these were elements of the frames described in Table 2. Thus, the index codes (summarized in Table 3 below) included a series of six "benefit" codes (scientific, medical/health, ethical, ecological, economic, other) and six "risk" codes (scientific, medical/health, ethical, economic, ecological, other). Additional index codes included coding for "Pandora's box" (discussion of CRISPR as presenting unknown risks, potential for catastrophe) and the related discussion around a possible "moratorium" on CRISPR research or applications. For the "Runaway frame" I included a codes for "inevitability" (gene-editing is discussed as an inevitability) and "runaway" (we are past the point of no return). The "Nature/Nurture" frame was captured by coding for invocation of the "somatic/germline" and "therapy / prevention / enhancement" distinctions as well as invocations of the term "designer babies". Additional index coding that does not figure into the present analysis included three codes that captured "Accountability" (policy/politics, scientific accountability, public accountability) and two codes relating to “Globalization.” In addition to identifying the presence/absence of these frame elements, the index coding included a designation for overall tone (mostly positive/lean positive/neural/leans negative/mostly negative) and coding of all actors who speak or are paraphrased in the discourse (e.g. scientists, bioethicists, commercial company rep etc.).

The set of *a priori* index codes were tested and refined over five iterations through coding sub-samples of articles with the primary author and a coding assistant. The process for refining the code book involved each coder applying the set of codes to the same sample of articles (usually 10 per round from across the corpus) and then meeting to discuss the application of the codes. Disagreements led to either refinement of the code at issue or dropping the code. After multiple rounds and refinements to the codebook, the coders attained inter-coder agreement on >90% of the values for each code. Once the codebook was finalized, I applied the index coding to the remainder of the corpus.

In this study, I mostly report the frequency of documents (articles) with the presence of the index codes (at least one appearance of the code). For many of the articles, a code may have been applied more than once, however, discussing the percent of articles in which a code was present (rather than the mean number of occurrences per article) proved a more reliable metric to use to make comparisons among the various codes. The different codes may appear in the same article (e.g. benefits to science/technology likely appear in the same articles that benefits to medicine or human health).

To assess the presence of the various frames in the discourse, I specified particular index codes as indicators of the presence of a frame (see Table 3 below). For example, the Progress frame is indicated by both “medical/health benefits” and “scientific/technological benefits” codings. Thus, rather than assigning a single frame to each article, frame presence is indirectly measured by the percentages of index codes that comprise each frame. Thus frames can be seen at the level of source, enabling comparisons between the sources, and at the level of the corpus overall. In addition, this analysis uses a guiding organization of three "master-frames" or narratives that are identified using a combination of frames, index and thematic codes, article tone and expert sources cited in the media.

There is some interpretive overlap among frame elements that make a retrospective typology like this somewhat imprecise. For example, the "moratorium" code was used to identify places in the media discourse where the possibility and merits of a moratorium on germ-line gene editing of humans was being debated by the scientific and bioethics communities. The presence of this debate is indicative of the "Pandora's Box" framing as it represents "calls for restraint in the face of unknown risk". At the same time, the code overlaps with "scientific accountability" as it represents the scientific community debating the appropriate response it should take in the face of unknown risks, which would have been coded separately. In addition, the relationship between the frames and the three master narratives that I define in this study is not one of mutual exclusivity. For example, the economic prospect frame is important for both the "cautious optimism" narrative and the "boosterism" narrative. However, the relatively minimal discussion of "economic risk" is particularly important for the "boosterism" narrative, which is buoyed by a significant amount of "benefits only" coverage.

In addition to the codes that provide the basis for quantitative measures, as coding proceeded, inductively generated themes were noted and coded along with the *a priori* themes and descriptive characteristics of each article. This thematic coding expanded throughout the coding process and informs the qualitative aspects of this analysis and I did not always return to previously coded articles to recode as I did not intend to use the quantitative measures of these themes in the analysis. For example, a theme in the coverage that emerged as I conducted the coding process was the patent dispute between UC Berkeley and Harvard over CRISPR. Applying a “patent dispute” code to these passages enabled me to go back to the corpus later to assess the characteristics of the discourse relating to this issue. Furthermore, MaxQDA’s autocode function also facilitated the ready identification of specific keywords and specific individuals across the corpus.

As with other approaches to coding, flexible coding incorporates the ongoing creation of research memos. Memos were composed within documents, at the document level, at the document group level, (e.g. 2015 NYT articles) and “cross case” memos that identify concepts and relationships across the different data sources (e.g. comparing NYT to WaPo, comparing left leaning to right leaning sources, comparing themes over time).

Article meta-data, frame codes, speaker codes (quoted or paraphrased sources sorted by categories) and thematic coding data were exported from MaxQDA for analysis in Microsoft Excel and Stata 16.

1.3 Results and Discussion

Discussions of CRISPR in the American news media from 2012-2018 cohered into three master narratives. The predominant narrative was “cautious optimism,” which draws on “mainstream” scientific, bioethical and commercial perspectives to tell a story of progress, hope, potential profits and due caution around core ethical questions. A related “boosterism” narrative amplifies the themes of progress, hope and profits but ignores risks, turns the ethical debates on their head and advances a maximalist view of how gene-editing will be beneficial to humanity. Finally, a less common “critical” narrative challenges the other narratives’ basic assumptions while elaborating ethical debates not often acknowledged by the mainstream narrative. U.S. news media discourse about CRISPR evinced a broad spectrum of complexity, from sophisticated scientific reporting to overly simplified and sensationalist coverage. In general, I found that the discourse managed to avoid previous eras worst tendencies tying genomics to naïve determinism, discrimination and perfectionism, but that these concepts still resonate in the discourse as the emergence of CRISPR brought urgency to the ethical questions around gene-editing.

1.3.1 "Cautious Optimism" – The Dominant Narrative

The story of CRISPR most often told by the U.S. press focused on scientific and medical progress and economic prospects weighed against ultimately manageable ethical concerns. The "cautious optimism" narrative gets its name from Condit, who used it as a characterization of public views of genetics (Condit 2001). The cautious optimism narrative balances benefits with risks, emphasizes potential treatments for genetic diseases and potential profits for innovators, and matches enthusiasm with due mindfulness of ethical challenges. To summarize the cautious optimism narrative somewhat crudely, it goes something like: *The health, scientific and economic prospects of CRISPR are immense and realizable, assuming we can manage the technical challenges and as long as we don't get tripped up by the ethical challenges or reactionary regulations.* Empirically, I observed the cautious optimism narratives in articles that emphasized progress frames, consistently paired benefits with risks, included discussion of ethical risk, but was broadly enthusiastic about the potential for this technology across multiple sectors.

1.3.2 Scientific, Medical and Financial Progress

Like the coverage of genomics and biotechnology in earlier eras, progress framing has been central to the mainstream media narrative around CRISPR. As early as 2015, articles extolled the benefits of CRISPR as a new scientific technique with ground-breaking, Nobel prize worthy potential. For example, a *Wall Street Journal* article from November of 2015 heralded CRISPR as a success story of basic science research, an incredibly important and powerful discovery that was driven by the basic curiosity of molecular biologists seeking to understand the boundaries of their field. Articles drawing on the progress frame portray CRISPR as a success story of modern science and a singularly good example of why we should support basic science research. They detail the many ways that gene-editing can be applied to intervene in the natural work on our behalf: from the potential for advances in health and medicine, to production of more efficient and nutritive crops, to the possibility of using gene-editing to destroy species responsible for vector-borne diseases and even to somewhat extravagant possibilities such as xenotransplantation or modifying existing elephant species to become more akin to wooly mammoths in a bid to rebalance the ecosystems of the steppes of central Asia. In a reflection of the progress frame's centrality, 65% of articles referred to health benefits and 48% referred to benefits to science or technology. Table 1-3 summarizes the presence of frames that appeared in the media coverage of CRISPR as a function of the percentage of articles that contain the frame elements.

Table 1-3. Summary of Frames and Frame Elements

Frame	Related Index Codes	Percent of articles with code
Progress	Benefit: Medical/Health Benefit: Sci or Tech	65% 48%
Economic prospect	Benefit: Economic Risk: Economic	30% 8%
Ethical	Risk: Ethical Benefit: Ethical	44% 5%
Pandora's box	Pandora's Box Moratorium	12% 11%
Runaway	Inevitability Runaway	12% 3%
Nature/nurture	Somatic/Germline Distinction Treatment/Prevention/Enhancement Designer Babies	31% 23% 16%
Public accountability	Politics, Policy, Regulation or Governance Scientific Accountability Public Accountability	31% 20% 19%
Globalization	Competition Globalization	12% 3%

1.3.3 Tone and Focus of the Corpus

Consistent with prior studies, the corpus was overwhelmingly positive or neutral in the tone of the coverage of CRISPR (Table 1-4). In addition to the thematic frame elements, the framing of CRISPR in the news corpus was impacted by the overall tone of each article. Following prior work (Gaskell et al.) after applying the frame and thematic codes for each article, I assigned an overall tone code that assessed each article as "mostly positive," "leans positive," "neutral/mixed/difficult to discern a lean," "leans negative," or "mostly negative". To explicate the difference between "neutral," "leans," and "mostly," in many cases of assigning a "leans positive" for the tone code, the article tended to under-describe CRISPR and generally presented benefits without discussion of risks. In these cases, it was not appropriate to say that the tone was neutral or difficult to determine because the invocation of CRISPR was part of an otherwise positive story (i.e. a company using CRISPR just got Series A funding). "Mostly positive" was coded in the cases where there was explicit, active support or enthusiasm expressed for CRISPR in the article and this support, on the whole, outweighs any mentions of risks or concerns about CRISPR.

Table 1-4. Tone of Articles (N=304)

VARIABLE	**CATEGORIES**	**%**
TONE	Mostly Positive	36%
1 code/article	Leans Positive	27%
	Neutral/mixed/difficult to determine	26%
	Leans Negative	9%
	Mostly Negative	2%

Along with the progress frame elements highlighting medical and scientific benefits of CRISPR, the overall optimism of the dominant narrative derives from this pronounced positive tone of articles across the corpus. This tendency for stories about CRISPR to have a positive tone is consistent across the corpus with the exception of *Breitbart*, which was the only source to publish more "leans negative" than "leans positive" stories about CRISPR. None of the articles in the *Washington Post*, Huffington Post or *Mother Jones* were leaning or mostly negative in tone. The *New York Times* and *USA Today* were the most balanced in terms of the tone of their coverage, while the *Wall Street Journal* and *Foxnews.com* coverage had a much more pronounced skew towards stories with a positive tone. Taken in the aggregate, the positive tone of a majority of the articles across the entire corpus, combined with the predominance of "progress" framing of CRISPR emphasizing the benefits for science and health to come are important contributors to the overall dominance of "optimism". Figure 1-1 summarizes the assignment of tone codes by source.

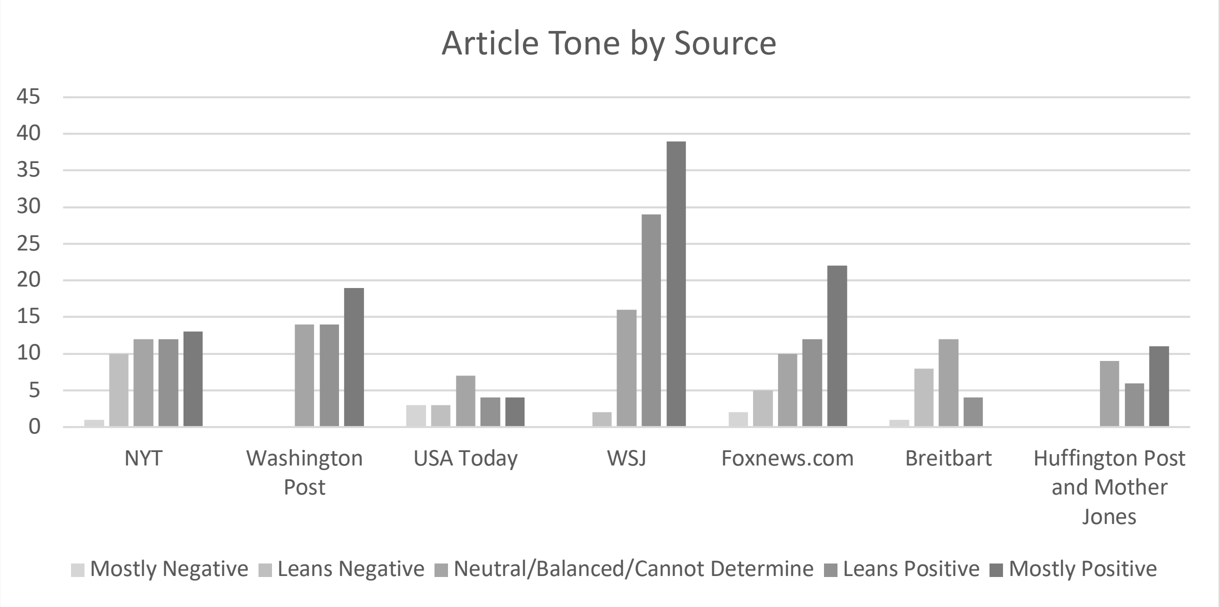

Figure 1-1. Article Tone by Source

1.3.4 Economic Prospects Encourage Optimism

The frequent framing of CRISPR in terms of its potential economic benefits is an important contributor to the optimistic narrative, with 30% of articles in the corpus discussing the economic benefits that are implicated in the growing technology. Unsurprisingly, this framing of CRISPR is particularly salient in the *Wall Street Journal* (52% of articles in the WSJ contained the economic benefit code), representing 49% of the total number of articles that were coded with the "economic benefit" code. The *Wall Street Journal* emphasized stories about the emerging biotech sector around CRISPR (e.g. Editas, Intellia, CRISPR Therapeutics), but also featured numerous experts from the private sector discussing the prospects and advantages of CRISPR for spurring economic growth in a variety of domains. In addition, stories about the finance and investment activities supporting biotech firms also tended to promote an optimistic picture of the future of CRISPR.

Discussion of economic benefits were less salient outside of *Wall Street Journal*, but certainly not absent. *USA Today* (33%), *Washington Post* (28%), Huffington Post (28%), and 20% of the articles on *Foxnews.com* included discussion of the economic benefits of CRISPR. For example, across the corpus, articles describing the patent battle between MIT and UC Berkeley over the foundational intellectual property claim to CRISPR-cas9 made clear that there were significant economic stakes in the development of CRISPR and that the efforts to claim the patent prize were entwined with rosy projections of a multi-billion dollar industry built on these foundational discoveries (Ledford 2016; J. Sherkow 2017; J. S. Sherkow 2017). A November 2015 piece in the *New York Times* described how amidst all of the enthusiasm for the various applications for CRISPR, the greatest potential was understood to be "speeding up the drug pipeline" because it would allow researchers to much more efficiently identify which mutations in a gene were significant and which mutations to target as they designed therapies. So even if the goal wasn't a CRISPR-based gene-therapy, the use of the basic science of gene-editing was rapidly seen as a fiscal boost for pharmaceutical companies.

1.3.5 Prominence of Scientists and Industry Impact Optimism

As with previous eras of news media discourse around genetics and biotechnology, coverage of CRISPR featured a significant influence of academic scientists and industry figures driving the news coverage and framing the narrative in their appearances in stories. The focusing event, or what prompted a story to be written, for 29% of the stories in the corpus was the publication or reporting out of a scientific finding or advance related to CRISPR, while 13% of stories were driven by commercial or financial announcements or news. Furthermore, scientists and financial or industry representatives were the two categories of participants in the discourse to be most commonly cited or paraphrased. Scientists appeared in 55% of articles across the corpus, by far the most heavily represented voices, while commercial or industry representatives appear in 14% of articles across the corpus. The predominance of scientific and industry voices in telling the tale is consistent with previous eras and further help explain why "optimism" about CRISPR was a salient feature of the discourse overall. These institutions and actors have strong vested interests in promoting the benefits of this evolving technology and communicating a positive, hopeful future that it will contribute to.

In relaying the story of CRISPR, the media trained its focus on a small group of innovators who became standard bearers and "heroes" of the field. 8% of the articles in the corpus were structured as features or long-form interviews of one or more key figures in the story of the invention and growth of CRISPR. These articles tend to draw attention to the moments of discovery, the challenges associated with success and often a humanizing touch of detail that reassures the reading public that these innovators are pursuing their science with noble intentions and cognizant of the possible harms or risks associated with their work. No single scientist did more in this role to promote a cautiously optimistic view of CRISPR than Berkeley scientist Jennifer Doudna. In 2021, Doudna was awarded the Nobel Prize alongside Emmanuelle Charpentier for the discovery of CRISPR-cas9, and was an important voice of optimism across the discourse. Doudna both frequently made herself available to journalists and actively sought to encourage public awareness and understanding of the technology she discovered. She is perhaps the key proponent of the "cautious optimism" approach, across the discourse. In the following passage from a lengthy *New York Times* feature piece on Doudna and the discovery of

CRISPR, we can see her both earnestly detailing the scientific potential of her discovery, while also being a notable voice of caution and concern around ethical questions and potential abuses of CRISPR from the earliest days.

> In practice, Doudna has said, it will most likely be years before we can safely edit the DNA of an embryo. But she also notes that the prospect of editing embryos so that they don't carry disease- causing genes goes to the heart of Crispr's potential. She has received email from young women with the BRCA breast-cancer mutation, asking whether Crispr could keep them from passing that mutation on to their children — not by selecting embryos in vitro, but by removing the mutation from the child's genetic code altogether. ''So at some point, you have to ask: What if we could rid a person's germ line, and all their future generations, of that risk?'' Doudna observed. ''When does one risk outweigh another?''

Such measured enthusiasm and the cautious approach to new applications, laced with the silver lining of potential medical breakthroughs, is a typical example of how the "cautious optimism" narrative unfolds.

1.3.6 Ethical Benefits Suggest Reasons for Optimism

One final thread that contributed to the "cautious optimism" narrative worth noting is the emergence of arguments about the ethical benefits of CRISPR and gene-editing. These arguments, advanced by bioethicists, transhumanists[3], commercial representatives and mainstream scientists alike suggest several possible ways that gene-editing either solves existing ethical problems in our current practices relating to human reproduction, agriculture, animals or medicine, or its advantages compel us morally to adopt the technology where possible and feasible. The primary "ethical benefit" argument is that a given proposed application of gene-editing will minimize or eliminate suffering, whether the suffering of individuals struggling with a debilitating disease, families facing an uncertain future based on a prenatal diagnosis,

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[3] Transhumanism is a social and philosophical movement whose adherents advocate the use of a variety of genetic and cognitive enhancing technologies in order to extend the life-span and radically enhance human health and capacities.

populations bearing the burden of vector-born illnesses like malaria that CRISPR-based[4] technologies might lessen. A June, 2018 article in the *New York Times* offers a typical example of this framing:

> Some ethicists see only good in the prospect of eliminating diseases that condemn families to misery. After all, don't childhood vaccinations amount to using technology for that very same purpose? Yet few people regard measles or polio shots as unacceptable fiddling with the natural world.

One notable example of an ethical benefit that is advanced in the media coverage of CRISPR comes up in the context of assisted reproduction. In the current practice for fertility clinics, multiple embryos are typically discarded in the process of fertilizing and selecting the best embryo for implantation. In this strain of the discussion, gene-editing is seen as morally advantageous to those who are especially concerned about this destruction of embryos since, in theory, gene-editing could be used to limit the number of embryos needed for a successful IVF process by eliminating embryos that carry the undesirable genotype. Geneticist George Church is cited in a *Foxnews.com* article from August 2017 advancing this idea that "genetic diseases affect about five percent of births, causing great suffering" and while "the mainstream medical approaches today kill embryos…this offers a route to avoid that…(through a process of) engineering the eggs". Similar arguments are advanced in the *Wall Street Journal* and the *New York Times* by mainstream voices. Editing or engineering embryos will allow us to avoid the moral danger that comes from the "kill(ing of) embryos". This argument, and Church's choice of words especially, seems calibrated to speak to a conservative audience who might otherwise be concerned about the use of gene-editing in human reproduction. This rhetorical shift, promoting

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[4] In this case, the application of CRISPR editing to enact a population-level "gene drive". There are several approaches to enact "gene drives" to eliminate populations, but the basic idea involves engineering individual members of a species to spread a particular version of a gene at a higher than Mendelian rate (>50%). Such a gene might be designed to block the unwanted risks posed by the species or cause a population collapse. See (Scudellari 2019) for a brief, accessible overview of gene-drive.

the image of gene-editors as champions of embryos, becomes a tactical move in a public debate, with a particular audience in mind.

The arguments for ethical benefits that may come from a CRISPR-mediated future are far less common, however, than the measured invocation of ethical risks which are the key piece of the “caution” in the “cautious optimism” narrative. I now turn to show how the “cautious” elements of the narrative were built across the news media. The key pieces include an emphasis on pairing progress with ethical risk, the invocation of “scientific reality barriers” to suggest ways that the development of the technology was under control (either nature or science) and finally the presence of bioethicists as key participants in the formation of the discourse around CRISPR.

1.4 Caution

1.4.1 Ethical Risks

Figure 1-2 presents the pairings of the six benefit and risk categories as they appeared in the corpus. These six risk and benefit categories are primary framing elements in this analysis (see Table 3) and include: medical or health, scientific or technological, economic, ecological, ethical or other.

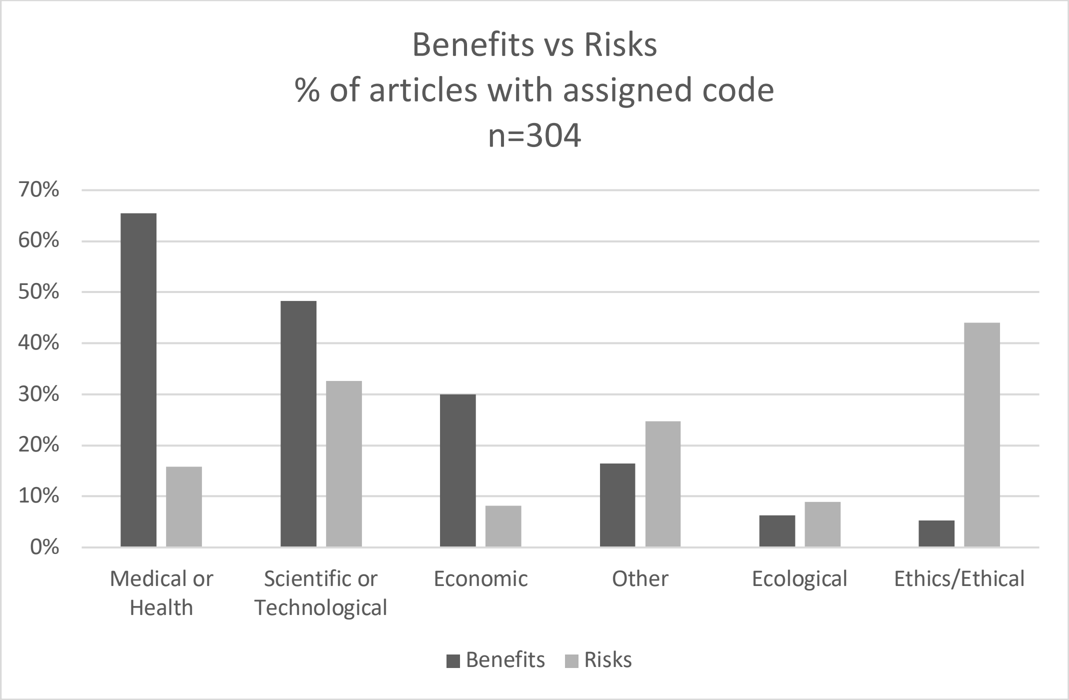

Figure 1-2. Benefits vs Risks

While it is possible to reconstruct a fairly rich menu of ethical challenges from the corpus, the typical presentation of such risks focused on the specific issues associated with germline gene-editing. This is reflective of an apparent consensus among scientists and elite bioethicists that somatic applications are generally not ethically problematic - this is largely due to the typical case being considered that of applying gene-editing to cure an existing condition in an individual where any genetic changes made would only impact that individual[5]. Thus, for gene-editing applications in humans, the germline issue is presented as the key ethical barrier that is being weighed against the prospects for human health, scientific progress and profit. The invocation of the somatic/germline distinction in the corpus thus served the function of

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[5] There has been a relatively minor pushback against the consensus view that somatic gene-editing is less worthy of attention and reflection. (Polcz and Lewis 2016) argue that the issue of somatic gene-editing has been largely ignored as a controversial issue, which my media analysis confirms. I coded for the "somatic non-controversy" and found that <3% of articles in the corpus included discussion of the possibility that somatic editing deserves greater scrutiny.

demarcating those applications of CRISPR that would be viewed as (for the most part) ethically unproblematic, from those that raise the significant ethical concerns such as the absence of consent of the future child, the prospect of altering the germ-line in unpredictable ways, the prospect of future harms due to undetected mosaicism or off-target effects etc. Thirty percent of articles discussed the somatic/germline distinction and 37% discussed some type of ethical risk, indicating the extent to which the progress and profits framings were offset with the framing of ethical risk.

The second most salient ethical risk concern is related but conceptually distinct from the specific concerns around germline editing. The issue of using gene-editing for enhancements, as opposed to treatment or prevention, raises the prospect of using CRISPR to modify the phenotypes of future people that would confer advantages such as greater strength, height or eyesight. In addition, there is discussion of cognitive behavioral modifications such as enhanced intelligence, greater sociality (minimized asociality) or fortifying aptitude for various activities such as sports or music. 23% of articles invoked the distinction between applications focused on *treatment* versus those aimed at *prevention* of future disease or *enhancement* of some trait. In addition, the concerns around enhancement were captured with coding of instances of the use of the terms “designer baby(ies)” and “designer genes,” a phrase that appears in 16% of the corpus.

In his recent analysis of the structure of the bioethical debate on gene-editing, John Evans fixes the terms of the debate around the figure of a “slippery slope” (Evans 2020). At the top of the slope, we find relatively uncontroversial applications of somatic gene therapy (e.g. using gene-editing to treat an adult disease with no prospect of genetic changes being passed on). At the bottom of the slope, we find the dystopian image of a society radically altered by the effects of widespread adoption of gene-editing, with enhancements and germline modifications common or normative (i.e. Brave New World or Gattaca). The “cautious optimism” narrative suggests that we can be assured that once we step out onto the slope, we will not slide down, either because of judicious regulations, thoughtful application of ethics or possibly the limitations of what the technology can actually do.

Because “cautious optimism” pairs progress with ethical risk framing, the narrative acknowledges the discomfort or uncanniness that innovations may provoke, but generally is quick to dismiss or minimize these concerns. Apparent risks are identified as merely apparent. For example, in November 2015 the *Wall Street Journal* published an article voicing “thanks” for innovations that "save babies". In this piece, which is written as a kind of thank you note to scientific innovations that led to things like CRISPR, the author analogizes CRISPR to incubators and claims that CRISPR and gene-editing is just as strange to our generation as incubators were to the first generation of patients 100 years ago. There were risks associated with incubators (as there are with gene-editing), but the overwhelming benefits make those risks seem small in retrospect and strongly suggests that the reader ought to have gratitude for innovators for these life-saving gifts. On this view, CRISPR is presented primarily as a medical intervention that will one day seem as familiar to us as the Neonatal Intensive Care Unit and the incubator for preemies.

Across the discourse, scientists typically don't have the language or inclination to talk in depth about issues like societal risk, eugenics, market eugenics, stigmatization of populations by phenotypes, discrimination etc. Instead, when addressing concerns about gene-editing, they tend to focus, first and foremost, on the technical risks the science imposes on them as scientists (risk of failure) or in terms of direct risks to patients or research subjects (risks of harm). As I demonstrate below, it is primarily the critics who are voicing the long term and societal level questions. Thus the risk discourse tended to center on proximal, near term, ongoing practices of gene-editing already underway or on the close horizon. In this way the discourse around CRISPR in the media, particularly in articles shaped by the "cautious optimism" narrative tended towards Evans' idea of a "thin" discourse. Longer term, and de-personalized societal risks seem to be more frequently waved off, even though they may be used by journalists to "hook" readers. Such risks worked as a way to evoke the science fiction and dystopian scenarios, but are typically dismissed in the course of an article by suggesting that they are either far off in time, unlikely to be possible due to technical limitations (scientific reality barriers) or will be stopped by judicious regulations or scientific norms.

1.4.2 Scientific Reality Barriers – Technical Risks and Polygenicity

Evans' conceptual tool of the "scientific reality barrier" can aid in understanding an important feature of the media discourse on CRISPR and the "cautious optimism" master frame in particular. The notion of the scientific reality barrier suggests that in debates over new technologies or scientific fields, the limits of discussion should go no further than the known and well-characterized limits of the science or technology. This is a rhetorical and philosophical move that seeks to keep such debates squarely on the side of known facts and thus avoid the intrusion of values or speculative discussion of potential applications. In a debate around CRISPR and germline gene-editing the invocation of the "scientific reality barrier" suggests that it is fruitless to engage in ethical debates when we don't yet know *if* or *when* such practices would even be feasible much less desirable. Evans argues that whether advanced in a strong form ('we'll never be able to do this dystopian thing you imagine') or a weaker form ('we will only pursue such things if we know they are safe to do') this barrier is ever changing and crumbling as our scientific knowledge and mastery over the technology advances. The "scientific reality barrier” cannot settle the matter of what is a just application of gene-editing in principle and can never, on its own, be a justification for why we would choose to do any particular act of gene-editing (just because we had the capacity to safely do something doesn’t entail that we should). On Evans’ view, it is foolish to not inquire about the ethics and desirability of as yet unrealized technical possibilities, since if we wait for such investigations until we arrive at the capability, we will always be caught unprepared. Further, Evans notices, though doesn’t develop in detail, that the invocation of the barrier can serve an “an ideological purpose of obscuring the scary bottom of the slope to increase the likelihood of moving past barriers further upslope” (Evans, 2020, p. 149). For the present study, this conceptual tool offers an additional way to understand how the “cautious optimism” narrative took prominence in the media and helped to support the consensus perspective that the scientific community, perhaps in consultation with bioethicists, would be largely capable of determining what would count as an ethically sound application of the technology.

Compared to earlier decades of coverage of genomics, much of the CRISPR coverage evinces a more sophisticated grasp of the technical risks and complexities of gene editing, helping journalists avoid naïve boosterism. In the “cautiously optimistic” discourse around CRISPR, scientific reality barriers were advanced to suggest the ways that CRISPR gene-editing may not be able to push us down the slippery slope, as Evans envisaged, towards the dystopian outcomes that some fear. Two such barriers are captured in the presence of technical risks and polygenicity. These offer a window into how the dominant discourse around CRISPR matched a sense of judicious caution with its optimism and how the discourse of risk and the role of polygenicity have shifted from earlier eras.

One third of articles across the corpus invoked the technical limitations of CRISPR in terms of risks that the technology was not (and possibly might never be) safe enough for broader applications. The most common technical risk cited was the potential for the CRISPR enzyme to make a double-stranded break in the wrong part of the genome. These “off-target” effects on the genetic sequence could have deleterious, uncertain and possibly unrecognized downstream impacts for patients, animals or plants. In addition, the risk of mosaicism, where the desired genetic transformation is incompletely realized across a person’s genome, leaving them with only partially modified DNA, was commonly mentioned as a technical risk. A small batch of articles discussing a study that found that CRISPR might trigger the immune system in certain people, leading to cancerous mutations of cells, raised the prospect that CRISPR-based therapies might not work for some (if not many) people. Such coverage of technical risks and potential limitations on the future of this technology was often followed in the financial press with reporting on the dropping stock values of key CRISPR-based therapeutics companies.

These technical limitations on CRISPR were invoked to reinforce a scientific reality barrier and offer readers a realistic sense of the kinds of challenges that the technology still faced before the potential applications might be expected to become available. Focusing on the technical details of the incremental nature of the science of CRISPR was an important way that the optimism was tempered with caution in this narrative and is the sort of journalism that scholars of media reporting on genetics and biotechnology have called for (Caulfield 2004; Condit 1999) to counteract the negative effects of scientific hype. Nonetheless, invoking this reality barrier in the discourse served also enabled the discussion to veer away from the downstream concerns and “thicker” ethical debates that Evans called attention to.

A small number of articles (5%) also tempered optimism about quick advances by reminding readers that most human traits are not controlled by single genes. While simple deterministic models of genetics have long been eclipsed by more complex models of polygenicity (Croucha and Bodmer 2020), gene by environment interactions (Boyce, Sokolowski, and Robinson 2020), epigenetics (Hughes 2014; Weinhold 2006) and multi-omics models (Hasin, Seldin, and Lusis 2017), Condit found that deterministic accounts of genetic causation persisted up through the turn of the 21st century. A trait is considered polygenic (as opposed to monogenic) when it is understood that multiple genes contribute to the expression of that trait. For example, the genetic basis of Sickle Cell Disease is understood to be monogenic, due to a single point mutation on the hemoglobin-Beta gene on Chromosome 11. On the other hand, many traits including height, musculature, intelligence etc. are understood to be caused by the product of several genes. Such polygenic traits are generally less well understood and are seen by the gene-editing community as a challenging (if not impossible barrier) to overcome for future possible uses of gene-editing. A further complication is that many genes are understood to be triggered by environmental factors which interact with organisms throughout the life course. Such gene-environment interactions also pose a challenge for gene-editing from a feasibility standpoint as the environment is changing and specific gene-environment interactions aren't sufficiently well characterized to know which genetic alterations would be beneficial.

The invocation of polygenicity or gene by environment interactions can be seen as the news media taking on a more sophisticated understanding of human heredity, moving away from simple (or simplifying) narratives that suggest most human traits are monogenic and well-characterized, towards the heightened complexity that is our current state of understanding. In earlier eras of media discourse, Condit and Peterson found that polygenicity and gene-environment interactions tended to be ignored as important pieces of the explanatory puzzle around genomics. Eliding these dimensions of genetic causal accounts of human disease and human difference tended to support the overly deterministic, even over-simplified, narratives about genetics that, in turn, supported deterministic conceptions of humanity. In the CRISPR era, while many articles still tend towards determinism and simple monogenic conceptual models aren't absent from media discourse, the use of polygenicity has changed.

I found that the idea of polygenicity in particular was invoked as a way to underscore the complexity of using gene-editing to engineer future people. Journalists, scientists and bioethicists alike advanced the idea that most of our traits, and many of the traits that raise concerns about enhancements (e.g. intelligence, behavior, appearance), are too complex in origin to be amenable to gene-editing. In the media, polygenicity was thus often invoked with a rhetorical purpose, namely as a way to minimize or allay concerns that are raised, usually within the same article, about the specter of "designer babies" or frivolous enhancements. A good example of this type of article is found in the *Washington Post* from August, 27, 2017, in an article debunking "myths about CRISPR". The author sets out to debunk the wildly optimistic idea that "CRISPR means a future without genetic diseases". They point to headlines in other outlets hyping the potential for CRISPR to cure all genetic disease, then argue:

> There are about 10,000 single-gene disorders that we've discovered - diseases caused by a specific, individual gene mutation. But there are thousands more that are caused by multiple genetic factors. Moreover, some genetic conditions are the result of new, spontaneous changes in DNA, called "de novo" mutations.

Polygenicity in the media discourse is thus an example of a "scientific reality barrier" that can serve to reassure readers that nature itself puts limitations on our editorial ambitions for the species. For readers, however, the push and pull here may be a bit confusing. On the one hand, they are told that CRISPR is poised to modify our essential characteristics and potentially transform humanity. On the other, there are hard limits (as far as we can tell), around the very nature of genetic causality that will put a brake on how fast or how far scientists can go with their efforts to modify us at the genetic level. As Evans observes, scientific reality barriers are ever-shifting as the techniques and adaptations of basic scientists to overcome the limitations imposed by the barrier continue to expand. CRISPR itself is a tool that has seen multiple significant steps forward since the initial discovery of CRISPR-cas9 as a gene-editing platform in 2012, e.g. CRISPR Prime and CRISPRon/off (Anzalone et al. 2019; Frederick 2021; Nuñez et al. 2021; Platt 2019). This kind of see-saw movement between poles of capability and aspiration is characteristic of the dominant "cautious optimism" view. While public discourse may be moving towards a more sophisticated, less deterministic conception of genetic causality, the very polygenicity that Condit and Peterson found wanting in the earlier eras of media discourse takes up a new role in the discourse around CRISPR as a scientific reality barrier that is used as a rhetorical tool to both assuage the fearful and reign in hype.

1.4.3 Bioethicists Supporting "Cautious Optimism"

As mentioned above, apart from the journalists and editorial contributors, the story of CRISPR told largely by the scientists who appear in 55% of the articles in my corpus. Notably, however, bioethicists are quoted or paraphrased in 12% of articles, and represent the third most common category of such participants across the corpus. There is significant heterogeneity of opinion among bioethicists on the issues surrounding gene-editing and their role in the discourse can be seen supporting all three of the main narratives. Their commentary ranged from highly supportive, hopeful, critical, reflective and cautionary. Bioethicists are called on to help clarify the ethical issues at stake around the various aspects of gene-editing in general and CRISPR in specific, offer supporting arguments for the morality of gene-editing given appropriate protections and assurances, offer reassuring (even calming) insights that suggest ways that the ethics of CRISPR modifications are well understood (its no different from IVF, or assortative mating) concerns are overblown and that the scientific community can manage these challenges. While there are exceptions, bioethicists in the discourse were often a key source of support for the dominant narrative of "cautious optimism." For example, the following passage cites one of the most frequently cited bioethicists, Alta Charo of the University of Wisconsin.

> Alta Charo, a bioethicist at the University of Wisconsin at Madison who is co-chair of the National Academies committee that looked at gene editing, said concerns about the work that have been circulating in recent days are overblown.
>
> "What this represents is a fascinating, important and rather impressive incremental step toward learning how to edit embryos safely and precisely," she said. However, "no matter what anybody says, this is not the dawn of the era of the designer baby." She said that characteristics such as intelligence are influenced by multiple genes and that researchers don't understand all the components of how such characteristics are inherited, much less have the ability to redesign them.

In this passage, Charo invokes the above discussed scientific reality barrier of polygenicity, while maintaining a sense of optimism about the prospects for future developments.
The case she is referring to in this passage is an experiment carried out in the U.S. to modify human embryos in 2017 in such a way that, had they been brought to term, would be less prone to developing heart disease.

Defending "cautious optimism" includes providing a positive moral case for future applications of gene-editing or simply clarifying the benefits of the new technology. Bioethicists provided such justifications, sometimes couched in moral language and sometimes by being highly accessible. For example, a July 2018 article appearing in *Breitbart* quotes a bioethicist claiming that "heritable genome editing may one day become an option for parents "to try and secure what they think is the best start in life" for their children." Grounding the reasonableness of adopting germline editing in an appeal to parental wishes for their children in this way is one way bioethicists kept the discussion grounded in concrete and relatable contexts. In a June 9, 2016 article in the *New York Times*, bioethicist Elizabeth Heitman offers a positive moral defense for continuing with gene-editing research to impact the environment: “The potential to reduce human suffering and ecological damage demands scientific attention… Gene drive is a fascinating area of science that has promise if we can study it appropriately."

One of the primary criteria for journalists when considering which sources to include in an article is that they provide good quotes. Bioethicists may be prized as sources in part because they have honed their communication skills, can usually speak to the scientific and ethical issues at stake in a story and often strive to be accessible. An example of bioethicists demonstrating a knack for accessibility can be seen in a 2017 *Foxnews.com* article, which quotes Hank Greely giving an account of why CRISPR is preferable than other approaches to genetic engineering: "When you stick a chunk of DNA in randomly, sometimes it works well, sometimes it does nothing and sometimes it causes harm…The advantage with gene editing is you can put the gene in where you want it." Another example of this accessibility of bioethicists is Alta Charo making the case that gene-editing will not likely be adopted by couples for “trivial reasons” in the *New York Times* (8/2/2017): “Sex is cheaper and it’s more fun than IVF, so unless you’ve got a real need, you’re not going to use it.” Such folksy descriptions of the scientific and societal issues in gene-editing contribute to the overall “cautious optimism” narrative by making the benefits of the technology tangible and the risks less worrisome.

The presence of bioethicists across the corpus supported the “cautious optimism” narrative in a variety of ways including sharing their own enthusiasm for gene-editing, defusing anxieties about slippery slopes, placing risks in context, offering positive moral cases for using and expanding gene-editing and by generally serving as an accessible bridge to the science.

In this section I have characterized the primary narrative around CRISPR as "cautious optimism" and detailed the framing of the discourse around enthusiasm for scientific progress and the market potential of gene-editing across multiple sectors. In addition, I found that this was matched with a strong presence of discussion of ethical risks that have followed the gene-editing debates for decades and a measured caution around the risks that the technology poses. Furthermore, I found that like earlier eras, though, the ethical debate carried out in the spaces dominated by "cautious optimism" tended to be ethically "thin."

1.5 Boosterism – Selling A Gene-Edited Future

As described above, media coverage of biotech has a history of becoming a venue to boost the image of science and scientists for readers (Briggs and Hallin 2016; Caulfield and Condit 2012; Condit 1999; Nelkin 1987; Priest 2001; Priest and Eyck 2003). The era of CRISPR is no exception and the enthusiasm around this technology is so prominent that it feeds into a second major narrative, which I am referring to as "boosterism". The boosterism narrative is characterized by the minimization of risks, valorization of "heroic" scientists, playing up the imminent potential for scientific, medical, agricultural breakthroughs, and heavy emphasis on the potential for financial gains associated with the technology. Boosterism exceeds the optimism of the master cautious optimism narrative by abandoning discussions of risk, minimizing or dismissing ethical considerations, and hyping the potential for gene-editing to improve society.

1.5.1 "Benefits Only" Coverage

Presenting the story of CRISPR as exclusively one about health, medical or financial benefits (real or imagined), without mentioning any of the various risks was fairly common across the corpus and contributes to "boosterism". One way to gain some perspective on the pervasiveness of this framing of CRISPR is to identify the percentage of articles that mentioned benefits of CRISPR without discussing any risks (Fig. 1-3). The 34% of "benefits only" articles gives an indication of the significant presence of boosterism in the corpus whereas "risk and benefit" coding was the most common (58%) pattern and, as discussed above, is characteristic of the "cautious optimism" narrative. Not *all* "benefits only" articles reflect boosterism to the same degree; some were too brief to give much detail at all. But the absence of *any* risk framing in such a large portion of articles is a clear departure from the mainstream habit of matching benefits with risks and points towards some of the known bad habits of hyping and over-selling the promise of new technologies that scholars have identified as problematic in media representations of the genetics revolution (Caulfield 2004, 2018; Caulfield et al. 2016; Caulfield and Condit 2012; van Lente et al. 2013; Musunuru 2017).

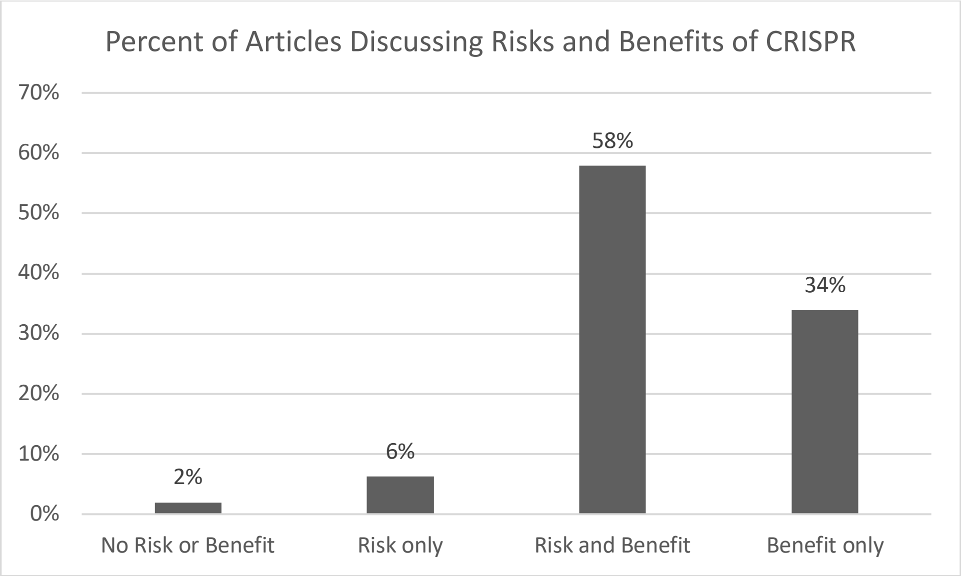

Figure 1-3. Percent of Articles Discussing Risks and Benefits of CRISPR

Not all sources were equally likely to use "benefits only framing. While 34% of the total corpus are classified as "benefits only" on my coding system, two sources, the *Wall Street*

Journal (50%) and *Foxnews.com* (44%) were the outlets that most commonly presented stories about CRISPR that did not include content that was coded as "risk" of any kind (Fig. 1-4). In the *Wall Street Journal*, such articles were commonly finance/investment-oriented news items that tended to include only capsule descriptions of CRISPR and its potential to impact biotechnological advancement, tying this progress to the economic prospects of biotech firms that embrace it. For *Foxnews.com*, the "benefits only" pieces were typically stories about applications of CRISPR that held the potential to solve a wide range of issues, from various diseases to the prospect of mitigating future shortages of chocolate. The only publication that always paired discussions of benefits with risks was *Mother Jones*, which publishes longer-form, magazine style journalism.

Some of the internal divisions in the American right-wing may be appearing in the news media coverage of CRISPR. Specifically, there is a notable difference between the *Wall Street Journal* and *Foxnews.com*, on the one hand, and *Breitbart* on the other with regard to the "boosterism" narrative. These findings suggest that there is more to the story of "boosterism" than a left/right split alone, with right-leaning outlets particularly prone towards market boosterism and left leaning outlets more skeptical of the commercial biotech, thus less likely to fail to mention risks or be prone to benefits only coverage. Among other things, *Breitbart* is known for its "anti-elite" or populist conservatism and economic nationalism. These dispositions can be observed in the fact that their coverage of CRISPR was heavily concentrated on the He Jiankui affair, with 15 of 25 articles focusing on the events, fallout and commentary on the rupture that this experiment caused. We also see in *Breitbart* a greater presence of traditional bio-conservative positions in the commentary and opinion pieces, whereas the *Wall Street Journal* and *Foxnews.com* published opinion pieces supporting the market potential for gene-editing. Thus the corpus reflects a spectrum of cultural and economic views on the right, with pro-market, libertarian conservatives represented in the boosterism of *Wall Street Journal* and *Foxnews.com* and the anti-elite, nationalist, traditional bio-conservatives appearing in *Breitbart*.

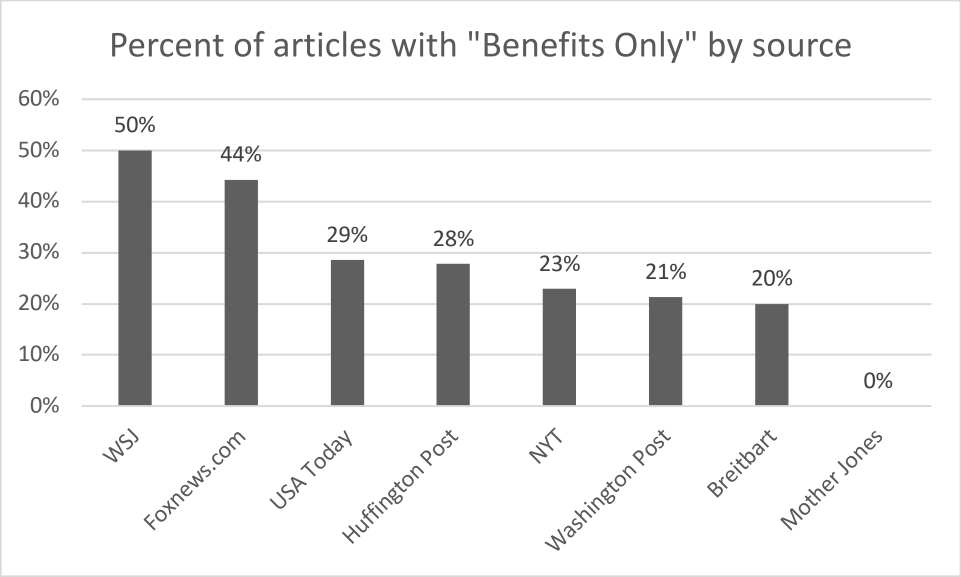

Figure 1-4. Percent of Articles with "Benefits Only" by Source

1.5.2 Scientific Boosterism

Often, the boosterism narrative focused on scientific potential. A *Washington Post* article from January 14, 2016 focused on the patent fight between UC Berkeley and the Broad Institute featured the following opening paragraph:

A futuristic gene-editing technology holds almost fantastical promise to turn biologists' wildest dreams into reality. The technology, called CRISPR, could one day be used to delete HIV from patients' cells, create a limitless supply of organs for transplant and produce better crops. It's already being used in laboratories around the world.

This enthusiastic language, veering towards hyperbole, proposing limitless scientific potential is an apt example of the kind of scientific boosterism that is typical across a good portion of the media discussion of CRISPR.

A *Wall Street Journal* piece from December 20, 2015, reporting on a new joint venture between Bayer Pharmaceuticals and Cripsr Therapeutics AG, a biotech startup founded by MIT's Feng Zhang, is a good example of what a typical "benefits only" piece looked like. Zhang was both a key figure in the development of CRISPR technology and a party to the intense patent dispute between the Broad Institute and UC Berkeley over who held the foundational patent for the CRISPR-cas9 editing platform. The article highlights the potential for CRISPR-based cures of diseases as well as the significant amount of commercial activity as the biotech startups that the leading figures in developing CRISPR began to partner with larger, more established pharmaceutical giants. The enthusiasm of pharmaceutical companies eager to position themselves so that they have a hand in the future of CRISPR-based therapeutics is captured by Bayer's head of the Life Science Division: "If we want to do the ultimate drug, what would be the technologies we would actually like to go for? And the top of the list was Crispr-Cas9 technology." Throughout the article, only the slightest misgiving about the potential for CRISPR-based therapies to eventually arrive are quickly moved past in a reassuring and somewhat simplified descriptions of CRISPR's potential, as in the following passage:

> "Still, Crispr-Cas9's potential remains unproven. Researchers have been exploring how to ensure Crispr-Cas9 finds and edits the correct cells once inside a body. Crispr Therapeutics said it has so far been successful in gene-editing human cells that can be extracted from the human body. The goal of that kind of treatment would ultimately be to return the treated cells to a patient."

The speculative nature of CRISPR's scientific potential is kept in view, while the possibility that it may not work as planned is looked past in such benefits-only articles.

Another example of scientific boosterism using benefits-only framing is found in a 2018 *Foxnews.com* article that describes the potential benefits of using CRISPR-based gene-drive technologies to eliminate mosquito populations from places where malaria is endemic. The piece fails to mention the possible ecological risks that gene-drive experiments pose (which are well characterized and examined in other pieces in the corpus) that are being contemplated by the scientific community. The challenges that public health officials face in addressing endemic malaria in resource poor countries are counterpoised with the potential slingshot solution of using gene-drive to impact the mosquitos.

> "The issue with this is that active compliance and participation means people taking antimalarial drugs, removing larval breeding sites and using bed nets, all things which are not always possible in areas where resources are scarce. Johns Hopkins' genetically modified (GM) mosquito, on the other hand, represents a suitable solution because it does not require any such active participation."

This passage illustrates a phenomenon that Arguedas-Ramirez (Arguedas-Ramírez 2020) calls techno-paternalism, a colonialist form of medical paternalism wherein scientific interventions at the level of the genome are viewed as preferable to the alternative of enacting solutions at the societal level that can improve access to resources and public health services for those populations. This is not to deny that the challenges of addressing endemic malaria in resource poor settings aren't especially daunting. Rather, the concern is that such techno-paternalism guides governments and NGOs away from finding workable solutions for the distribution of drugs, use of bed nets and removal of larval pools. Boosterism, and to a degree cautious optimism, narratives take such techno-optimism, the general disposition to valorize cutting edge technological approaches as almost inherently superior, for granted. What singles this article out for boosterism though is the failure to address the serious concerns about gene-drives raised by ecologists, activists and citizens in countries where gene-drive experiments have been proposed.

Similarly, a 2015 editorial in the *Washington Post* promoted "investment in health" and singled out CRISPR as a "startling accomplishment" of NIH funding in basic research that will surely pay dividends for all of society down the road. Like other "benefits-only" articles, the potential application that is mentioned is presented only in terms of its potential to bring revolutionary change. It is notable that as early as 2015, which was the first year that the *Washington Post* began reporting on CRISPR, the technology was being singled out for its "revolutionary" potential. While the cautious optimism narrative sought to stress CRISPR's continuity with previous discoveries and applications in genetics, the Boosterism narrative leaned into the language of revolution and the explosive potential that represents.

1.5.3 Economic Boosterism

Other articles focused on hyping CRISPR's economic potential. This economic boosterism was particularly prominent in the *Wall Street Journal*, which frequently provided a platform for commercial actors. For example, an early piece from December 20, 2015 highlights executives from Bayer Pharmaceuticals gushing over the potential for CRISPR-based therapies to bring cures for diseases that barely have effective treatments. This piece also was an early indicator of how major pharmaceutical companies would be positioning themselves in terms of their investment in CRISPR. It highlights new models of collaboration being explored in the formation of joint ventures (as opposed to licensing of intellectual property or outright acquisitions), where the nimble CRISPR start-ups, with mastery of the technology, would be the ones to lead discovery and later capitalize on the strengths of the pharma behemoths as needed, rather than the other way around. While risk of failure to develop or overcome the technical limitations are suggested, overall there was seemingly not much holding them back from striking gold in the economic boosterism narratives told here.

Overall, much of the *Wall Street Journal*'s coverage seemed primed to boost investor confidence by minimizing risks, downplaying concerns about fallout from the patent dispute, and hyping the sector and CRISPR's prospects as a platform for therapeutics. A typical example of boosting the sector's success as a means to prime the pump for future investment is a November 4, 2016 piece that summarizes neatly how CRISPR-focused companies' entry into the biotech sector emerged on the edge of a steady biotech boom, highlighting a streak of 166 venture-backed health-care companies that went public from 2013 through 2015, according to market tracker Dow Jones Venture Source. Another article from later in 2016 reports on a major investor in CRISPR therapeutics raising $350million. This kind of reporting, which is common in the WSJ tracks the major moves by investors and companies but offers no further context surrounding the technology.

The *Wall Street Journal* mixed longer form pieces on the advances in CRISPR science and the related technologies and techniques that CRISPR was making possible (e.g. xenotransplantation). There was also a fair amount of coverage of the patent dispute and the various moves by the three main CRISPR-based biotech firms (Intellia, Crispr and Editas) and the venture capital that supported them. The large number of brief reports on developments among the biotech firms focused on CRISPR were notable not only for their tendency towards benefits-only boosterism, but also their almost exclusive focus on applications for healthcare and medicine to the exclusion of agriculture. While a subset of articles did cover the agricultural sector's adoption of gene-editing, the majority of investment-oriented coverage in the *Wall Street Journal* was tied to tied CRISPR's prospects for medical advancements. In the words of one Biotech executive: "Mr. Bouchon (Bayer) said that both the Crispr and Versant endeavors aimed to harness new medical technologies to push the pharmaceutical industry to tackle "the challenge of moving from treatments to cures." (WSJ, 12/9/2016)

Considerations of “economic risk” were far less prevalent across the corpus with the *Wall Street Journal* (n=9) and *Washington Post* (n=7) the only sources with more than 5 articles discussing the prospect of CRISPR as an economic liability or risky investment. This result was somewhat surprising given the boom and bust cycles of biotech firms and the high-profile implosion of Silicon Valley biotech darling Theranos during the study period (Paradis 2016). I anticipated economic risk to be more salient in the media coverage of CRISPR, given the variety of ways that biotech investments can fail to bear fruit: potential for public rejection or backlash against the technology (cf. GMO), the possibility of scientific regulation slowing down this progress (cf. stem cells) or the potential for a failed experiment (or rogue actor) to set the whole CRISPR-as-medicine project back (cf. Jesse Gelsinger and He Jiankui). These or other economic risk concerns appear not to have been especially worrisome or salient issues for the *Wall Street Journal*, thus making way for the hype and economic prospect framing to tilt the coverage in this influential source towards boosterism overall.

When a failed experiment or a new discovery placed the scientific and economic prospects for CRISPR in doubt, savvy boosters knew how to manage the possible fallout. Here again, George Church serves as an exemplary source, when he reveals himself to be an astute observer of the relationship between science reporting and fluctuations in the stock market. For example, when a study revealed a potential risk that CRISPR derived gene-edits could trigger an immune response in humans, thus casting a shadow over the potential for CRISPR based therapies, and the stock market reacted negatively to this news, Church appears quite ready to move beyond the CRISPR hegemony on gene-editing, as he opined in the *New York Times*

(6/12/18): “We’re going to have a whole new generation of molecules that have nothing to do with CRISPR… The stock market isn’t a reflection of the future.”

While the economic risks associated with the patent dispute were covered as a salient issue, they were not seen as risks that would likely derail the future prospects of CRISPR and CRISPR-based therapeutics. As a September 9, 2016 report specified: “Some legal experts said that with the rights in dispute, the risk of getting sued for patent infringement is low, and a company without cash for multiple licenses in the U.S. could be better off pushing ahead with its own research and waiting until the dispute is resolved.” This passage suggests that the patent dispute need not weigh heavily in investors’ minds. Fears that an adverse decision (betting on the wrong horse) would undermine an investment should be weighed against the reality that the companies will surely license the tech if they win the dispute (so it may be costly to lose, but not wholly undermining of the endeavor).

Some individuals in the discourse were uniquely poised to tie together the threads of scientific and economic boosterism, none more so than Harvard scientist George Church, an iconoclastic figure who holds a position of considerable prestige in both academic science and translational biotech companies. Church plays an outsized role in the corpus as an *agent of hype* around the scientific, economic, ecological and societal prospects for CRISPR and genetics, a kind of “all purpose booster.” Widely available to journalists across the spectrum, Church appears in articles discussing the entire gamut of topics from the discovery of CRISPR, the patent battle (in which he was a key actor), the use of CRISPR in humans, ethical and policy questions, the use of gene-editing to support esoteric seeming projects like xenotransplantation and de-extinction of animal species and others. There was seemingly no topic relating to CRISPR and gene-editing that Church was not asked to weigh in on. Church was even among the few Western scientists to offer a partial defense of He Jinakui in the wake of the scandal that erupted around his experiments with CRISPR. Church appeared in 37 out of 304 articles about CRISPR, second only to Jennifer Doudna who appeared in 48 articles.

Church was also frequently cited in articles discussing the intense patent battle between UC Berkeley and MIT/Harvard/Broad Institute and on these occasions, demonstrated considerable market and media savvy. While most of the scientists at the center of the dispute tended to express annoyance or frustration with the dispute, in a 2016 *Washington Post* article Church offers a different perspective, suggesting that the patent dispute may ultimately be good for CRISPR business:

> I think genetics is going to be the source of lot of big decisions that are made by stock analysts, politicians and so forth, and it's about time we got excited about genetics," said Church, who holds CRISPR patents that have not been challenged. "If CRISPR didn't have a race for the technology, there would have been less attention.

Here Church is injecting enthusiasm for the commercial market for CRISPR into the discourse and offering the perspective that the patent battle helped to promote the technology among investors and other key stake holders. As is the hallmark of contemporary bioscience, a number of individuals in the CRISPR story occupy the dual roles of scientific leader and entrepreneur, Church is simply the most visible. Twinning the prospects of the science to economic futures was important for the mainstream cautious optimists and boosters alike, the differences more a matter of degree than of kind[6].

1.5.4 An Ethical Duty to Edit Genes

A key feature of "booster" coverage was neglecting ethical risks. A few articles went even further, identifying an ethical *imperative* to pursue gene editing. For instance, a 2018

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[6] A rich literature spanning multiple fields critically examines the entwinement of the scientific and economic dimensions of genomics that I do not have the space to review here, including: (Callahan 2006; Hughes 2011; Parthasarathy 2017b; Reardon 2017; Rose 2007; Sunder Rajan 2006).

Foxnews.com article quoted a Harvard Business School professor gushing over the potential for CRISPR to “allow us to, in real-time, edit life on a grand scale”. Further, he makes the extravagant claim that “the technology would greatly increase the amount of lives that could be saved on a daily basis,” and that the goal is ultimately to “take control of our own evolution.”

One of the arguments advanced by transhumanist philosophers is the idea that not only are technologies like gene-editing acceptable for use by willing individuals, but once the safety and efficacy of these techniques can be assured in germline editing, then we have a positive moral obligation towards future people to use them (Green 2017; Gyngell, Bowman-Smart, and Savulescu 2019; Hesman Saey 2017; Savulescu 2001; Savulescu et al. 2015). This question is raised in a *Mother Jones* article from 2017:

> Does the ability to fix genetic defects in our children force upon us the responsibility to do so? Does it mean that passively allowing nature to take its course is no longer a morally acceptable position? Probably. If I see a child about to get hit by a car, passivity is not an option.

This question of an imperative to use gene-editing is tied to both rationales for expanding basic research and expanding applications of the technology. In a 2016 meeting at the National Academies, the gene-editing community was weighing a debate over whether or not a moratorium on gene-editing research that involved embryos should be adopted. A *Foxnews.com* article from this period quotes the philosopher John Harris advancing the claim that "We all have an inescapable moral duty: To continue with scientific investigation to the point at which we can make a rational choice. We are not yet at that point. It seems to me, consideration of a moratorium is the wrong course. Research is necessary.” Harris, along with Julian Savulescu, is one of the more well-known proponents of transhumanist thought and this suggestion that that advancing research is an “inescapable moral duty” indicates the tenor of his position. This passage is also a clear articulation of the view that moral debate is only pertinent when all scientific constraints on a technology have been overcome, and highlights the boosterish tendency to minimize precautionary dialogue.

The argument for a positive moral duty to utilize CRISPR for germline editing is, in philosophical terms, a significant distinction from the arguments advanced by mainstream bioethics bodies, for example the U.K.'s Nuffield Council which endorsed the possibility of germline editing in a modest double negative. A spokesperson for the council is quoted in an article from 2018, "it is our view that genome editing is *not morally unacceptable* in itself…no reason to rule it out in principle" (*Breitbart*, 7/18/2018).

While most bioethicists and scientists endorsed the cautious ethical "yellow light" of the National Academies and Nuffield Council reports for germline editing, He Jiankui unsurprisingly took a more boosterish "green light" view of what was permissible and even morally required when speaking in defense of his gene-editing experiments. An article published in *Breitbart* from November 27, 2018 cites the argument He advanced in one of several YouTube videos that were released to stage the announcement of his work:

> "We believe ethics are on our side of history. Look back to the 1970s with Louise Brown. The same fears and criticisms then are repeated now," he said, referring to the first person to be born through in vitro fertilisation."

In another video, He advances the further claim that not only are the ethics on his side, but that the ethics of the situation compel him to act:

> "If we can help these families protect their children, it is *inhuman of us not to…*" (WSJ, 11/26/18)

One final example in a similar vein has a scientist contemplating the use of gene drive to eliminate the aedes aegypti mosquito who is quoted in the *Wall Street Journal* in 2016 advancing a similar ethical duty argument: "…it is our moral duty to eliminate this mosquito."

As discussed above, arguments promoting the ethical benefits of using gene-editing, while somewhat rare in the corpus overall, promoted a variety of ethical advantages of CRISPR that support both the optimistic view of the mainstream narrative and play into the boosterism view that sees the key solutions for the challenges we face across society in technology. For example, a December 12, 2018 article in the *Wall Street Journal* suggests that the use of gene-editing to engineer cattle without horns would be seen as ethically praiseworthy as it would “obviate the need to dehorn them”.

In this section, I have argued that a boosterism narrative played a distinct but sometimes supporting role to the dominant narrative around CRISPR in the U.S. media. Boosterism encompassed frequent use of “benefits only” framing, emphases on scientific and economic prospects and a supporting ethical framework that advanced the notion of an ethical duty to use gene-editing. In the final section of this analysis, I turn to the third key narrative, which was much less prevalent, but nonetheless present and possibly in need of amplification, the critical perspective.

1.6 Critical Challenges to the Dominant Narratives

Consistent with the findings of previous scholarship, the critical narrative in media discussions of CRISPR is far less salient than the mainstream “cautious optimism” narrative or the “boosterism” narrative. Nonetheless, there is enough of a presence of critical and activist voices to discern what a more robust critical narrative about CRISPR could be and what it would offer by way of contrast to the dominant story. As shown above, 11% of articles had a negative tone, and 6% discussed risks of CRISPR and no benefits. These are imperfect but useful approximations of the salience of the critical narrative across the entire corpus. In what follows, I draw together elements of a critical narrative that encompasses a more expansive set of social and ethical questions around gene-editing and is more openly pessimistic about the prospects for gene-editing to fulfill our ambitions for it. In a sense, the critical narrative displays a willingness to take the questions of "*whether and why"* we should use gene-editing technologies more seriously than the more commonly posed "*when and how*" questions. The critical narrative, insofar as it appears in the discourse, was largely present in non-mainstream sources and was supported by a small collection of outsider critics, activists and some bioethicists.

The critical narrative emerges in the U.S. media discourse through a very limited presence of critical voices, activists and among some bioethicists. In the early years of CRISPR, a few relatively well-known critics of CRISPR technology emerged as important voices in the debates among professionals at conferences such as the CRISPRcon, which has been convened annually since 2017, in academic and popular literature and on social media. While their critical interventions in the debate vary in terms of their receptivity to the less controversial applications of CRISPR (e.g. somatic treatments), these critics raise concerns and perspectives that tend to be underemphasized or unarticulated in most of the leading discussions around the technology. As compared with the voices of the scientists, entrepreneurs and cautiously optimistic bioethicists, most critical voices have not made inroads into the U.S. media discourse around CRISPR.

The critical narrative was marked by pessimism about the potential for CRISPR to fulfill our aspirations for it. These aspirations include not only our scientific, medical, agricultural or ecological hopes, but also our ethical, societal and even democratic hopes. This pessimism is a marked contrast from the techno-optimism that permeates the other master-frames. One notable example of such pessimism came from the interjection of famed physicist Stephen Hawking into the discourse. Hawking's posthumously published 2018 book included his views on the future of humanity and a bleak assessment of the impact of CRISPR (and Artificial Intelligence) on humanity. Hawking's views only made a brief appearance in the U.S. media with coverage in three articles in *USA Today*, *Foxnews.com* and *Breitbart*, which headlined his worries about CRISPR contributing to a race of "superhumans". This passage from *USA Today* summarizes his pessimism about the technology and its implications for society:

> Hawking said initially gene-editing technology will be used to correct genes leading to diseases like cystic fibrosis, but people won't resist using the technology to make them stronger or smarter. "Once such superhumans appear, there are going to be significant political problems with the unimproved humans, who won't be able to compete," wrote Hawking. "Presumably, they will die out, or become unimportant. Instead, there will be a race of self-designing beings who are improving themselves at an ever-increasing rate."

As I discuss below, this passage also demonstrates Hawking's serious concern for the "slippery slope" argument. Hawking lived with a debilitating case of ALS for decades and was a high-profile advocate for people with disabilities throughout his career. This perspective, combined with his scientific acumen and accomplishments, suggest that his perspective would be one to take seriously in these debates, particularly as techno-pessimism is otherwise so rare. The disability rights community and scholars have articulated similar perspectives on genetic technologies for a number of years, but are virtually absent in the media sample (Benjamin 2016; Boardman 2020; Garland-Thomson 2020; Parens and Asch 2003). The potential for gene-editing to exacerbate discriminatory and perfectionist uses of genetic selection, and thereby move society towards a market eugenics, are significant concerns for activists and scholars. But without significant media presence, the broader public has little access to such arguments.

1.6.1 Critical Voices in the CRISPR Debate

The main (really sole) exception to this pattern was Marcy Darnovsky who is the Executive Director of the Center for Genetics and Society (CGS) an organization known in the bioethics community as vocal critics of the rapid advance of genomic technologies. Politically left-of center, Darnovsky is deeply concerned about the justice and equity implications of advancing genomic science, the tendency for genomics to overlook the disability community's critiques of genomics and the blindspots that contemporary genomics has around its legacy of being at the philosophical and scientific core of the eugenics movements of the late 19th and early 20th centuries. Thus Darnovsky's critique of CRISPR and gene-editing is not premised on concerns about "playing God" or overriding divine creation, but rather the ways that our ambition to rewrite the genome might tend to exacerbate existing social inequities and entrench social divisions even deeper. Interestingly, of her 9 appearances in articles, 3 are in *Foxnews.com*, 2 are in *Mother Jones*, 2 are in the *New York Times*, 1 is in Huffington Post and 1 is in *Breitbart*. It is notable that one of CRISPR's most well-known critics (at least in bioethics circles), makes most of her appearances in the newer and more editorially ideological sources, while the prestige and mainstream press largely ignores her perspective.

Darnovsky's contributions to the discourse include calling for a "much broader range of voices" in policy discussions (NYT, 6/11/18), underscoring that decisions to advance with gene-editing are decisions that "will affect us all" and suggesting that heritable gene-editing would be a "society altering technology" (*Foxnews.com*, 12/1/15). A *Mother Jones* piece from February 2016 gave Darnovsky a considerable amount of space to present her concerns with CRISPR, starting with the concern that the off-target edits and unexpected mutations that are commonly a by-product of using CRISPR tend to be downplayed and that the technology may not be as precise and safe as it is typically portrayed to be. She also argues that that there are alternative ways (besides gene-editing) to limit the spread of inheritable diseases, cautions about the risks involved in harvesting eggs for reproductive engineering purposes and underscores the likelihood that the technology will be only accessible to the wealthy.

The notion of the "slippery slope," discussed above, has been an important fixture of the bioethical debate around gene-editing since at least the 1970s. In Evans (2020) view, two major barriers have been invoked as the keys to how society can safely step onto the slope to realize the benefits of gene therapy, but also avoid sliding inexorably down to the dystopian bottom where germline enhancements are commonplace. With the notable exception of He Jiankui's experiments, the somatic/germline distinction has held in both regulations and scientific practice, thought the door to germline editing appears to be unlocked. The treatment/enhancement distinction has also been fairly well upheld, with the scientific and public consensus converging around the idea that enhancements or non-medical uses of gene-editing should be off the table. Both of these barriers have proven to be remarkably durable as figures in the debate, advanced by both scientists and bioethicists as the key markers for discerning the desirable or good applications of gene-editing from the undesirable applications, though Evans argues we are much further down the slope already than we tend to acknowledge (Evans, 2020).

Unlike many of the bioethicists who tend to dismiss the idea that a trend of increasing somatic clinical applications of CRISPR will lead us collectively down the slippery slope towards enhancement and heritable modifications, Darnovsky raises the specter of the slippery slope argument in her appearances in the news media:

> Allowing gene editing for medical reasons would open the door to designer babies with cosmetic changes, too, she added. "It would alter future human societies, perhaps profoundly so," Darnovsky said Tuesday. (*Foxnews.com*, 12/2/15)

In a September 2017 article in *Mother Jones*, Darnovsky takes the slippery slope image one step further:

> "Sometimes I feel like we're not on a slippery slope—we're flying off a cliff," Marcy Darnovsky, executive director of the Center for Genetics and Society, which opposes the use of human germline modification for any purpose, told me recently. "People used to see this as a speculative science-fiction future, and now it's an urgent social-justice challenge."

On the release of a 2018 report issued by the UK based Nuffield Council on bioethics that addressed the prospect of future applications of germ-line editing in humans, *Breitbart*.com's coverage (7/18/2018) of this report included quotes from the report's authors defending the position they took, but gave Darnovsky the last word:

> Marcy Darnovsky at the Center for Genetics and Society in California said, however, that the report opens the door to gene editing for enhancement and cosmetic purposes, something generally considered ethically problematic.
>
> "They dispense with the usual pretence that this could – or, in their estimation, should – be prevented. They acknowledge that this may worsen inequality and social division, but don't believe that should stand in the way," Darnovsky said.
>
> "In practical terms, they have thrown down a red carpet for unrestricted use of inheritable genetic engineering, and a gilded age in which some are treated as genetic 'haves' and the rest of us as 'have-nots,'" she said.

These arguments that treat the slippery slope as a relevant and serious concern are rare in the CRISPR discourse. For the reading public, including this type of argument suggests that there are objections to the consensus view and that there are advocates for a far more precautionary approach than is being advanced in the dominant narrative. To be clear, Darnovsky is not opposed to all forms of gene-editing research or clinical applications[7]. Rather, she is casting a light on the blindspots in the dominant narrative. I next look at three of these blindspots that pose a challenge from a regulatory point of view and show how Darnovsky brings those issues in to the discourse.

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[7] As she told a Mother Jones reporter in 2016, "It's not exactly the technology itself that I'm worried about—it's with the application of creating genetically modified human beings. The gene-editing technology itself is first of all scientifically exciting, and second of all it could be used to help people who are sick. That could be great."

1.6.2 Regulatory Blind Spots – Fertility Clinics, Medical Tourism and Private Funding

In a *Mother Jones* article from 2016, Darnovsky advanced concerns about the unregulated fertility clinic space creating incentives and drawing in hopeful parents with potentially risky, dubious or ethically suspect interventions:

> I think it's very possible that once you unleash this technology onto the market and set it in motion, commercial and competitive dynamics would set in, and you'd see people that wanted to give their future children the best start in life. You can really see the ad copy writing itself.

Joining the critical narrative, bioethicist Arthur Caplan raises a similar concern about the social pressures that could impact commercialization of gene-editing in a November 23, 2015 article in Huffington Post arguing:

> Everyone's out talking about fixing diseases or making lab animals to fix diseases, but if you look at how interested people are in getting their kid into the right nursery school so they can get them into Harvard Business School — they're going to be interested in how they can engineer their kid to be more successful…

These questions about market pressures around fertility clinics important from societal and regulatory points of view, but like much of the critical narrative, this issue barely registers in the media discourse, thus depriving readers of a fuller sense of the kinds of issues that may arise in the future as the technology evolves and is adopted. A concern related to the expansion of gene-editing in fertility clinics is the prospect that even if regulations could successfully protect would be parents from dangerous or ineffective treatments domestically, markets will nonetheless open abroad where such services could be purchased (Béland and Zarzeczny 2018; Crooks et al. 2010; Hall 2011).

Darnovsky appears again in *Mother Jones*' coverage of the 2017 CRISPR experiment conducted on human embryos by scientists in Oregon. Although the US doesn't publicly fund such research through the NIH or NSF, and the FDA will not consider medical interventions based on germline editing, there are fewer regulations governing research using CRISPR on human embryos that is privately funded, as the Oregon work was. This third blindspot in the U.S. regulatory landscape, in addition to the fertility clinics and medical tourism issues, is another important area that the critical narrative casts some light on, but is largely ignored. The *Mother Jones* story ends tying together the threads of medical tourism, unregulated fertility markets and private funding. In the final sentence, Darnovsky is asked about the possibility that someone was already engaged in using CRISPR in a reproductive setting, presaging the birth of the Chinese twins He Jiankui just 14 months later.

> Do not expect the powers that be to stop our slide down this slope. "No one's minding the store on this stuff," Darnovsky told me. Congress passed a law in 2015 forbidding the Food and Drug Administration from reviewing applications for germline editing of human embryos, meaning no clinical trials can move forward. But research continues around the world, and the lack of regulation in some countries means that anyone who wants to escape the rules can do so. Fertility tourism is a major global industry; countries like India, Mexico, and Thailand already offer IVF at a fraction of the US price. China, which produces much of the cutting-edge research in the fertility field, seems to be enthusiastically exploring gene editing. When I told Darnovsky that I often wondered whether a scientist in some little-known lab had already created a genetically engineered child, she said, "I wonder that, too." (*Mother Jones*, 9/1/2017)

In this discussion, I have emphasized the contributions of Marcy Darnovsky to the discourse not to advocate for the positions she takes vis-à-vis gene-editing or CRISPR, but to demonstrate ways that critics contribute ideas and framings to the discourse that can be beneficial to the reading public. These positions challenge both the dominant tone of optimism, enthusiasm and potential for health and scientific breakthroughs represented by CRISPR, but also offer a contrast to the cautious optimism ("if we can just get the balance right…") framing that bioethicists tend to use. The relative dearth of such vocal critique in the media discourse around CRISPR overall, and especially the limited appearance of such positions in the mainstream and prestige outlets, leaves a conceptual gap for the reading public and an incomplete picture of the scope of viewpoints.

In addition to Darnovsky and the occasional critical interjection by a bioethicist, I also identified 34 speakers representing or affiliating with activist organizations who contributed to the critical narrative. These participants in the discourse offered the reading public a range of perspectives, typically focused on societal and ethical implications, that were otherwise overlooked or deemphasized by other experts.

Unlike Darnovsky, who, I noted above, was cited in the newer and more ideological outlets, other activists' contributions to the discourse were typically made in mainstream prestige outlets. Figure 1-5 summarizes activist contributions to the discourse and the sources where they appeared as compared with Marcy Darvnovsky. It is notable that while some activists, like Darnovsky, offer distinctively critical points of view, others make far more moderate contributions that carry the implication that activist communities are generally in line with mainstream views. I focus on the more overtly critical positions as they illustrate the ways a critical narrative casts the mainstream narrative in relief.

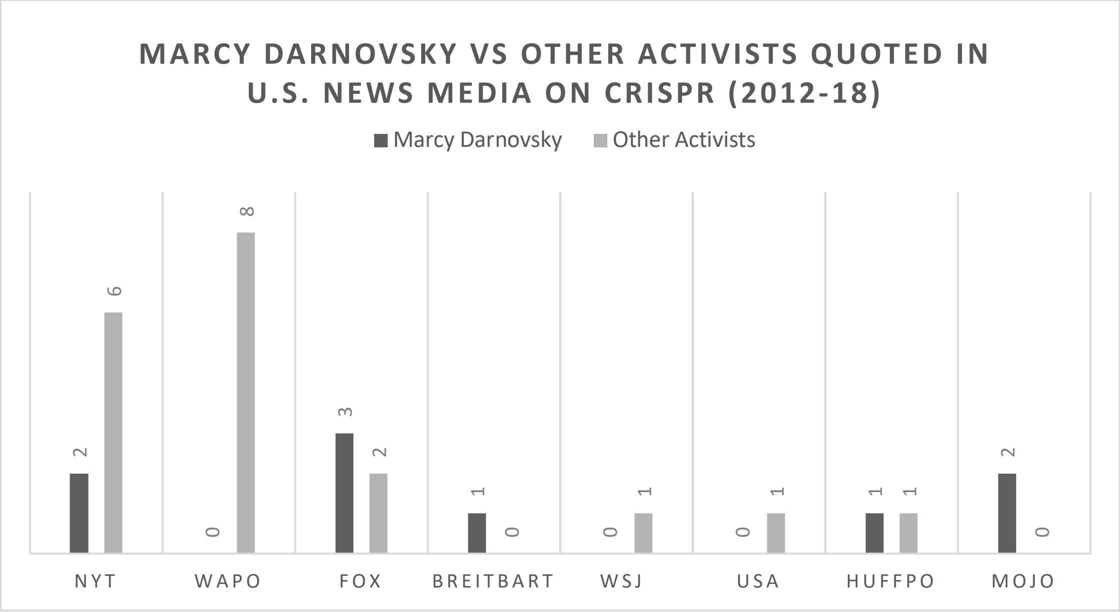


Figure 1-5. Marcy Darnovsky vs Other Activists Quoted in U.S. News Media on CRISPR (2012-18)

Activist contributions to the critical narrative tended to either focus on the science of gene-editing or the dominance of commercial and industrial interests in the development and deployment of these technologies. Those activists opposed to the gene-drive experiments and genetic modification of animals were among the most strident critics of the technology and its users. For example, Jim Thomas of the ETC Group is quoted in a press release from 2016 comparing the invention of a working gene-drive to "biology's nuclear moment," which holds "awesome power, potential widespread destruction and has significant geopolitical ramifications" (*Washington Post*, 6/9/2016). Meanwhile, Marianne Bassey-Orovwuje, an activist speaking out against gene-drives from the perspective of the communities who may be impacted by field tests, speaks frankly: "In Africa we are all potentially affected and we do not want to be lab rats for this exterminator technology" (*Washington Post*, 12/3/2018). Animal rights activists advocating for a rejection of the use of gene-editing to minimize the suffering of animals are likewise direct in their critique. David Byer of PETA is quoted in the *New York Times* arguing "People should stop consuming dairy or meat or eggs, not further manipulate animals by playing with their DNA." These perspectives enhance the discourse by presenting a view that challenges the foundational assumption that the technology should be employed once it has been deemed sufficiently safe and efficacious. Their rejection of the possibility that the technology holds the solution for their communities of concern help cast the techno-optimism of the mainstream in sharper relief. More attention to such perspectives would enhance the reading public's ability to perceive the broader set of possible rationales, principles and values that inform such critique.

Some activists focused on GMOs in agriculture were somewhat more open to the possibility that CRISPR-edited crops are indeed sufficiently different from the earlier recombinant DNA and gene-splicing techniques of earlier GMO as to warrant a cautiously optimistic approach, striking a more conciliatory tone. But others, less convinced of this distinction, offered highly critical views that focused on the concern that close relationships between corporate entities and government regulators might compromise safety and oversight. For example, Dana Perls of Friends of the Earth is quoted in the *Washington Post* raising concerns about the relationship between biotech firms and the National Academies being too close, that a report issued by the Academies includes “deceptive recommendations” and that the Academies are “biased towards industry interests.” This commercial skepticism was echoed by Jim Thomas of ETC who claimed that consumers “don’t trust (gene-edited crops) and we don’t trust the companies that are pushing it.” As above, this decidedly critical perspective on the use of gene-editing presents to the reader a broader set of concerns than those raised by boosterism or cautious optimism.

Priest and Eyck (2003) argue that activists need to be a part of the news media discourse in order for their messages to be heard by a sufficiently large audience. Furthermore, for activists and critics, “it is important that a dissenting message is publicized by the news media – that the rhetoric of a group of people with a particular, especially a non-mainstream, opinion, is made available for public reflection. This has the effect of extending the range of public debate.” I found that in the media discourse about CRISPR, the range of opinions and topics were indeed extended by the presence of critics, but that they were too few and far between to compete with the dominant framings and narratives of CRISPR. Critics like Marcy Darnovsky raised issues about human gene-editing that tended to be minimized by more mainstream bioethicists and scientists, including the construct of the slippery slope and the extent to which a consumer driven eugenics might be facilitated by wide-spread adoption of gene-editing and regulatory blindspots that imperfectly govern the applications of this technology. The comparatively small presence of critical voices suggests that these perspectives are struggling the most to be a part of the discourse at this point and that the dominant cautious optimism narrative, and the supportive boosterism narrative, would be enlarged by a more sustained engagement with critical perspectives.

1.7 Conclusion

Coverage of CRISPR in the U.S. news media in the years 2012-2018 was dominated by "cautious optimism." This narrative was marked by progress framing, a heavy emphasis on scientific and medical benefits, and a predominantly positive tone. It was told with support from scientists (who were by far the most prevalent type of quoted expert), commercial representatives, and bioethicists. Potential benefits were regularly paired with discussions of ethical risks, keeping the dominant narrative from slipping too far into techno-hype. This caution was further reinforced through sophisticated discussions of the science of CRISPR, including risks associated with CRISPR (off-target effects and mosaicism) and polygenicity. In previous eras, the invocation of polygenicity was exceedingly rare. In CRISPR discourse, the invocation of the polygenicity of human traits took on the rhetorical role of quelling anxieties that CRISPR would rapidly and surely lead to a dystopian future where any and all genetic changes would be ready to hand and easy to accomplish. Scientific reality barriers thus contributed to the due sense of caution that is characteristic of the dominant narrative.

The "Boosterism" narrative was a secondary, but important feature of the discourse that drives a techno-optimistic vision of the future of gene-editing. A substantial minority of articles invoked only benefits and no risks. These articles hyped both scientific and economic benefits of

CRISPR, and sometimes argued that society now has a positive moral duty to adopt this technology in the service of minimizing the suffering of future generations. Boosterism was prominent in some but not all right-leaning sources, reflecting fractures within the U.S. right-wing between traditional bio-conservatives becoming more focused on economic nationalism and competition with China (*Breitbart*) and market conservatives emphasizing the economic prospects of CRISPR (Fox, *Wall Street Journal*). The heavy emphasis of progress framing and the strong presence of "boosterism," particularly in certain outlets that haven't typically been included in analysis of media discourse of biotechnology, suggests that the era of CRISPR has continued the observed tendency towards hype, minimizing of potential risks, and upselling of the potential for cures and profits. We still have work to do to minimize hype, to more assiduously note risks along with benefits and to not over-sell the potential for cures.

Finally, critical voices and dissenters from the CRISPR revolution were included in the media discourse but only to a limited extent in the third "Critical" narrative. This continues the previous eras trend towards marginalization of critical voices. The importance of this relative lacuna in the media is aptly advanced by Priest and Ten Eyck (2003) who argue that the reading public needs to see the full range of perspectives on complex issues that have relatively low salience in order for such framings to become part of the mainstream discourse and potential. Marcy Darvnovsky and other activists presented perspectives that were either not present or were de-legitimized in articles advancing "cautious optimism". Following Conrad's observation that journalists tend to include marginalized or critical voices only when a concerted social movement is behind them, it may be that until an organized social movement emerges with gene-editing as a focal concern, such voices will continue to be relatively obscure in the overall public debates.

The critical narrative was marked by pessimism about the potential for CRISPR to fulfill our aspirations for it (Arguedas-Ramírez, 2020). These aspirations include not only our scientific, medical, agricultural hopes, but also our ethical, societal and even democratic hopes. As Arguedas-Ramírez argues, “The value of incorporating the vision of technological pessimists in these discussions is that the exploration and analysis are thus broadened. The inclusion of technological pessimism reminds us of the duty to apply the precautionary principle with rigor and seriousness” (Arguedas-Ramírez 2020). Pessimistic views of technology are clearly less popular amidst the enthusiasm surrounding gene-editing and may be dismissed with charges of ludditism, ignorance of the science or paranoia. The struggles that pessimistic views about gene-editing face to hold a place in the U.S. media discourse may have many sources, but the role of optimism is tied to deeper cultural affinities.

The pervasiveness of the “cautious optimism” perspective in the US media is, at least in part, a reflection of the dominant view of science in American society as a generally trusted institution and pathway to not only the truth, but also a key engine of social and economic progress (Funk 2017). The mainstream expert views that typify the cautious optimism narrative overlap considerably with the prominent statements that come from the quasi-official National Academies of Science, Engineering and Medicine (NASEM) reports from 2015 and 2017. These reports are broadly conceived as influential benchmark statements for the global scientific community. They are also viewed as having signaled a “yellow light” for the germline gene-editing experiments that He Jiankui pursued in 2018. Critics of the NASEM reports (Arguedas-Ramírez, 2020) observe that “…the conversation about the ethics of opening the door to [human germline editing] occurred between people who, in one way or another, profess technological optimism” (Arguedas-Ramírez 2020). Techno-pessimistic positions tend to not have a place in the articulation of consensus views and thus, almost by definition, relegate critics to the role of gadfly to establishment (and booster) actors and institutions. This outsider status translates to the marginalization of pessimistic perspectives in media (Arguedas-Ramírez, 2020).

1.7.1 Determinism, Perfectionism and Discrimination

The news media discourse around CRISPR placed a heavy emphasis on ethical risk framing and, I have argued above, the ethical risks that were the primary focus related to the prospect of using CRISPR to make edits to the germline or to use gene-editing to enhance individual traits (e.g. height, strength, memory, intelligence). These prospective abuses of the technology and the dystopian society that is portended by such abuse was often signaled by the frequently abused label "designer baby," which served as often as a way to introduce the topic and as a straw man to be later dismantled. This figure of the "designer baby" and a society made more unequal by the use of CRISPR to biologically exaggerate the advantages held by the well-off, encapsulates all three of the concerns that Condit traced in her seminal analysis of news media depictions of genetics across the 20th century: determinism, perfectionism and discrimination. The discovery of CRISPR brought these concerns back to the forefront of bioethical debate; however, I found that the news media has only partially captured the complexity of these issues. In many respects, the sophistication of the coverage around CRISPR helped to avoid naïve genetic determinism and the heavy reliance of scientists who are, by now, careful to avoid giving the impression that most traits follow single gene Mendelian inheritance patterns. The invocation of polygenicity in the discussions around CRISPR was interestingly not only about portraying an accurate picture of genetic inheritance, but also about making a rhetorical move to allay the anxieties provoked by the notion of a genome that is highly amenable to editing at will.

Perfectionism is a persistent theme in the debate with the strong current of ethical discussion focusing on the issue of treatments vs. enhancements. I found that the "cautious optimism" narrative tends to downplay concerns about using the technology for enhancement purposes, holding fast to the notion that a scientific "consensus" can serve as sufficient to regulate the behavior of gene-editors. However, I also found some in the bioethics community expressed a certain fatalism about the wide-spread adoption of gene-editing for enhancement purposes given the competitive nature of some societies, including the U.S. Meanwhile, at the far end of the spectrum, I also found transhumanists and "boosters" more generally were openly supportive of the notion of using gene-editing for enhancements. This is a vector of the debate that will surely continue to divide proponents and detractors.

Finally, the issue of discrimination is manifest in two key questions. Who will have access to the technology if it works? What does the choice of traits to edit say about which "kinds" of people are favored and which are disfavored? The first question is about the distributional issues that attend any new technology and, in the context of an already unequal health care system, how such distributional issues may tend to favor the advantaged with privileged access, while denying access to those lacking the appropriate kinds of advantage. The second question gets to the heart of the disability community critique of gene-editing and the debates surrounding it. As Ruha Benjamin notes, the disability community and their needs and interests ought to be front and center in the debates over the future of a technology like CRISPR as their very identity is placed into question by the prospect of editing certain ways of being human out of existence (Benjamin 2016). As I found, however, this perspective has been almost completely absent so far in the media discourse. When critics of gene-editing worry about the potential for malign commercial influence from unregulated fertility clinics, they are concerned about how future parents will confront the option of making deliberate choices about the genotype of their offspring, which will empower them to, in a sense, guide the evolution of the species. As one bioethicist in the corpus notes “eugenics is the ghost at the table”. The media debate so far has left news consumers in the U.S. ill equipped to face this prospect.

CHAPTER 2 - Always Too Soon, Until it's Too Late: Seeking the Public in Debates about Gene-Editing

2.1 Introduction

The gene-editing technology CRISPR-cas9 has, in under a decade, rapidly evolved into an indispensable tool of biology. Given the profound implications of gene-editing, whether in plants, animals or humans, the technology has provoked a number of calls for including society in the debates and discussions around future applications. These calls have come from CRISPR's leading innovators and leading scientific and bioethics professional bodies (Comité Consultatif National d'Éthique pour les sciences de la vie et de la santé (National Advisory Committee on Ethics in life sciences and health 2020; National Academies of Sciences Engineering and Medicine 2017; Nuffield Council on Bioethics 2016). But CRISPR has also faced controversy and legitimation challenges that resulted in experts engaging in what sociologists of science call "boundary-work." (Epstein 2011; Gieryn 1983, 1995) One of the primary challenges facing CRISPR-cas9 is that it is a field where the interface between the questions of science and the questions of ethics that it provokes are profound, abundant and visible. The need to include non-scientists (including the wider public) in the discussion and debates around the ethical uses of this technology suggests that the scientists will be ceding some of the control over its future, but as with any such struggle over professional autonomy, it is unclear whether this is truly a welcome prospect. Many in the CRISPR field have embraced and encouraged one vision or another of this openness in public statements and actions. Notably, CRISPR pioneer Jennifer

Doudna herself recognized that scientists tend to shape the terms of the debate over new, controversial technology in her own calls for greater public involvement in discussions of CRISPR. Others are less comfortable with what this might mean.

This chapter asks two related questions:

3. What roles have there been for the "general public" to play in the media discourse surrounding CRISPR?
4. What can the news media discourse about CRISPR tell us about why the voice of the "public" has been relatively silent so far in the CRISPR debates?

To answer these questions, this study draws on U.S. news media coverage of CRISPR from 2012-2018 to examine who appears (and does not appear) in media discourse, to unpack challenges to the authority of scientists to shape the terms of use and terms of the debate around CRISPR, and to uncover discursive strategies that scientists and bioethicists alike use in discussing CRISPR that tend to not make space for publics. I find that in spite of multiple calls for public engagement and public debate coming from within the scientific and bioethics communities in particular, neither the journalists covering the CRISPR revolution, nor the experts who appear in the media coverage of CRISPR, have sought out or conceived of which publics *could* be engaged to speak to the challenges posed by this scientific advance. Further, a close look at boundary struggles reveals practices that protected the authority of scientists, and to some extent professional bioethicists, to determine who are legitimate users and what are legitimate uses of this technology. In brief, the public is largely absent from the media discourse, but when they are present they appear as a force to be managed or educated in a uni-directional fashion. I find and describe a dynamic whereby the scientific and bioethics communities who are calling for public inclusion and engagement suggest that there is no rush for this to take place, but when urgent crises emerge or when the ethical challenges become more salient, journalists and expert communities rush to respond and the time for public engagement no longer seems possible. We end up with an implicit arrangement where it is always too early for public participation, until it becomes too late. If CRISPR science is going to be open to being shaped by the views and values of a broader public, then these trends suggest there is much work to do to broaden the discourse.

2.1.1 Public Engagement and Inclusion in Scientific Debates

Calls to engage the public around complex issues relating to scientific, technological and medical innovations have been around for several decades. These calls may seek to increase the democratic legitimacy of policies, address moral concerns provoked by innovations, to inform scientific regulations and policies, and/or to improve the quality of the scientific endeavor (Cunningham-Burley 2006; Degeling et al. 2015; Fung 2015; Solomon and Abelson 2012). STS scholars have argued that there are untapped forms of lay public expertise that may improve our understanding of some issues. Wynne's now famous study of how the insights of Cumbrian sheep farmers made substantive contributions to the scientific community's understanding of the long tail of the fallout from the Chernobyl disaster is a cornerstone of this body of work (Wynne 1992a). Alternatively, efforts to engage the public may serve instrumental goals: shoring up public support for the funding and autonomy of science and industry, receiving a public imprimatur of status quo policies governing technologies, or proactively testing for sources of dissent and opposition in the public (Greenberg 2001). The controversies that surrounded GMOs and stem cell research are two illustrative cases where public backlash was attributed in part to scientists' failure to get out ahead of the issue in the public imagination and discourse, and some fear the prospect of turning to a divided public to inform the debates over gene-editing (Burall

2018). In the present case, we can therefore be mindful that engaging the public, while typically initiated by those in positions of power, may be undertaken for a variety of motives and with a variety of objectives.

To an increasing degree, scientists and governing bodies have actively invited public engagement in the debates and discourse around issues in science, technology and health. Much of the work of assessing public understanding of science and public engagement with science and health has been conducted by social scientists and, in the case of genomic technologies, researchers funded by the ethical, legal and social implications (ELSI) branch of the NHGRI, using either aggregative means or deliberative means (Baker et al. 2021). The former seek to aggregate a broad representative sample of the public's perspectives on particular issues (e.g. surveys, willingness to pay experiments, etc.). Deliberative methods aim to identify and elucidate the underlying values and rationales for the positions and revealed preferences of smaller samples of publics ("mini-publics") assembled explicitly for the purpose of this task (Abelson et al. 2012; Baker et al. 2021; Blacksher et al. 2012; Degeling et al. 2015; Goold et al. 2012; O'Doherty et al. 2012; Solomon and Abelson 2012). Both aggregative and deliberative methods face critiques and limitations, as well as ongoing efforts to refine and improve the quality of inputs and outputs.

(Degeling et al. 2015)'s comprehensive review of deliberative methods used in health policy and public health research identified three configurations of "public" that have been articulated in scholarship from the STS tradition and the health policy literature. "Citizens" are configured in public engagement research as naïve participants invited to a deliberative event to become educated about a topic in health or health policy and then asked to deliberate with fellow citizens to seek some sort of consensus or, if consensus is not sought, then to allow ample space and time for all to voice their values, perspectives and, importantly their underlying reasons.

"Patients" or "consumer" populations are expected to be speaking from individual experience with the relevant health care systems and policies (Fredriksson and Tritter 2017) (Degeling et al. 2015) (Condit 2001) They are convened specifically because their experiences have primed them to be attentive to particular aspects of a particular health policy or ethical issue. Consumers are often particular patient populations and are seen in deliberative contexts as having a particular authentic expertise, based on their experiences, that can be especially helpful for informing policy.

Finally, advocates and members of social movements have also sometimes played an influential role in efforts to convene the public to deliberate about scientific questions. Advocates, or members of the "partisan public," represent interest groups, political organizations or social movements and may themselves hold technical expertise in a particular issue pertaining to health policy or ethics (Degeling et al. 2015). All three of these classes of "publics" have been included in public deliberations on various health policy issues and the analytical distinction is useful for thinking about which "publics" might be anticipated to appear in media discourse around health and health policy as well.

2.1.2 Deficit Model

Despite calls for rich and nuanced public participation, many efforts to engage the public are merely top-down science communication based on a deficit model. The "deficit model" suggests that an ignorant or scientifically illiterate public needs to be educated about science, and that this education will promote acceptance of scientists' priorities and support for science funding (Davies 2006; Marris 2015; Morrison and de Saille 2019; Simis et al. 2016; Wynne

1992b). This view of a public as largely ignorant and in need of education as a pre-condition to acceptance of new biotechnologies manifests in the ways that scientists discuss and frame the "public" in their media appearances. One potential pitfall of this approach is that the relationship between increased knowledge of genetic science and technology and increased support for genetic research may not be as linear as the model presupposes (Condit 2001). Some efforts at public engagement have been more bi-directional, with a goal of having public stakeholder views informing policy or shaping the future implementation of a technology. For example, although it has fallen in and out of favor in the U.S., the process called Technology Assessment or Health Technology Assessment has been an influential means for publics to participate in the ethical and policy dimensions of new technology adoption (Banta 2009). However, as (Cook, Pieri, and Robbins 2004) found, the rhetorical strategies and framings that scientists use in their interactions with the public can have the unintended effect of undermining and discouraging public engagement writ large.

To be sure, the deficit view is not uniformly held among all scientists. (Simis et al. 2016) found in their study of scientists' views of the public that 15% of their study participants held positive views of the role of the public in science and 13% of the scientists interviewed took a critical view of the term "public," rejecting it as suggesting a homogenous group that they themselves are outside of, and unconnected to. Nonetheless, the "deficit model" remains a dominant way that the expert scientific community relates to the public and shapes the form and content of many engagements at the intersection of science and society (Cook et al. 2004; Simis et al. 2016)

2.1.3 Boundary Work

In addition to an often tacit acceptance of a “deficit model” view of publics, we also often see scientists and experts draw a boundary between the technical and moral concerns that come with new scientific innovations, with public input limited to the latter (Morrison and de Saille 2019). Invoking hard distinctions between technical and moral concerns has the effect of dividing up the topography of possible engagement spaces. Technical concerns are understood to be the clear and unambiguous domain of scientific experts to debate, frame and make decisions on, while the public are cast as having only a legitimate claim to weigh in on “moral” concerns about the applications of the technologies. (Jasanoff 2012) shows how cultural variation in approaches to regulation might impact the nature of this dichotomy, depending on whether regulatory regimes target the process, products or research programs at issue. But the fundamental distinction between technical and ethical matters keeps scientists – and others accepted into the expert community – squarely in a position of authority to dominate discourse around the technology (including the assessment of risks and benefits). Moreover, the definition of which issues are moral and which are technical provides another site for scientists to set the terms of the debate. As J. Benjamin Hurlbut argues, the strong divide between technical and moral dimensions of genomics research reinforces “the notion that those who are in a position to make the technological future are also the most competent to declare what possible futures warrant public attention. This renders society and its institutions inevitably and perpetually reactive”(Hurlbut 2015).

Furthermore boundary-work, understood as the work scientists engage in to shore up the autonomy and authority of a particular scientific paradigm when facing a demarcation or legitimation challenge, can have impacts beyond the local struggles of scientists and fields (Gieryn 1983, 1995). In this chapter, I argue that boundary work of this sort can also have implications for the prospects of including publics in the debates and discourse over the future of a controversial technology. I find that the intense efforts aimed at *expulsion,* boundary work involving "insiders efforts to expel not-real members from their midst" (Gieryn 1995), that followed a controversial use of CRISPR in 2018, served to cast out the "rogue" He Jiankui, but also had the effect of excluding the public from participating in CRISPR debates.

2.1.4 Role Of Public And Experts In News Media Coverage Of Health And Science

Previous studies have shown that the people primarily quoted in news articles about science tend to be credentialed experts (Briggs and Hallin 2016; Caulfield and Condit 2012; Condit 1999, 2001; Conrad 1997, 1999c, 2001; Evans 2002) Studies that have classified the professional status of contributors to the discourse have identified a range of experts that are typically employed by news journalists to "make sense of the genetic revolution" including industry and industry scientists, university scientists, doctors, government officials, financial investors and advisors (Eyck 2005; Priest and Eyck 2003). In addition, bioethicists have become indispensable participants in the debates around biotechnology and have come to occupy the preeminent role in commenting on the ethical and societal dimensions of emerging biotech (Evans 2002), largely supplanting religious figures in media. Eyck (2005) describes the role of experts in these contexts as "agents of legitimation" (p.306), whose task is to either support or discredit the specific biotechnology at issue in a given article. This heavy reliance on experts accords with the "biomedical authority" model elucidated in (Briggs and Hallin 2016)'s study. News coverage in this model recapitulates a linear path from scientific knowledge produced by researchers and companies, passed on through accredited mechanisms of peer-review and publication, onward to doctors and producers of medical interventions and then into popular awareness and consumption. A related model is news coverage that is comprised of voices that constitute an “elite public sphere”. In this case the experts may voice contrasting views and perspectives on the issue at hand, but the field of potential participants is still delimited by domains of expertise.

To explain why media coverage of science tends to reproduce the point of view of the scientific community, scholars have noted that collaboration between reporters and scientists is required to assure accurate coverage of complex or technical issues (Conrad 1999c). Reporters often view the institutions of science, such as peer review, as license to let science reporting be “source driven” and “source framed” (Nisbet and Lewenstein 2002). Still others point to a shared culture between media and science that is driven by market logic, which can incline towards biotech “boosterism” around “investment opportunities” and “potential social benefits”(Priest and Eyck 2003). (Timothy Caulfield, 2018; C. Condit, 2001; Susanna Hornig Priest & Eyck, 2003)

When non-experts are quoted, they are often representatives of social movement organizations (Briggs and Hallin 2016; Condit 2001; Conrad 1999c). (Briggs and Hallin 2016) identify a deep *ambivalence* in news coverage of social movement actors overall; on the one hand showing *sympathy* for the energized and suffering citizen-scientists looking for justice, healthy communities or both, while on the other reinforcing the epistemic dominance of science conducted by credentialed experts (Briggs and Hallin 2016). Nonetheless, social movements can play an important role in getting the voices of affected publics into media coverage. (Conrad, 1999b) that the LGBT community’s political activism encouraged news reporters to consult them about genetic findings around homosexuality. This stood in stark contrast to the cases of alcoholism and mental illness, where journalists told Conrad that the prospect of seeking quotes from advocates for people struggling with alcoholism or mental health “simply hadn’t occurred to them” (p. 300).

The general public plays a much more limited role in media discussions about health advances. (Briggs and Hallin 2016) argue that in media coverage of health and science, members of the public often play roles the deficit model would assign to them: as passive recipients of information that equips them to engage with the medical profession if and when some particular constellation of symptoms occurs to them. Lay people are either presented in news stories to add a human-interest focal point, as health care consumers (e.g. coping with illnesses or learning how to use medical information), or they are the intended audience of news stories. In their role as audience, the general public is expected to interpret, understand and apply the information contained in the story to benefit their own health or become more informed consumers of health overall. In this configuration, the lay public do not contribute to health debates or the production of health knowledge. However, according to Briggs and Halin’s (2016) ethnographic analysis of health news producers (journalists, scientists, public relations professionals etc.), the intended audience of health news is often *not* the general public, but rather attentive policy makers, medical and finance professionals. The public is often “relevant mainly as an imaginary presence constructed in order to persuade policymakers or funders” (Briggs and Hallin 2016).

In sum, the public’s role in media discussions of health and biotechnologies has been found to be subordinate to the voices of experts and industry figures who have dominated this space of public discourse. Apart from the occasional instances where social movement actors have found a voice in media debates, the roles that seem to be most common for publics to play are as a passive audience, as consumers-in-waiting, or as an “imaginary presence” that must be contended with by industry, government or scientists. Expert and commercial anxiety around public backlash (real or imagined) against new innovations tends to reinforce both deficit model approaches to public engagement and ongoing boundary work to delimit the legitimate space and scope of public discourse.

2.1.5 CRISPR-CAS9

CRISPR is an important new technology that has emerged at a time of increasing public attention to genetics in scientific, clinical and consumer contexts. As I show in this analysis, CRISPR is also notable for the extent to which the expert community appears to want the public to be engaged in discourse about the future of the technology. Previous efforts have been made to assess the public's views of CRISPR have been dominated by public opinion surveys (Blendon, Gorski, and Benson 2016; Chan 2016; Funk and Hefferon 2018; Funk, Kennedy, and Sciupac 2016; Grant 2017; Kohl et al. 2019; McCaughey et al. 2016; Michie and Allyse 2019; O'Keefe et al. 2015; Riggan et al. 2020; Singer, Corning, and Lamias 1998). Deliberative efforts to understand public perspectives on CRISPR in the United states have been comparatively limited (Persaud et al. 2019; Riggan, Sharp, and Allyse 2019; Snure Beckman et al. 2019). Efforts are underway in European nations to engage larger publics on these issues. Ambitious plans to develop a global observatory for gene-editing, which would incorporate efforts to bring more public voices into the discourse, have also been undertaken but have not yet been put into action (J. Benjamin Hurlbut, Jasanoff, Saha, et al. 2018; Jasanoff and Hurlbut 2018a). Ongoing survey and deliberative research is needed as the shifting dynamics around the implementation of CRISPR in various arenas continues to evolve and thereby transform our sense of what is possible to do with the technology, as well as our thresholds of uncertainty.

In addition to surveys and deliberative efforts with mini-publics, research on public perspectives on biotechnology also can mine public discourse or "what is said in public" about the matter at hand (Condit 1999, 2001). The present study pursues this third dimension by turning to the news media. There are a number of important sites to capture this public discourse, but the news media plays a significant role in both reflecting and shaping public debate and influencing downstream policy.

We do not yet know what roles (if any) the public has played in public discourse around this revolutionary technology and how various "publics" have been configured in the public discourse by experts and journalists. We don't know how dynamics such as the deficit model, boundary work and reliance on expert voices and an elite public sphere, observed in previous studies of media discourse, played out in the era of CRISPR. This study helps to fill the gaps in our understanding of how these calls for inclusion of the public were made, how they unfolded in the media and how the elite public sphere reacted to controversies and challenges to their ability to control the narrative around the technology.

2.2 Methods

2.2.1 Media Sample and Coding Procedures

This study draws from a coded sample of 8 U.S. news media sources spanning 2012-2018. See Chapter 1 for a description of the sampling and coding procedures.

2.2.2 Descriptive Statistics

For this study, descriptive statistics were calculated for the identified speakers (using the code "experts and expertise") and other counts of relevant themes or comparisons within or between sources or years as needed. Speakers cited in the corpus were classified according to how they were presented in the news coverage. In addition to various experts, I coded for three categories of participants from the "public" that were called upon to participate in the narrative around CRISPR: "public or public opinion", "patients/consumers" and "advocates."

2.3 Results

2.3.1 Who got to "speak" in the U.S. news media about CRISPR?

Table 2-1 summarizes the presence of the various categories of participants that appeared in the news media sample.

Table 2-1. Participants in U.S. News Media Discourse about CRISPR

		Percent of Articles
Experts		
	Life Scientist	56
	Commercial	14
	Bioethicist	13
	Government	9
	Other Experts	20
Publics		
	Activist/Watchdog	9
	Patient/Patient Advocate/Citizen	2
	Consumer group/ Disease advocacy org	1
	Other Publics	4

Note: Percentages sum to more than 100% because articles can include multiple participants

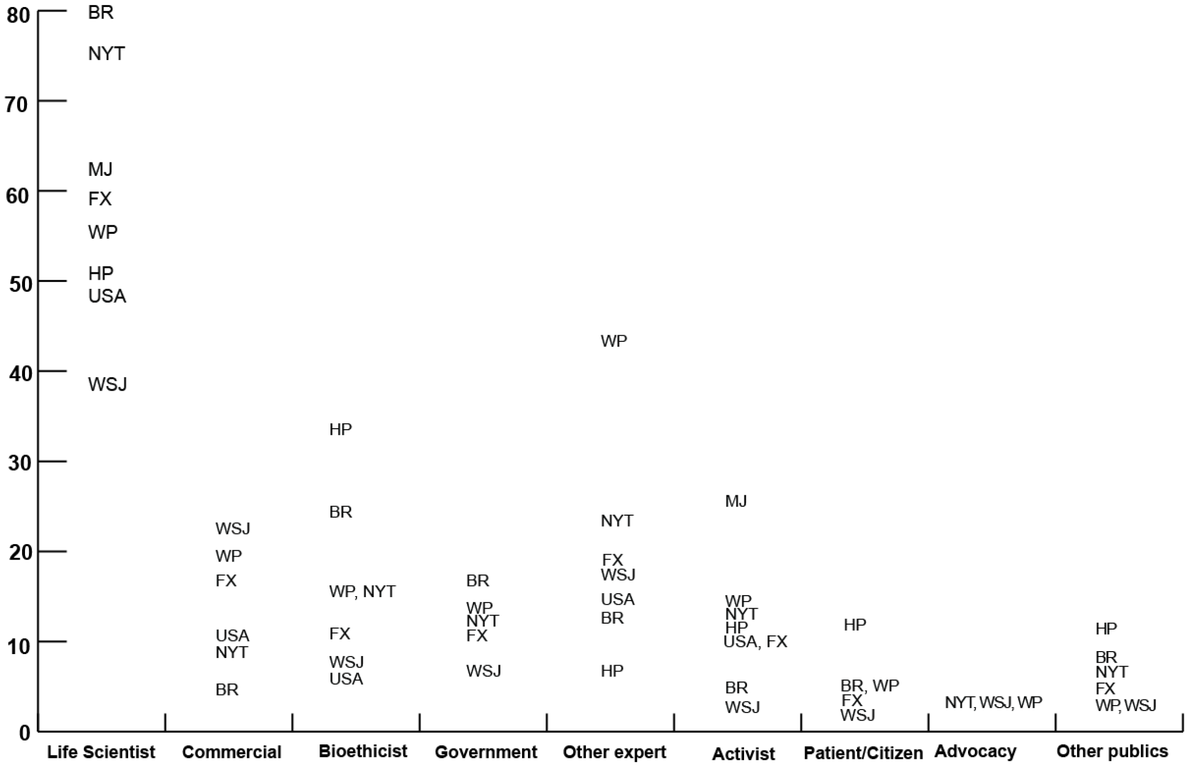
Experts identified as some form of life scientist associated with a University (e.g. Professor of Genetics, Assistant Professor of Biology) were the most prominent class of individuals in the corpus, being quoted or paraphrased in 169 of the 304 coded articles (56%). The story of CRISPR has so far largely been a story told by the scientists who are developing and using the technology. This finding is consistent with previous analyses of news coverage of biotechnologies that looked at the question of who participated in the discourse (Briggs and Hallin 2016; Eyck 2005; ten Eyck and Williment 2003; Listerman 2010; Marks et al. 2007; Priest and Eyck 2003).

The second most heavily represented group were representatives of the commercial industries involved in the translation of CRISPR science into various applications such as basic science, medical interventions, and agricultural innovations in animals or crops. Executives and representatives of most of the major companies in the agriculture and pharmaceutical sectors are called on to comment and (often) wax enthusiastic about the potential commercial applications of CRISPR across the corpus.

Four sub-categories capture the different "publics" that might have a voice in the discourse: "activists/watchdog," "patient/patient advocate/citizen," "consumer group/disease advocacy organization" and "other" which includes references to public opinion polling, religious figures or biohackers. Compared with the various experts, all four sub-categories are underrepresented in the corpus across all eight sources, however, the "activist" category was the most common among the various categories of "publics". Considering activists as part of the public is a debatable decision as they may or may not represent the perspectives of the broader public, but are more likely to have a voice in public discourse. I chose to align them with the publics in this analysis however, because relative to scientists, corporate representatives or government officials, activists tend to hold social positions more akin to members of the public, with little institutional influence.

How did the presence of various expert or public voices vary by source? Figure 2-1 summarizes the appearance of experts and non-experts in the media corpus by source, presented as a percentage of the total number of articles coded for each source. Life scientists are quoted or paraphrased in 75% of all articles written about CRISPR in the *New York Times*, while this group of experts appeared in 38% of the *Wall Street Journal*'s coverage of CRISPR. Unsurprisingly, representatives from commercial entities appear in 22% of the *Wall Street Journal*'s reporting on CRISPR. Commercial representatives also hold a strong presence in the *Washington Post* and *Foxnews.com*'s coverage of CRISPR, but are ignored by the left-leaning sources. This suggests that media analyses seeking to incorporate the perspective of the biotech sector should consider how omitting financial-oriented news sources will impact the sample. Bioethicists appear in a larger proportion of articles in sources with stronger ideological identification (Huffington Post and *Breitbart*), though the smaller total article yields in those sources should be kept in mind when interpreting this distinction. Articles in the *Washington Post* notably included a larger of array of experts that were collapsed under the "other" category (e.g. social scientists, lawyers, representatives of NGOs) compared with other news sources.

Figure 2-1. Experts Appearing in CRISPR Coverage



Percent of articles quoting or paraphrasing at least one expert of each type, by publication. Abbreviations: NYT = *New York Times,* n=48; WP = *Washington Post*, n=47; WSJ = *Wall Street Journal*, n=86; FX = *Foxnews.com*, n=51; USA = *USA Today*, n=21; BR = *Breitbart*, n=25; HP = *Huffington Post*, n=18; MJ = *Mother Jones*, n=8

Overall, when tallied and calculated as a percent of the total number of instances of source citations, contributions from the various types of "experts" represent 87% of the total of tallied contributions, while the various "public" participants account for 13% of this total, with the largest "share of voice" coming from activists. The public has yet to join the CRISPR discourse in the news media.

2.3.2 Engaging Publics vs. Managing Public Opinion: The Case of GMO 1.0 vs CRISPR

I found that news media coverage of CRISPR was predominantly focused on the technology's applications in humans (68% of the articles in my corpus) and only secondarily focused on agricultural applications for plants and animals (23% of the articles in the corpus). In this section, I focus on news media coverage of applications of CRISPR in agriculture to establish a contrast with the ways the public was figured in the discussions around CRISPR applications for humans. While there appear to be multiple motivations for engaging with publics around human health applications of CRISPR, I find that in media discussion of agricultural applications, the motives for engaging the public are more explicitly instrumental, aimed at shaping or managing public opinion, and guided by fears of public backlash.

In media coverage of CRISPR's potential to revolutionize the agricultural sector, CRISPR was hailed as an opportunity for a "reboot" on the debates around genetically modified organisms (GMOs) that dominated much public discourse in the 1990s and early 2000s (Fedoroff and Brown 2006; Krimsky and Nestle 2019; Priest 2001; Pringle 2005). The need for a reboot was a function of what has long been understood to be a disastrous unfolding of a science/society dispute over the health and safety of genetically modified foods going back several decades. The disjunction between public and expert views on GMO foods in the United States is aptly captured in a 2016 Pew survey that found (among other things) significant gaps between expert and lay public comfort with GMOs in the food supply, mistrust of commercial companies' motives, and skepticism about the quality and independence of media reporting about GMOs (Funk and Kennedy 2016). In the present study, the burden of past and ongoing challenges of this debate are palpable among the scientists and commercial companies leading the charge on adopting CRISPR in the agricultural sector, even as they extol the virtues of CRISPR crops and voice cautious optimism that the regulatory and public struggles will be far different this time around.

The fears of farmers and biotech sector companies around public rejection or backlash was a prominent theme across all media. A *New York Times* piece from November, 26, 2015 conveyed the awareness among some industry groups of the potential for discord between producers and consumers, citing dairy industry group representative expressing concern about public perceptions of gene-editing: “I think dairy farmers are going to want to see how this [CRISPR modified hornless cattle] is interpreted by the general public.” Meanwhile, a *Washington Post* article (6/14/2017) captured the sense of deep anxiety over replaying past controversies, describing earlier GMO debates as “an unqualified public-relations disaster” for industry and highlighting the different approach industry was taking this time around to include “proactively neutralizing skeptical consumers – years before these crops will even be available.” A year later, an activist from the Center for Science in the Public Interest was quoted in the *Washington Post* (11/27/2018) describing the “battle scars from the GMO debates” and the prospect of “…questions raised about this technology.”

News media coverage of GMO 1.0 (as it is referred to in media reporting) vs CRISPR-edited crops reveals a distinctive view of the public as a force to be *managed* and *preemptively persuaded* to embrace the fruits of CRISPR-ed crops. Unlike the cases of human gene-editing and gene-drive, where the scientific and bioethics communities sought first consensus and then later at least discussion, the agricultural sector embracing CRISPR sought to address the public through public relations and public persuasion. The aforementioned *Washington Post* article from June 2017 featured discussion of DuPont Pioneer’s strategy for public relations, which included convening focus groups with people in government, agricultural and environmental organizations in order to “learn more about the public's CRISPR concerns and use them to inform future messaging efforts. In addition an informational website was seen as "’the first step’ in a larger campaign to win consumers' trust for the technology.” The explicit goal of engaging with the public is thus “persuading consumers to support gene-edited crops…” (*Wall Street*

Journal, 10/10/17) and, as a DuPont executive cited in *Washington Post* put it "getting social license for this technology." As is apparent in the above passages, companies took on the tactics of public relations and consumer persuasion in anticipation of a feared backlash. There is little suggestion here that publics ought to be participants in discussing, debating or seeking consensus on the appropriate and ethical applications of gene-editing in agricultural practice.

2.3.3 Hope that a Scientific Distinction Can Assuage Societal Fears

Advocates for agricultural applications of CRISPR hoped that a key scientific distinction between GMO 1.0 and CRISPR-based GMO would rescue them from public disapprobation. This strategy was summed up in the *Wall Street Journal* in 2017, when a Dow DuPont executive argued that "gene editing is different because the technology can be used to make edits within a plant's existing genetic code, without adding any outside genes.“ He likened it to ”the centuries-old process of breeding together different strains of plants to produce an improved version“ (WSJ, 10/10/17). The distinction between transgenic organisms, where genetic material from a second species is introduced into the plant genome of interest, and gene-editing of crops where the genetic modification is merely a modification done to the genome of the plant DNA itself was seen by the advocates of CRISPR-based agricultural innovations as a distinction that would resonate with the public and allay the concerns of GMO activists. Interestingly, the discussion of the differences between GMO 1.0 and CRISPR crops is a notable exception to the general tendency to keep such technical distinctions outside the realm of public concern and debate. The existence of an entrenched, activist anti-GMO movement and the growth of the lucrative market for "non-GMO" food products help explain why the commercial and scientific communities developing gene-edited crops may see a need for engaging the public on the level of the scientific details of gene-editing.

While they were often excluded from the media discourse, a few activists indicated that the more open approach to debating the science could be warranted. For example, a May 18, 2016 article in the *Washington Post* cites an activist named Jim Thomas from ETC Group, an organization focused on issues of technology and corporate influence, offered a critique of the National Academies report on gene-edited crops that suggests the activist communities would find the distinction unsatisfactory:

> In our view the [National Academies] report is inconsistent on the crucially important question of whether or not to regulate the new techniques such as genome editing and synthetic biology. That is the most urgent question regulators face right now…the potential for gene-editing techniques to have "off-target" effects should persuade regulatory agencies to focus on the process and not just the ultimate product…"

Given these concerns, the strategy of invoking the distinction between GMO 1.0 and CRISPR in order to insulate the new practice from protest might yet face headwinds.

Given the aforementioned mistrust in commercial actors that was found in the Pew survey, the question of *who* is best positioned to bring a positive message about gene-edited crops becomes an interesting one. Scientists were found to be among the most trusted voices when it comes to the facts about GMO products and it seems that the industry is aware of this and hoped to foreground voices from the scientific community, a dynamic captured in the *Washington Post* (6/14/2017), which cited a "pro-GMO activist suggesting that "public-sector scientists may be best positioned to deliver messages about CRISPR." This GMO advocate claims "There's great optimism that this time we'll do communications better…the great hope is that CRISPR is going to be different." However, putting a trusted face on a commercial message can be risky, as this activist/critic noted in a 2016 *Washington Post* article: "I'm concerned that [the National Academies] findings and recommendations are deceptive and even biased toward industry interests".

Meanwhile, light-hearted pieces, such as a January 9, 2017 piece in the *New York Times* describing a private dinner, with celebrity guests and gene-edited foods prepared by a celebrity chef, are indicative of the kinds of collaborations between commercial interests and journalists that are directed towards softening public opinion towards the use of gene-edited crops in the food supply. This drama is still unfolding, so it is yet to be determined if the skeptical public will view the two modes of modification as dissimilar in the way that commercial companies developing this technology hope and embrace new food crops created with CRISPR. For the purposes of the present analysis, the takeaway is that vocal advocates for gene-editing in agriculture opted for a public relations approach designed to win over skeptics and avoid the damaging battles of a previous generation. As far as including the public in debate or discourse on the future of the technology, this approach only leaves one role for the public to play, namely consumer. As we will see in the next section, this stands in contrast to the scientists, bioethicists and commercial representatives focused on gene-editing applications in human health, where from the early days of the technology calls for public inclusion were made, even when the means and ends of such “inclusion” were undefined.

2.3.4 Calls for “Broad Societal Consensus” or Calls for Societal Debate

The concern among scientists around the potential for CRISPR to ignite significant controversy and the need to include the public in debate was articulated in several position statements published by leading scientific and ethics bodies, most notably the National Academies of Science and Medicine 2017 report on Human Gene Editing (National Academies of Sciences 2017). These calls took somewhat different forms, but the main sentiment is well-captured by the following passage from the *New York Times* from December 3, 2015.

> An international group of scientists meeting in Washington called on Thursday for what would, in effect, be a moratorium on making inheritable changes to the human genome. **The group said it would be "irresponsible to proceed" until the risks could be better assessed and until there was "broad societal consensus about the appropriateness" of any proposed change**.

The desire for "broad societal consensus" was thus suggested from the early days of the CRISPR era. The above passage was from a report on the 2015 Napa conference that was convened by David Baltimore and David Berg, two key scientists associated with the famed Asilomar conference of the 1970s, which was held in order that the scientific community developing the emerging technology of recombinant DNA (rDNA) could address a variety of uncertain risks and fears associated with this technique. The multiple calls for societal input or consensus indicate that the scientific community building CRISPR technology was not only keenly aware of the broad societal implications represented by gene-editing but also that the "public," however that concept is construed, ought to have a say in how the technology develops.

Calls for inclusion began in 2014, a mere two years after the initial discovery of CRISPR-cas9 as an editing platform, and continued on through the end of 2018 and beyond. For instance, a 2014 *New York Times* article cited authors saying that CRISPR "warrants a public discussion right now." Calls for public inclusion varied in how they characterized the actual end goal that was sought from such inclusion. For example, coverage of the 2015 Napa conference picked up on the language of the report calling for "broad societal consensus," which, if taken literally suggests the need to adopt some appropriate process to arrive at consensus. Societal consensus is a much higher bar, and a much larger undertaking, than the more vaguely articulated needs for "broad public discussion," "societal consideration," "public conversation," or "public engagement." Consensus is a particularly problematic way to frame the idea that the public has important and meaningful contributions to make to debates about the future of CRISPR because publics are heterogenous and unlikely to unanimously support a single, unambiguous consensual perspective on the technology. As (Morrison and de Saille 2019) write, "if consensus means that every-one, or at least the vast majority of people, must agree that a technology is acceptable, then true consensus is very rarely if ever achieved at a societal level—never mind on a global scale."

Early discussions around gene-drive also presented the inclusion of society as aimed toward achieving a consensus, asking about *whether* to use the technology (as opposed to *how* or *when*). For example, the *New York Times* in December 2015 quoted a scientific journal stating that "the decision to deploy a gene drive must be made collectively by society."

The language of seeking consensus seems to drop out of favor after that initial 2015 meeting and less directive and policy-informing phrasing such as "societal consideration" (*Wall Street Journal*, 3/11/2016), "public engagement" (*Mother Jones*, 6/11/2016) or "public discussion" (*Washington Post*, 2/15/2017) became more common. This shift may reflect dissatisfaction with "consensus" as a goal for public engagement and inclusion in the debates over the future of gene-editing, but it leaves unanswered how serious engagement with the public should proceed, how it can be done in ways that avoid previous mistakes in public engagement and how it can avoid being seen as an attempt to simply convince the public to accept a series of pre-determined outcomes (Balsimme 2019; Degeling et al. 2015; Hurlbut 2015; Jasanoff 2012; Morrison and de Saille 2019).

While several notable scientists were making calls for public engagement, other scientists drew a firmer boundary between experts and the public, reserving key ethical questions for expert discussion. An op-ed published in the *Wall Street Journal* by David Baltimore and Paul Berg (April 8, 2015) sought to delineate the terms of the debate before the discussions about

CRISPR got going. Baltimore and Berg are two leading life scientists who (along with Maxine Singer) organized the famed Asilomar Conference on Recombinant DNA (rDNA) in 1975, a gathering of scientists to explore and determine how to mitigate the risks posed by rDNA. While lauded by some as an exemplary case of scientific self-regulation, the Asilomar conference has been also critiqued for its insular character and failure to include the perspectives of a broader array of experts (e.g. social scientists and science policy scholars) or the general public (Berg 2008; Greely 2015; Hurlbut 2015; Parthasarathy 2015).

In this op-ed, Baltimore and Berg maintain a focus on the well-established (Evans, 2002) concerns around germ-line modification as the key (possibly sole) source of serious ethical concern. Further, they advance a very clear preference to let the scientific community make the determinations about what is controversial or new about CRISPR and, importantly, how to proceed. Their call for an international meeting that is focused on the scientific community is a good indication of the boundary protecting that some scientific experts in the gene-editing world hoped might manage the debates going forward. On their view, the scientific community needs to sort out the legitimate boundaries for how and when to implement the most controversial uses of CRISPR and gene-editing, with no invitation to the public, patient communities, or other stakeholders to participate. Notably, the WSJ published two diametrically opposed letters in reply to the op-ed, one a physician's urgent call to apply gene-editing technology to solve serious health problems and not allow the science to get stalled by ethical debate, and the other presenting a fatalistic view that no regulatory controls could adequately safeguard the technology from rogue actors or abuses.

2.3.5 How vs. Whether: Which Comes First?

Following the release of the National Academies report on gene-editing in 2017, the *New York Times* quoted bioethicist Alta Charo, one of the lead authors of that report, as setting forth the temporal order for public engagement around the specific issue of moving gene-editing towards clinical trials. Her remarks also conveyed an urgency for getting the discussions underway; she stated that "it is essential for public discussions to precede any decisions about whether or how to pursue clinical trials of such applications… And we need to have them now" (NYT, 2/14/17). The *Washington Post*'s coverage of the release of the National Academies report also mentioned the report's recommendation that public discussion *precede* clinical trials.

By contrast, Richard Hynes, co-author of the 2017 NASEM report, suggests the opposite order. He appears to claim in a 2017 NYT story that societal debate around gene-editing should occur after the technical and safety issues associated with germ-line editing have already been worked out by the scientific community:

> "We've always said in the past gene editing shouldn't be done, mostly because it couldn't be done safely," said Richard Hynes, a cancer researcher at the Massachusetts Institute of Technology who co-led the committee. "That's still true, but now it looks like it's going to be done safely soon," he said, adding that the research is "a big breakthrough."
>
> "What our report said was, *once the technical hurdles are cleared, then there will be societal issues that have to be considered and discussions that are going to have to happen*. Now's the time." (NYT, 8/2/17)

This quote is a bit confusing. Is "now the time" that the scientific community needs to work on the technical and safety issues, or is it time for the discussions? Either way, the underlying temporal ordering suggested here (science first, then public discussion) is notably the opposite of Charo's suggestion above.

John Evans suggests in his analysis of the human gene-editing debate that a common strategy that is invoked to delay debate is the invocation of a "scientific reality barrier" (Evans 2020). "Scientific reality barriers" serve a rhetorical purpose in that they can be invoked whenever an unwelcome call to debate the larger societal and ethical questions that a new technology like CRISPR put into play is invoked. The scientific reality barrier suggests that since we don't actually know what is fully possible with an evolving technology, it doesn't make sense to engage in prospective debate and discourse around the applications of the technology. Debate interlocutors who invoke a scientific reality barrier are urging others to put debate and discourse into abeyance while the scientists do their work. This type of rhetorical move tends to shut down public debate, particularly as the boundary around the technical and safety questions is drawn tightly under the purview of scientific experts, what STS scholars refer to a "black boxing" the technical complexity of a system from view and thereby only focusing on inputs and outputs (Latour 1999). The temporal dynamic that I am tracking across the media is an echo of an underlying philosophical debate about which should come first, a technical debate about "how" gene-editing can be done or socio-ethical debate about "whether" gene-editing should be done (Baylis 2019; Cwik 2021; Evans 2020).

2.3.6 Already Too Late? Public Debate is Lagging the Science

A related concern, namely that the science of CRISPR was *already* outpacing the public discussion, was voiced at several points in the corpus. This sense that the technology was moving so fast that we have missed our opportunity for fruitful engagement with the public is underscored by the frequently expressed view that wide-spread future use of gene-editing was a fait accompli. The NYT called readers attention to this dynamic already in 2015, stating that "the rapid advent of gene-edited animals threatens to outstrip public discussion of their risks and benefits" (NYT, 11/26/15). In a 2017 *Wall Street Journal* piece discussing Jennifer Doudna's book *A Crack in Creation*, which was meant to introduce the general public to the story of the discovery of CRISPR, the issue is tied to the scientists' own misgivings about it possibly being too late to engage the public:

> Scientific discussions, Ms. Doudna acknowledges, too often take place behind closed doors. Long before the public even realizes what is happening, scientists "define the terms of the debate," she notes. **By then, it may be too late for the public to have any influence…** "A Crack in Creation" is an important start, **but there is still more to know—not only about CRISPR but also about the views of all those who will be affected by it**. (WSJ, 6/13/17, emphasis added)

Thus the calls for public inclusion in debates around CRISPR were made alongside the voicing of pessimistic views that the science will move faster than any public dialogue could ever fruitfully inform. One final example of this theme brings this sense of mismatch between the time cycle of science and the time of societal engagement to a head:

> No one is pretending that such a consensus now exists. But in the year that the committee was deliberating, Ms. Charo said, the techniques required to perform this sort of gene editing have passed crucial milestones. (NYT 2/14/17)

By 2018, more critical voices entered the debates around inclusion in the media, suggesting that the proposed public dialogues take on a much broader idea around inclusiveness. For example, an article in the *New York Times* from June 11, 2018 cites an activist calling for policy discussions to "include 'a much broader range of voices' than just scientists." In the wake of the fallout around He Jiankui's experiments, *Breitbart*, reporting on November 26, 2018, brought the scholars Sheila Jasanoff and J. Benjamin Hurlbut into the discourse. Brieitbart cites their appearance in a Science article arguing for "a broad-based, inclusive dialogue regarding the ethical aspects of the new technology." The goal, of such broad inclusiveness according to Jasanoff and Hurlbut is to determine "…how the potential of science can be better steered by the values and priorities of society." The ambitions for a richer and more meaningful approach to public engagement, that is not outpaced by the development of science, articulated in these passages is laudable, but also suggests a far more coordinated, sustained and directed development of infrastructure for engagement than currently exists. Given the mismatch of ambition and infrastructure, it may indeed be already too late for meaningful, sustained, policy-informing engagement designed to steer the development of the science of gene-editing by the "values and priorities" of society. As noted by (Solomon and Abelson 2012) downstream public deliberations come too late for the public to make substantive contributions to the full scope of relevant considerations and leave the consulted public with a limited set of alternatives to deliberate. Many participants in the media discourse eschewed such pessimism though and sought to inject a sense of urgency around public inclusion in the debate. As we will next see though this sense of urgency was often matched with the language of deferral. Is there a right time?

2.3.7 The Push and Pull of Urgency and Deferral: Is there Time for Consensus?

The urgency of sparking a public debate leading to some kind of 'societal consensus,' regarding the appropriate uses of gene-editing was made apparent by experts speaking in a 2017 *New York Times* piece detailing the release of the National Academies of Science and Medicine (NASEM) report. The NASEM report was notable, in part, for setting forth a set of conditions under which the more controversial applications of gene-editing, namely human germline gene-editing, might be justifiably pursued. As this was a move that put the US out of step with European countries that maintain strict prohibitions on human germ-line gene-editing, the report provoked concerns that this would be taken as sanctioning and encouraging individual scientists to set down this path before a process of societal debate might be undertaken. Thus leaders of the NASEM report were eager to encourage that the debate begin:

> "Previously, it was easy for people to say, 'This isn't possible, so we don't have to think about it much,'" said Richard Hynes, a cancer researcher at the Massachusetts Institute of Technology, who helped lead the committee
>
> "Now we can see a path whereby we might be able to do it, so we have to think about how to make sure it's used only for the right things and not for the wrong things," he said.

This sense of urgency gets tempered with deferral several paragraphs down where the time scale returns to the distant future:

> No one should expect to design a baby anytime soon. It will probably be years before gene-editing techniques tested in animals can be shown to work in humans. And for the moment, the Food and Drug Administration is prohibited from using federal money to support research that results in genetically modified offspring.

This article is a good example of a kind of “push and pull” between invoking a strong sense of urgency around public inclusion in debates and discourse around CRISPR on the one side, while also suggesting that the time-scale for the implementation of the technology is so far off in the future that such urgency might be overstated.

In 2017, when a team of scientists, including a group of researchers in Oregon reported the results of a study using CRISPR in human embryonic research, the reaction of the scientific community was mixed. Many were surprised to learn that the NIH ban on funding such research still leaves privately funded projects room to proceed. Reporting on this occasion surfaced the familiar sets of ethical concerns and again the disorienting “push and pull” of time, with claims of urgency and inevitability paired with efforts to highlight deferral and a longer time horizon. Leading experts from the scientific and medical communities came to the defense of the work done by the Oregon scientists and articulated an “inevitability narrative” around germline gene-editing. The urgency and excitement, paired with competitive pressures coming from other countries’ efforts, suggest that the science of gene-editing is steaming ahead at full pace, as captured in the following passage from the NYT (7/14/17):

> One prominent genetics expert, Dr. Eric Topol, director of the Scripps Translational Science Institute in La Jolla, California, said gene editing of embryos is "*an unstoppable, inevitable science, and this is more proof it can be done*."
>
> Experiments are in the works now in the U.S. using gene-edited cells to try to treat people with various diseases, but "in order to really have a cure, you want to get this at the embryo stage," he said. "*If it isn't done in this country, it will be done elsewhere*." …
>
> Dr. Robert C. Green, a medical geneticist at Harvard Medical School, said the prospect of editing embryos to avoid disease "*is inevitable and exciting*," and that "with proper controls in place, it's going to lead to huge advances in human health."

But in the same piece, bioethicists are cited removing urgency from the narrative. Rather than invoking "inevitability," global competition, and urgency, these experts suggest calm and measured assessments of the implications of a single experiment. For example, Alta Charo and Hank Greely, two of the most highly cited bioethicists in the corpus, make frequent appearances when the specter of controversy emerges around CRISPR. For example, in the following passage Alta Charo seeks to calm the reading public about the implications of an experiment:

> "This was *purely laboratory-based work* that is incredibly valuable for helping us understand how one might make these germline changes in a way that is *precise and safe*. *But it's only a first step*," she said. "We *still have regulatory barriers in the United States* to ever trying this to achieve a pregnancy. The *public has plenty of time" to weigh in on whether that should occur*, she said. "Any such experiment aimed at a pregnancy would need FDA approval, and the agency is currently not allowed to even consider such a request" because of limits set by Congress. (NYT, 7/14/17, emphasis added)

Blending enthusiasm and the reassurance of deferral, Hank Greely, is also cited in this piece:

> Hank Greely, director of Stanford University's Center for Law and the Biosciences, called CRISPR "the most exciting thing I've seen in biology in the 25 years I've been watching it," with tremendous possibilities to aid human health.
>
> "*Everybody should calm down*" because this is just one of many steps advancing the science, and there are regulatory safeguards already in place. "*We've got time to do it carefully*," he said.

Alta Charo also appears in a *Washington Post* story describing this controversial experiment to modify human embryos in the US, and again offers reassurance about the time horizon:

> Alta Charo…said concerns about the work that have been circulating in recent days are overblown.
>
> "What this represents is a fascinating, important and rather *impressive incremental step toward learning how to edit embryos safely and precisely*," she said. However, "no matter what anybody says, *this is not the dawn of the era of the designer baby*." She said that characteristics such as intelligence are influenced by multiple genes and that researchers don't understand all the components of how such characteristics are inherited, much less have the ability to redesign them.

In these examples, bioethicists appear in the CRISPR discourse, at least in part, to calm and allay public concerns about a potentially transgressive experiment that could appear to be triggering a slide further down the slippery slope towards "designer babies". The public (as reading audience) in these instances are viewed as potentially irrationally fearful and seemingly in need of pacification around the prospect of runaway science.

As the competing narratives around time-scales in the evolution of CRISPR played out, some in the news media became aware that this may have become of source of confusion for readers following the ebb and flow of enthusiasm and cautionary statements around gene-editing. A *Washington Post* piece from 2017 identified "CRISPR will be available for widespread use soon" as one "five myths about CRISPR."

Part of the confusion over time scales is that experts in this discourse are simultaneously seeking to convey enthusiasm and excitement about the novelty of CRISPR and its potential applications, while also seeking to manage public expectations about what it likely can or cannot do (which is largely unknown) and when it may start to become an integral part of clinical treatments (also unknown). The science of CRISPR and gene-editing advanced at a rapid pace in the early years, so much so that scientists are frequently expressing their amazement at the pace of growth and understanding of the technology (e.g. Eric Topol in the *Washington Post* in November, 2017: "I've been following medicine over 30 years. I've never seen anything move at this velocity.") These competing motives underscore the complexity of expert participation in media discourse around novel technologies. They are simultaneously stoking enthusiasm among certain audiences such as investors and other scientists, soothing a presumed to be fearful public, reassuring would-be regulators that the scientific community is managing the risks and complexities just fine and fulfilling the role of accurately describing and translating the technical details of scientific advances. For the purposes of the present study, however, the push and pull of urgency and deferral around the ethical and societal issues that surround gene-editing and CRISPR leave the reading public both triggered to jump into a debate (without any obvious point of entry) and also told reassuringly that there is plenty of time for such things. This dynamic reinforces a sense that there may never be a right time for public inclusion.

To sum up the findings of this section, early calls for including the public in debates around CRISPR varied, with some experts imagining discussion, dialogue or engagement, and others a more ambitious and potentially impossible "consensus process." Experts contended with the issue of pacing, with several participants in the media debate arguing that the public engagement must precede clinical trials of gene-editing in humans or in gene-drive experiments, even while the persistent worry that the science was outpacing public debate was voiced through the years. Finally, a disorienting push and pull of urgency and deferral around when the public should become engaged created an added sense that good entry points for public participation have yet to be created.

2.3.8 Suddenly Too Late: Expelling Rogue Scientists

So far, I have argued that the calls from the scientific community for public engagement or inclusion in debates about CRISPR were confusing and seemed to be framed as either always premature or always too late. In 2018, He Jiankui used CRISPR and in vitro fertilization to edit the genes of three children. This experiment ignited a global firestorm of reproval that demonstrated how the call for public engagement to help shape the direction of this new technology was indeed too late. Such an event was anticipated by scientists, bioethicists and critics alike, and yet, when it came, the community reacted with shock and rallied decisively in a protective stance in order to expel a "rogue" from their community and defend the profession and the enterprise. In this intense effort of boundary work, the public and calls for public involvement receded as the community of experts sought to repair the damage and then retreat from the spotlight to let things calm down.

Policing the boundaries of who does and does not count as a legitimate scientist, or whose scientific work is seen as legitimate or not, is a common manifestation of a type of boundary-work that Thomas Gieryn identified as "expulsion" (Gieryn 1983, 1995). In the case of CRISPR, the boundary struggles that triggered the work of expulsion have been less about the legitimacy of the science itself, but have centered around cases of *who* counts as a legitimate user of gene-editing technology.

2.3.9 Before He Jiankui and the #crisprbabies

The boundary work to expel *would-be* rogues from the community of gene-editors emerged as a feature of the media discourse years before He Jiankui's experimental use of CRISPR shook the field. In a 2015 experiment, Chinese researchers used CRISPR to attempt to modify embryos to eliminate the genetic defect that is believed to cause the blood disorder Beta Thalassemia. This was reported at the time as the research community's worst fears coming true, namely that someone would use CRISPR to research gene-editing on human embryos and that this would eventually lead to someone attempting to implant a modified embryo. While this particular experiment was viewed as having failed, and the scientists involved had no intention of implanting the modified embryos (they died or were destroyed within days of the experiment), the news sparked strong reactions from the scientific community in the US, where a debate was happening over a possible moratorium on human germline editing experiments. Dr. George Daley, Dean of the Harvard Medical School, was quoted in the *New York Times* articulating how the scientific community feared the next step would involve someone using gene-editing on embryos that would lead to a live birth.

> "This type of intervention would achieve worldwide acclaim," Dr. Daley said. "I think that is the sort of deranged motivation that sometimes prompts people to do things. (NYT 4/24/15)

Daley's use of the phrase "deranged motivation" invokes a hard boundary between the acceptable and unacceptable applications of the technology and identifies anyone crossing the boundary as morally corrupt. When we take stock of the context and realize that this is coming from a leading medical scientist from the most prestigious medical school in the country, speaking in the most prominent newspaper in the country, then this rhetorical line-drawing can be seen as an example of field protective boundary work. From its earliest days, the field of gene-editing has contemplated the prospect of using the technology to alter the human germline and potentially alter evolution. To maintain a firm boundary between what is acceptable and what is not acceptable has been one of the most difficult challenges even as the line of what is "possible" has shifted rapidly and dramatically. The strong boundary-preserving work that the 2015 study provoked foreshadowed the all-hands efforts to come and it was only three years after this initial experiment on human embryos that the capacity to hold the boundary was tested.

2.3.10 Expulsion

On November 25, 2018, MIT Technology Review was the first news outlet to report that a Chinese scientist named He Jiankui had been engaged in a clinical trial to use CRISPR-cas9 technology in embryos from volunteers enrolled in a study, implant them and bring them to full term (Regalado 2018). As the world would soon learn through a series of carefully crafted promotional videos released on YouTube and a high stakes appearance at the 2nd International Summit on Human Genome Editing in Hong Kong, He Jiankui had in fact used CRISPR-cas9 to modify the CCR5 gene in a pair of twin embryos[8], prior to implantation, in an attempt to confer future protection from contracting HIV (Henry T. Greely 2019; Henry T Greely 2019). As news

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[8] The existence of a third child born to another set of parents only came to light after the summit and initial furor over the twins.

of this shocking experiment began to spread across social media, experts and lay observers alike began to weigh in.[9] He Jiankui, for his part, sought to maintain that his experiment was conceived with the altruistic motive to help couples afflicted with HIV have children that were protected from contracting the disease. However, as a number of commentators later detailed, the process of using IVF itself would have made it impossible for the children to contract HIV from their fathers. The use of gene-editing in this case was unnecessary for the goal he had in mind. Furthermore, the gene-editing work, or what is known about it, appeared to have been only partially effective so it was unclear if the change to the CCR5 gene would confer the kind of protection against future infection with HIV that was sought. Many also feared that off-target changes to the children's DNA was also possible but given the lack of transparency and absence of complete data, this remained speculation.

The events surrounding He Jiankui's CRISPR experiments were heavily covered in the press. A total of 13% of the articles in my news corpus were focused on detailing the narrative around the experiment, unveiling, reactions and subsequent fallout. *Breitbart*.com was particularly focused on these events, publishing 15 stories (out of its total of 25) on the affair that combined wire reporting and its own journalists' narratives and opinion pieces. The prestige press gave the issue due attention; the *New York Times* devoted 8 articles and the *Washington Post* 4. The two outlets identified in the first chapter of this dissertation as having most actively promoted a "boosterism" narrative about CRISPR, *Wall Street Journal* and *Foxnews.com*, downplayed the events by comparison, publishing only 2 and 3 stories, respectively.

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[9] Numerous articles and a growing list of books have since been published that offer detailed summaries of the experiments, the dramatic announcement and ensuing controversy. See esp. Henry Greely's *CRISPR People: The Science and Ethics of Editing Humans*, which offers a detailed, almost forensic, accounting of He Jiankui's experiment, the dramatic unveiling and global reaction to the experiment.

In addition to reporting the details of He Jiankui's experiments and the events surrounding the unveiling, a primary feature of the media coverage involved giving space to experts from the scientific and bioethics communities in particular to detail and unpack the significant scientific lapses and ethical transgressions in He's approach. Many in the scientific community believed they had reached a consensus that CRISPR-cas9 should not (yet) be used to make germ-line or heritable modifications of human DNA that resulted in a pregnancy. The assumption that the entire global scientific community would respect the cautious "yellow light" of a translational pathway from lab experiments towards clinical use turned out to be incorrect.

In addition to the news coverage, several official statements of condemnation were issued from notable figures, professional organizations and governmental agencies. These statements likewise focused on how many different ethical, scientific, and legal violations this experiment represented (Cohen 2018; J. Benjamin Hurlbut, Jasanoff, and Saha 2018; Schaefer 2018; Schrank 2018). This seemingly univocal reaction of Western scientists and bioethicists sought to marginalize He Jiankui so as to minimize any correlative reputational damage to the technology or what was viewed as its bright future[10]. Efforts from within China to marginalize the experiments and expel He Jiankui both rhetorically and literally (he was placed under arrest within weeks of the announcement) were also featured in the media's narrative. This collective effort to reinforce the boundary between legitimate and rogue uses of CRISPR-cas9 was born in no small part of the anxiety that past instances of reactionary over-regulation by governments might be repeated (e.g. human embryonic stem cells).

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[10] There were only a few exceptions of influential scientists defending He Jiankui as the story unfolded. For example, (Arguedas-Ramírez 2020) recounts how George Church was cited in Science minimizing He Jiankui's failings as largely about not getting his paperwork done correctly and that the reaction seemed like a "bullying situation".

The global scientific community quickly converged around the narrative of a “rogue scientist” and were eager to expose his various misdeeds for the public in the news media. Equally important was the work to defend the integrity of the scientific enterprise, scientists in general, and the science of CRISPR itself. George Daley, Jennifer Doudna, Francis Collins, Eric Topol and other leading figures in the scientific and bioethics communities were cited across the news corpus issuing declamations of Jiankui and defenses of the overwhelming balance of ethical, path-breaking gene-editing research being conducted around the world. For example, the following passage from a *Foxnews.com* piece published just days (11/26/2018) after the revelation of the birth of the twins in China quoted Doudna calling Jiankui’s experiment “a break from the cautious and transparent approach of the global scientific community’s application of CRISPR-Cas9 for human germline editing.” Doudna deemed it “essential that this report not cast an untoward shadow on the many important ongoing and planned clinical efforts to use CRISPR technology to treat and cure existing genetic, infectious, and common disease in adults and in children." She went on to call for continued “public and transparent discussion of the many uses of genome editing.” In another article, George Daley raised a similar concern about “backlash,” saying that “it would be unfortunate if a misstep with a first case led scientists and regulators to reject the good that could come from altering DNA to treat or prevent diseases” (*Breitbart*, 11/27/2018).

No regulatory regime can completely forestall inappropriate uses of a technology like CRISPR (Morrison and de Saille 2019) and the inability to completely monitor and enforce all regulations in all jurisdictions means that the ethical conduct of research must also rely on norms and consensus around what is considered within or out of bounds. While the outrage against He’s use of CRISPR in this case was deserving of rebuke, the effort to marginalize him as a “rogue actor" (Koerth-Baker 2018) had the potential of obscuring the broader issues that led to He's actions or the possibility of seeing the complicity of Western scientists in the broader system of incentives (personal, professional, national, economic) that characterize global biotechnology in the CRISPR era (J. Benjamin Hurlbut, Jasanoff, and Saha 2018; Hurlbut JB, Saha L, and Jasanoff S 2015; Jasanoff and Hurlbut 2018b). As one science writer noted, the normative force of complying with the received wisdom of one's field can come into direct conflict with the intense pressures of the scientific profession to be innovative and break barriers; "there's an incentive to push as hard — and as creatively — as possible" (Koerth-Baker 2018). Koerth cites Deborah Johnson, an ethicist working with the National Academies on efforts to reform the oversight around the responsible conduct of research, who suggests that the reforms in this domain involve a shift from "blaming individuals when they did something wrong to recognizing the system that created those people." Koerth then summarizes this tension:

> In other words, you could say that He is as much a product of the community of science as he is in violation of it. The mad scientist will never go away, either as trope or reality. This dark side of science is too much a part of how science works.

The fierce reactions and later imprisonment of He Jiankui may be a completely reasonable set of responses to someone who put two (possibly three) children's health and lives at risk and cast the entire gene-editing enterprise in a negative light. For the purposes of the present analysis, though, this expulsion is as clear a case of the scientific establishment protecting its boundaries from within as can be imagined. Greely (2021) analogizes the He Jiankui case to other well- known instances of scientific misconduct and subsequent expulsion, including Martin Cline's expulsion from UCLA in 1980 for ethical violations in a gene therapy trial and Hwang Woo-Suk, a South Korean scientist who had made fraudulent claims to have cloned human embryos and subsequently was fired and sentenced to jail for additional criminal violations in 2009 (p. 174).

In the rush to condemn the actions of He Jiankui, the importance of public dialogue, perhaps on an international scale, around the ethical and societal implications of gene-editing became simultaneously more salient and obsolete. At this moment of attention on CRISPR, the public's primary role as mute and passive consumers persisted in the media narrative. With few exceptions, the media narrative highlighted and centered what I have described as the intense boundary work undertaken by the expert communities of scientists and bioethicists who sought to expel a rogue and protect the public perception of the science of gene-editing. Very few non-experts had a voice in the narrative. Constituencies, such as the communities of HIV patients and activists, were not consulted or sought out for comment on this work or the prospect of using gene-editing to address something like susceptibility to contracting HIV. While there may be considerable barriers for American news outlets to access the parents involved in the experiments, little to nothing was reported on their experiences and reactions to the fallout. The controversial nature of this work and the profound ethical lapses that came with it suggest that the many calls for public engagement that I have detailed in this study were suddenly all the more salient, and they had become more complex as the global nature of the challenge of governing the future of this technology became clearer. But the boundary work required to protect the field left little room to consider how the public might join the discourse.

To be sure, the boundary-preserving efforts that typified coverage of the story helped clarify for the reading public how He Jiankui's experiments introduced unacceptable levels of risk to the children, with no clear balance of benefit to outweigh the risks. Further, his lack of transparency, ethical lapses working with vulnerable parents and questionable gene-editing work were made clear. However, as I also discussed, the intense focus on He Jiankui's unique failures as an individual rogue scientist had the effect of obscuring the larger or systemic issues that made his actions possible, even likely. The media-consuming public were given much less insight into the broader challenges associated with regulations, scientific norms and the intense pressure within the field to push boundaries and achieve recognition for conducting path-breaking work. With this latter discussion relegated largely to academic analysis readers were left with a story of a rogue who was successfully expelled (jailed) and a scientific community that would take stock of things in the way that large, bureaucratically organized enterprises like science tend to; a World Health Organization report was commissioned soon after the events.

With the work of expulsion complete within a month of the events surrounding the announcement of the twins, the coverage of CRISPR in the media died down. This case of "expulsion" oriented boundary work illustrates how scientists' boundary struggles crowded out space for publics to engage the issues even as the societal questions surrounding gene-editing and CRISPR became all the more acute.

2.4 Conclusion

(Briggs and Hallin 2016) found in their study analyzing large media samples of health news that the presence of lay public voices had increased significantly between the 1960s and 2000s, even while biomedical experts tended to dominate the discourse. In stories about medical breakthroughs or emerging health risks, a journalistic convention that they identify is to use the voice of a lay person to humanize the context and to serve as a stand in for the reading audience. In the case of CRISPR, it seems that such roles have yet to be imagined by journalists. I found that with the exception of activists, lay publics played a strikingly minor role in the news coverage of CRISPR between 2012-2018. This suggests that perhaps when the role of the lay public in relation to the medical discovery is less sharply defined, journalists may have less of a clear idea about how to incorporate lay voices into the news. As (Conrad 1999c) found in his analysis of news coverage of genetics, in the absence of a clear or obvious interested and organized lay public, journalists did not seek out the perspectives of lay voices.

In the case of CRISPR, scientific and commercial actors promoting its agricultural uses adopted a deficit model of the public, taking a PR-oriented approach to public engagement. I examined how the media coverage of CRISPR in the context of agriculture revealed an expert community inclined to see public engagement as needed or welcome, but rather sought to pursue strategies of impression management and public relations geared towards consumer acceptance. Previous and ongoing controversies surrounding GMOs had left industry and scientific actors in this domain far more explicitly wary of the public and eager to not repeat the battles of the past several decades. This public relations approach is thus another strategy that experts, in collaboration with journalists, can pursue in managing public opinion and consumer behavior. This was a notably different approach as compared with the calls for public engagement, debate or consensus that those considering the use of CRISPR in humans undertook, however confusing or destabilizing those efforts may have been.

In the case of human gene-editing, the active calling-in of publics into the debate space by the expert communities might have heralded a more robust effort to include public voices in the narration of the story of CRISPR. However, I found that the confusion surrounding the "calling in" betrayed a deep ambivalence and uncertainty about the means and ends that such inclusion would be directed towards. We are still unsure about whether societal consensus is needed or desired and we are still left unsure about which publics ought to be engaged and ultimately what to do with the outputs from such engagements.

The question of public involvement in discourse around gene-editing was further muddied by the issue of which should come first, the science or the debate. Some experts argued that debating the ethical or societal implications of gene-editing technologies should follow the progress of the science itself, otherwise the ethical debate risks being speculative or misguided. However, others feared that putting off debate, or invoking scientific reality barriers as a way to close down certain kinds of debate, would mean that we will only ever have a reactive or backward-looking debate. We find ourselves in a dynamic where we are always too soon, until we are too late. Furthermore, the media analysis revealed a significant theme of fatalism or a sense that the time for the public to weigh in has already passed since the key technological milestones have already happened and the tide of inevitability surrounding gene-editing, paired with commercial interests in pursuing a variety of applications, jeopardize the value of public debate and its potential to become policy-informing moving forward.

The push and pull of temporality, of urgency and deferral, added to confusion around the aspiration for public engagements on the ethical and democratic questions that CRISPR poses. When calls for an urgent debate that seeks societal consensus around a controversial new technology are paired with soothing reassurances that the scientific community is moving deliberately and with due consideration of societal norms, it is not surprising that patient, public and social movement actors might not have a toehold in such a discourse.

The lack of clarity about where or when the public can intervene in debates about gene-editing or, from the journalistic perspective, when to seek out voices from the public, was further compounded when the boundary work of exclusion reached a fever pitch around the case of He Jiankui and the CRISPR-edited twins. The case of the twins born with modified DNA raised a host of challenging legal, ethical and societal questions and it would seem an opportune moment to expand the discussion to include perspectives of patients (for example in the HIV community as the modifications were intended to confer protection from contracting HIV), prospective parents or well-known critics or skeptics of genetic technologies. Instead, I found that the boundary work of experts to denounce He Jiankui as a “rogue,” to chronicle the many flaws of his work and to disassociate him from the community of responsible scientists was the central goal of news reporting around the events. To be clear, I am not here claiming that condemning He Jiankui was inappropriate, rather, I am arguing that the expulsion by the scientific and bioethics community was so fast and thorough that the media narrative missed the opportunity to do what the experts who created the technology have been asking for all along: to bring the voice of the public into the discourse. Compounding the sense of missed opportunity was the fact that this was one of the most important (if controversial) developments in the history of the technology and thus garnered a significant spike in media coverage.

In the absence of invitations to participate, the “public” or representative “publics” are left out of the discourse altogether. This doesn’t bode well for a deep and sustained engagement of the sort envisioned in the NASEM report and elsewhere. A combination of the boundary-work strategies, an absence of clear pathways for inclusion in the debate and the lack of organized constituencies resulted in a public debate about gene-editing without the public.

Leading figures in the CRISPR field have pursued numerous strategies to engage the public, including public lectures made widely available over social media channels, hosting ask me anything events on social media, books written for lay audiences, funding efforts to engage a broader swath of academics and artists beyond the life sciences in thinking about CRISPR. These efforts have been salutary but have largely reflected a deficit model, uni-directional approach to engagement, where the goal is public education, sparking public interest and possibly quelling public anxieties, but less about inspiring two-way communication or channels through which public perspectives might fruitfully be elicited in such a way as to be policy informing.[11]

Scholars working in diverse fields (Medical Sociology, Public Understanding of Science, Science and Technology Studies) have argued that strict policing of discursive boundaries can lead to poorer decision making and that there are significant ways in which lay input, on even technical matters, can improve the quality of decision-making around biotechnologies (Epstein 1995; Hurlbut JB et al. 2015; Parthasarathy 2010; Petts and Brooks 2006; Wynne 1992a). Even if we take the less epistemically radical position and limit public inclusion in scientific debates to issues around the ethical and societal implications of scientific work, then there remain significant questions about how responsive science is to such inclusion, how such efforts should take place, what the expectations of the public ought to be around their inclusion among many others. For the case of CRISPR, one key question facing the task of public inclusion is whether or not the scientific community would heed the considered views of the public *if the public were to reject gene-editing* of one sort or another. If the tide of inevitability pervading the discourse around gene-editing is sweeping society toward a gene-edited future for humans, animals and plants, then, one might rightly ask why bother engaging the public in the first place. The skepticism over public inclusion in debates over the future of a technology like CRISPR is common. For example, the scientific community, and partisans of science in the public, have recently raised alarms about the impact of wide-spread public attitudes questioning the safety or efficacy of COVID vaccines based on rumors and conspiracy theories (Islam et al. 2021; Patterson 2021; Tollefson 2021).

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[11] Exceptions include Vence Bonham’s NIH funded effort to engage members of the sickle cell disease community.

However, the cost of public exclusion out of fear that the public will be too ignorant or too skeptical to have anything useful to contribute can also be significant. The scientific community extended a hand to the public in the early years of CRISPR by calling the public in to weigh the ethical and societal questions that gene-editing raises. My study found that it appears that so far the public hasn't found its way into this debate in significant ways. I have suggested that contributing factors include the confusing nature of the ask, the disorienting push and pull of urgency and deferral around the ethical and democratic issues at stake, the silencing effect born of the intensity of expert boundary work in the face of crisis and the relative marginalization of critical voices that can contribute to the publics understanding of the broad array of possible issues and positions at stake.

The media is not the only site for public debates over controversial technologies, and the relative absence of the public voice in my study should be weighed alongside work that looks to sites where the public is explicitly able to formulate and contribute to the discourse. Future work to look at how publics respond to news coverage in the comments sections of online news, in letters to the editor or on social media channels will be important contributions. Additionally, empirical analyses of other public engagement efforts are needed including survey research, deliberative democracy, patient advocacy organization engagement etc. Still, the silence of the public in the media reporting, the boundary work of experts and the confusion promulgated over issues of the urgency of public inclusion suggest that the goals of "societal consensus," or more modestly "public engagement" around CRISPR is at best a work in progress and at worst, a mirage of democratic aspirations[12]. I find that experts in the media discourse both sought to manage the public's fears about gene-editing and claim that we don't need to rush into public

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[12] I attribute the figure of a "mirage" to Peter Conrad's evocative title "A Mirage of Genes" (Conrad 1999b).

dialogue because the technical limitations put ethical and societal decision making far off into the unknown future, but then also rush to control the terms of the debate for fear of backlash when crises emerge. This use of time suggests that there may never be a right time for public participation in debates over the future of gene-editing.

CHAPTER 3 - Gene-Editing in the Eyes of the U.S. Public: Evidence From a National Survey

Daniel Thiel, Jodyn E. Platt, Sharon Kardia

3.1 Introduction

This chapter investigates how individuals in U.S. society are coming to terms with the complex array of issues that are provoked by technologies like CRISPR and gene-editing for human health generally. Why do some people in the U.S. view gene-editing technology more favorably than others? Existing survey research on public attitudes towards CRISPR tends to construct the dependent variables of interest (support/lack of support for genome editing technology) in the abstract, without provoking respondents to consider their own personal connections to this technology. This project uses data from a nationally representative survey sample and constructs three dependent variables that raise the personal stakes of CRISPR and gene-editing for respondents by first asking about respondents' willingness to donate biospecimens for gene-editing research, second about their comfort with tax dollars being spent on gene-editing research and third about their levels of anxiety and optimism about the future of this technology. We prompted respondents to consider the extent to which they are prepared and comfortable with making contributions towards a CRISPR-mediated future. In addition, we used OLS regression models to examine predictors of support and dissent from gene-editing. We find that majorities of respondents show support for gene-editing across multiple demographic, experiential and attitudinal factors, but that this support is somewhat ambivalent overall. We also find that attitudes towards gene-editing are bound up with some demographic categories, esp. sex, and respondents commitments and attitudes towards institutions, notably religious adherence and attitudes around trust in the health care system.

3.2 Background

Although gene-editing technologies such as rDNA, Zinc Fingers and TALENs have been available for over a decade, it was the discovery of the highly effective, comparatively affordable and accessible CRISPR-cas9 platform in 2012 that accelerated both the prospects for human gene-editing and put the ethical challenges surrounding gene-editing closer to the front burner of the public issue agenda (Jinek et al. 2012; Ormond et al. 2017). CRISPR-cas9 offers to gene-editors the most promising, precise and accessible means to gain mastery over DNA of plants, animals and humans (Doudna and Charpentier 2014). The scientific community has embraced this tool (while continuing work using ZFN and TALENS) with great enthusiasm and in less than a decade clinical trials employing CRISPR have been launched with the goal of treating some of the most intractable medical challenges including HIV, cancer and sickle cell disease (Akram et al. 2020; Couzin-Frankel 2020; Frangoul et al. 2021; Lambert 2019; Ledford 2020; Li et al. 2020; Mancuso et al. 2020).

Yet, given the ethical and societal complexities that surround gene-editing, it is not entirely surprising that the first CRISPR decade has also witnessed several high-profile controversies, most notably the 2018 births of three gene-edited children in China and the subsequent arrest and imprisonment of the scientists responsible for this experiment (Allyse et al. 2019; Greely 2021; Henry T. Greely 2019; Krimsky 2019). This incident sparked a heated, as yet unresolved, debate among members of the scientific community about how to best regulate this technology, with some seeking a complete moratorium on using CRISPR to make heritable changes in human gametes or embryos (Lander et al. 2019), others seeking to establish a global observatory for gene-editing (J Benjamin Hurlbut et al. 2018; Jasanoff and Hurlbut 2018b; Saha et al. 2018) and yet still others cautioning that an excessive regulatory over-reaction could stymie potentially life-saving research from moving forward (Daley, Lovell-Badge, and Steffann 2019).

Amidst all of the excitement, hype, controversy and debate amongst experts, where does the U.S. public stand? The era of the Human Genome Project inaugurated a parallel funded movement to support research on the ethical, legal and social issues (ELSI) of genomics and with this came a keen interest in engaging patient communities, civil society stakeholders and the broader general public. This disposition towards public engagement, given the contentious, ethically and legally complex nature of genomics research appears to have influenced the early innovators of CRISPR. Notably Jennifer Doudna (UC Berkeley), one of the pioneers in the discovery of CRISPR-cas9 has prominently voiced her own private concerns about misuse of gene-editing and articulated a need for ongoing public engagement on the future development and uses of this technology (Doudna and Sternberg 2017; A. Pollack 2015). In a more formal venue, the National Academies of Engineering, Science and Medicine issued a major study of the ELSI issues related to CRISPR and gene-editing in 2017 and reserved a large portion of their recommendations to support robust community engagement (National Academies of Sciences Engineering and Medicine 2017). In fact, with few exceptions, the attitude of the research community has been to endorse public engagement around gene-editing technology.

Attempts at deeper qualitative engagements with various publics to assess their views of gene-editing have been fairly limited (Hollister et al. 2019; Michie and Allyse 2019; Persaud et al. 2018; Riggan et al. 2020, 2019; Snure Beckman et al. 2019). Thus far, the primary mode for understanding public knowledge, attitudes and beliefs on gene-editing has been survey-based.

This body of work, reviewed below, has the virtue of being able to capture the broad sentiments (pro/con, support/anxiety) across the entire population over time and, if conducted with a nationally representative sample, of offering insights that can be reasonably extrapolated to the entire population

This study attempts to address two gaps in the survey-based research around gene-editing; a need to personalize the abstract question of supporting gene-editing and using statistical models to explore predictors of support or dissent for this technology. We found that most of the surveys have sought to determine support or opposition as a general matter, as in "should scientists pursue gene editing" or "should society embrace gene-editing of embryos". In other cases the question is direct, but abstract "Do you support gene-editing?" For this study we sought to concretize the issue and place respondents in the position of considering their own willingness to invest in a future with gene-editing either through the donation of their biospecimens to research on gene-editing or through their support for the use of tax dollars on gene-editing research. The issue of the donation of biospecimens is contextualized further to encompass the contexts of therapeutic vs enhancement uses of gene-editing and the issue of comfort with sharing de-identified vs identified biospecimens. In addition, we pose the question of whether respondents feel optimism or anxiety about a gene-edited future in relation to themselves, their families and for society as a whole.

The second gap we hope to address with this project is to explore predictors of attitudes towards gene-editing in greater depth than existing work. As such we use OLS regression to model how demographics, health experiences, cultural attitudes and trust factors predict the variation in attitudes towards gene-editing. The outcomes of these regressions help point towards future research to explore the attitudes and concerns of specific sub-populations and can be useful in guiding the deeper community engagement efforts that are widely recognized as necessary components of moving forward with gene-editing. We hope that these findings can also prove to be policy-informing as well since a better understanding of the reasons and sources of support and dissent around gene-editing technologies can guide the efforts of those moving this technology into clinical trials.

3.2.1 Prior Survey Research on Gene-Editing and CRISPR

Top Line Levels of Support Vary by Gene-Editing Application

Support for gene-editing in the U.S. public has generally followed the two key lines that demarcate the ethical debates of gene-editing in humans, namely the somatic vs germline and the therapy vs enhancement dyads. A recent systematic review of 17 public opinion surveys going back to the 1980s on genome editing found that most of the U.S. public consistently favors gene therapy for clinical use in patients with serious diseases but does not support gene editing in human embryos or germline cells (Blendon et al. 2016). Support for germ-line modifications tends to increase somewhat when the explicit goal is preventing disease from affecting future children, but decreases when the intention is enhancement, to “improve their intelligence or physical traits such as athletic ability or appearance”(Begley 2016; Chan 2016). This same rank ordering of acceptable uses of gene-editing was found in a 2017 survey of the U.S. public that reported majority support for somatic therapy and germline therapy, lower support for somatic enhancement and limited acceptance of germline enhancement (Scheufele et al. 2017) and in a 2018 survey given in the aftermath of the revelations around He Jiankui (Associated Press and NORC 2018). Global surveys have also tracked similar trends along these lines (Critchley et al. 2019; Gaskell et al. 2017; Hendriks et al. 2018; Middleton, Milne, Almarri, et al. 2020; Uchiyama, Nagai, and Muto 2018; Wang et al. 2017).

Blendon’s review of survey data, appearing in the *New England Journal of Medicine*, and the bulk of survey research appears to offer a kind of imprimateur of U.S. public opinion for those seeking affirmation that the public can be taken to be “on board” with the general contours of the CRISPR revolution. But just as the appearance of consensus among experts masks significant heterogeneity of opinion, surveys of the public suggest, but haven’t fully explicated, the sources of heterogeneity among attitudes in the public towards a CRISPR-mediated future.

One factor that deserves continued attention is the structure of survey items asking about attitudes towards gene-editing. For example, respondents were less supportive of CRISPR when they were exposed to language that emphasized risks (Weisberg, Badgio, and Chatterjee 2017). Further surveys that query attitudes regarding gene-editing of “embryos” or “unborn babies” (Harvard) need to take into account how these terms may bias results or leads to a confounding of attitudes towards gene-editing and attitudes towards research on “unborn babies” that cannot be clearly disentangled in the absence of further inquiry.

Demographic Variation

Few surveys on gene-editing have examined the predictive correlates of the attitudes they are tracking, but the exceptions provide some comparators for the present study. Four key demographic factors appear to be salient in multiple studies including respondent’s religion (denomination and religiosity), education, sex/gender and parental status. Evangelical protestants were generally the least supportive, but when they were asked to consider whether they would use gene editing for their own babies, these religious differences disappeared (Funk and Hefferon 2018). Intensity of religious commitment also appears to predict levels of support with those holding greater commitments corresponding with lower levels of support for gene-editing and lower levels of confidence in science to effectively regulate the use of gene-editing (Funk and

Hefferon 2018; Scheufele et al. 2017). Higher educational attainment, also sometimes measured directly as knowledge of genomics within surveys, has been found to correspond with higher levels of support overall for genomics, gene-therapy and gene-editing (Delhove et al. 2020). Attitudes towards gene-editing also varied by sex and parental status, with women and parents of young children voicing more caution across all survey items than others (Delhove et al. 2020; Funk and Hefferon 2018)

Funding Research on Gene-Editing

Two surveys have inquired about support for federal government funding of gene therapy research and found quite different results. The Harvard TH Chan study found that 64% of respondents approved of using federal tax dollars for such research, while the study conducted by AP/NORC in 2018 found that 48% opposed such spending, 25% neither favor nor opposed it and 26% favored it. Notably the Harvard study asked about support for funding for research on "unborn babies" and the AP/NORC study queried about support for funding for research on embryos. This lack of support for federal funding of this type of research may be picking up several explanatory factors that bear brief reflection. First, the mention of using human embryos or unborn babies in research may be a significant factor impacting both surveys. Given the aforementioned religious divisions detected by several surveys, and the significance of human embryos in the political disputes over reproductive health and abortion, this finding may reflect the percentage of respondents who hold prior commitments regarding the status of embryos and would be inclined to reject funding *any* kind of research using human embryos. Second, the item may be detecting aversion to federal funding of research in general, irrespective of the moral status of embryos. A third possibility is that respondents saw a connection between federal funding and their own income taxes and viewed this as not a high priority compared with other spending priorities. One final consideration regarding the 2018 Ap/NORC poll is that this poll was given in the aftermath of the revelations surrounding He Jinakui's experimental use of CRISPR to edit human embryos and it is possible the negative reactions associated with that revelation could be impacting the intensity of negative responses.

Whatever is driving this variation, the 9% who strongly support this funding in the AP/NORC survey stands in stark contrast to the 75% of respondents to the same survey who thought it somewhat or very likely that gene-editing would "wipe out many inherited diseases" and the 87% of respondents who saw it as somewhat or very likely that gene-editing would "lead to other medical advances." With 22% of research and development funding in biotechnology coming from the Federal government (Bluestone, Beier, and Glimcher 2018; Editorial Board 2015), there appears to be a disconnect in the public's views around the prospects of medical benefits of CRISPR and the fiscal commitments needed to build the road to get there. For the present study, we have therefore opted to continue to pursue this question of using tax dollars for research, but leave the potentially confounding issues of "embryos" and "unborn babies" aside.

Future Orientation: Optimism and Anxiety Around Gene-Editing

Respondents to the Pew survey were more likely to anticipate *negative outcomes* from gene-editing than *positive outcomes* (Funk and Hefferon 2018). Many feared that gene-editing of babies would be used before we fully understood the implications, that the technology would only be available to the wealthy and that gene-editing will encourage a feeling of superiority among those who have access to the technology. Other surveys found a range of views on how respondents viewed the prospects of gene-editing technology for the future, with concerns about affordability of gene therapies, the potential for misuse of gene-editing, high levels of optimism about the potential to offer cures and advance science, and the prospect that gene-editing would be used before properly tested for safety (Associated Press and NORC 2018). While these are all important dimensions of the future of gene-editing worth exploring, none places the future-orientation of the question squarely in personal terms. The present study uses a three-part question to query respondents' future-orientation (how they see the future of CRISPR) in terms of themselves, their families and society.

We do not yet know how public attitudes towards gene-editing technology may change when the question changes from abstract support to the possibility of contributing one's own biospecimens and data to research. Who is not only supportive in the abstract, but is willing to participate in building a CRISPR-mediated future by donating samples, data, time and funding? Which groups perceive themselves to be a part of the "sociotechnical imaginary" (Jasanoff and Kim 2016) that the use of CRISPR and gene-editing technology portends? Which groups do not see themselves as having a place and a stake in such a future? Prior work has found that willingness to donate biospecimens and health data for research may depend on trust factors that are also associated with key socio-demographic characteristics (Critchley, Nicol, and Otlowski 2015; Middleton, Milne, Howard, et al. 2020; Milne et al. 2019).

Individual willingness to participate in genomics research is a paramount concern for those who hope to see the fruits of the genomics revolution available to all in society. To consider one example of how *research participation in genomics* impacts both the science that is achievable and the societal implications of this work, recent scholarship demonstrates the extent to which racial minorities are dramatically underrepresented among research subjects in genomic studies (Popejoy and Fullerton 2016; Tung 2019). Scholars frequently point to the history of mistrust among minority communities in seeking to account for lower participation rates in genomics research (and medical research generally) that is tied to legacies of racism and abuses of power and position (cf. Jones 1992; Skloot 2010; Washington 2008) On the other hand, some have identified institutional failures such that willingness to participate may be undermined by a failure of researchers to invite participation (Underwood et al. 2013). Further, while many scholars have looked to account for support for biotechnology as a function of knowledge, others have found evidence to suggest that support for biotechnologies such as CRISPR are more closely tied to institutional trust factors (Hornig, Bonfadelli, and Rusanen 2003; Master and Resnik 2013). Factors stemming from individuals' views of institutions, especially those related to health care, have been found to be key determinants that impact variation in views of controversial, emerging health technology and in willingness to share biospecimens and data for genomic research (Critchley et al. 2015; Middleton, Milne, Almarri, et al. 2020; Middleton, Milne, Howard, et al. 2020; Milne et al. 2019; Nicol et al. 2017). In this chapter we ask whether demographics, cultural factors (politics and religion), health status and experiences (illness, discrimination seeking care), trust factors or altruism are associated with comfort with or support for gene-editing.

3.3 Methods

The data for this chapter are from a survey primarily designed to explore respondents' knowledge, attitudes and beliefs regarding health data and biospecimen sharing in the context of precision oncology. The survey queried respondents' views of health systems and providers, researchers and quality analysts, and commercial entities as well as experiences and attitudes about privacy, trust, altruism and discrimination. In addition, the survey interrogated respondents' views of gene-editing employing three sets of questions to get at the latent levels of support or dissent, enthusiasm or anxiety and the strength of respondent convictions around gene-editing.

The survey was conducted online by the National Opinion Research Center (NORC) in May 2019, using a probability-based, nationally representative sample of the US adult (21+), non-institutionalized population[13]. In the end, 2,157 participants completed the survey (66% complete response rate). To compensate for historical under-representation in surveys, we oversampled African Americans, Latinos and individuals earning less than 200% of the federal poverty level annually. NORC calculated post-stratification weights corresponding to the U.S. Census demographic benchmarks for age, sex, household income, education, and race and ethnic background to reduce bias from random sampling error. This survey weighting is applied this study.

Prior to going into the field, the survey was validated in several steps. First, we engaged the Institute for Social Research (University of Michigan) to conduct cognitive interviews (n=17) to assess the understandability of the questions. We then pilot tested the survey using Amazon's Mechanical Turk platform (N=750) to assess timing, compare and evaluate bias in response scales, and evaluate redundancy. Modifications to the survey items querying gene-editing were made based on analysis of the pilot survey round. For example, the pilot survey revealed that respondents did not differentiate between applications of gene-editing for *therapeutic* purposes and those aimed at *prevention* of future disease onset and thus we collapsed those into a single item to simplify the survey and heighten the contrast with *enhancement* applications of gene-editing. Finally, NORC pilot tested the survey with 115 panelists on its own platform and this resulted in several minor improvements in item clarity.

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[13] NORC's Technical Overview of the AmeriSpeak Panel can be found here: https://amerispeak.norc.org/Documents/Research/AmeriSpeak%20Technical%20Overview%202019%2002%2018.pdf This document summarizes key information about the panel including: sample frame, recruitment, response rates etc.

3.3.1 Dependent Variable 1: "Sharing Biospecimens"

Rather than asking survey respondents to register approval or dissent from gene-editing as an abstract matter, we developed survey items that would place them in the context of greater personal stakes in the development of the technology. Specifically, we queried attitudes towards sharing personal biospecimens, with varying levels of privacy protections, for research that is explicitly designed to develop gene-editing technology. We first asked respondents a pair of items about the use of their de-identified biospecimens: How comfortable are you sharing your **de-identified** biospecimens to develop gene-editing to **treat** disease/disability? How comfortable are you sharing your **de-identified** biospecimens to develop gene-editing to **enhance** a person physically or mentally?

While biospecimens are typically de-identified or pseudonymized to protect individual privacy, there are contexts where retaining identifying information increases the utility of the sample, even as it raises the possible privacy risks to the donor. The difference between sharing one's de-identified vs. identified biospecimen can thus be understood as demarcating a line of comfort or trust in the research enterprise. To explore the impact of this increased privacy risk, we asked the following paired items: "How comfortable are you sharing your **identified** biospecimens to develop gene-editing to **treat** disease/disability? How comfortable are you sharing your **identified** biospecimens to develop gene-editing to **enhance** a person physically or mentally?" We interpret those willing to share identified biospecimens as more willing to bear the associated risks, more trusting and supportive of the endeavor to develop gene-editing.

A second important dividing line for gene-editing technology is that between the use of this technology for therapy vs. enhancement[14]. As discussed above, prior survey work has

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[14] The National Academies report (NASEM, 2017) identifies an important third category to consider here, namely prevention. In their model there is a continuum from treatment to prevention to enhancement and there is

consistently found that people are generally more comfortable with the use of gene-editing to treat disease or illness, but are very uncomfortable when the goal is to enhance individuals beyond "species normal" functioning for such things as intelligence, strength, beauty or athletic performance. We used this 2 x 2 variation to create a scale that plots respondents' enthusiasm for gene-editing as a function of their comfort with A) the privacy trade-offs of de-identified versus identified biospecimen sharing and B) the use of gene-editing for therapy (less controversial) or enhancement (more controversial). In this analysis, we refer to this as the "sharing biospecimens index" (Table 3-1).

Table 3-1. 2x2 Model for D.V.1 - "Sharing Biospecimens"

	De-Identified Biospecimens *Lower Personal Privacy Risk*	**Identified Biospecimens** *Greater Personal Privacy Risk*
Treatment *Less Moral Controversy*	De-ID x Treatment	ID x Treatment
Enhancement *Greater Moral Controversy*	De-ID x Enhancement	ID x Enhancement

N.B. Responses to all four items are compiled in a single index variable

Prior to responding to these four items, participants responded to 24 questions about their comfort sharing both health information and biospecimens with various users (researchers, quality analysts, commercial entities). Further, they had been asked about each of these use cases in the context of both *identified* and *de-identified* biospecimens and health data. "Health data," "biospecimens," "de-identified" and "identified" had been all defined several times.

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considerable grey area in defining the distinction between a therapeutic intervention and a prevention. Likewise the distinction between prevention strategy and enhancement may be increasingly difficult to determine and make ethical determinations about. As mentioned above, we explored the possibility that prevention ought to be considered its own category in our pilot survey (unpublished, contact lead author for more information), however, we found that the survey respondents held virtually identical views of treatment and prevention. This was sharply contrasted with their views of enhancement. Given the results of our pilot study, and fiscal and time constraints, we opted to collapse treatment and prevention in the final survey, but we flag this as an important area for future research to explore. In particular, we feel that the complexities of unpacking these grey areas are better suited to in-depth qualitative work, such as interviews, focus groups or deliberative democracy.

Respondents were thus familiar with the item construction before considering the question of their comfort with regard to sharing identified or de-identified biospecimens for research on gene-editing.

Table 3-2 summarizes respondent frequencies to each of the four items in this construct. We used a paired t-test to compare the mean responses between the *de-identified* and *identified* conditions and found respondents' greater caution (less comfort) when sharing **identified** biospecimens was statistically significant ($p<0.05$, results not shown). Further, a similar test revealed the mean comfort reactions to "treatment" focused items were statistically significantly higher than the mean comfort reactions to enhancement items ("enhancement effect"). Thus our survey items track with the prior research findings that enhancement applications are far less supported than therapeutic applications.

TABLE 3-2. Dependent Variables Descriptive Statistics – "Sharing Biospecimens" (N=2,049)
% within category

Comfort Sharing **De-Identified** Biospecimens	...to develop gene-editing to treat disease/disability (Treatment)	Not comfortable	18
		Somewhat comfortable	27
		Fairly comfortable	27
		Very comfortable	28
	...to develop gene-editing to enhance a person physically/mentally (Enhancement)	Not comfortable	41
		Somewhat comfortable	24
		Fairly comfortable	20
		Very comfortable	15
Comfort Sharing **Identified** Biospecimens	...to develop gene-editing to treat disease/disability (Treatment)	Not comfortable	33
		Somewhat comfortable	31
		Fairly comfortable	21
		Very comfortable	15
	...to develop gene-editing to enhance a person physically/mentally (Enhancement)	Not comfortable	53
		Somewhat comfortable	23
		Fairly comfortable	15
		Very comfortable	9

Table 3-2. Dependent Variables Descriptive Statistics – "Sharing Biospecimens"

To generate the dependent variable "Sharing Biospecimens," we combined all four items into a single index on a scale from 0 (very uncomfortable with any biospecimen sharing) to 12 (extremely comfortable sharing identified or de-identified biospecimens for treatment and enhancement) (Fig.3-1). This index thus encompasses the respondent’s comfort with both *de-identified* and *identified* biospecimen sharing and use cases of treatment/prevention and enhancement.

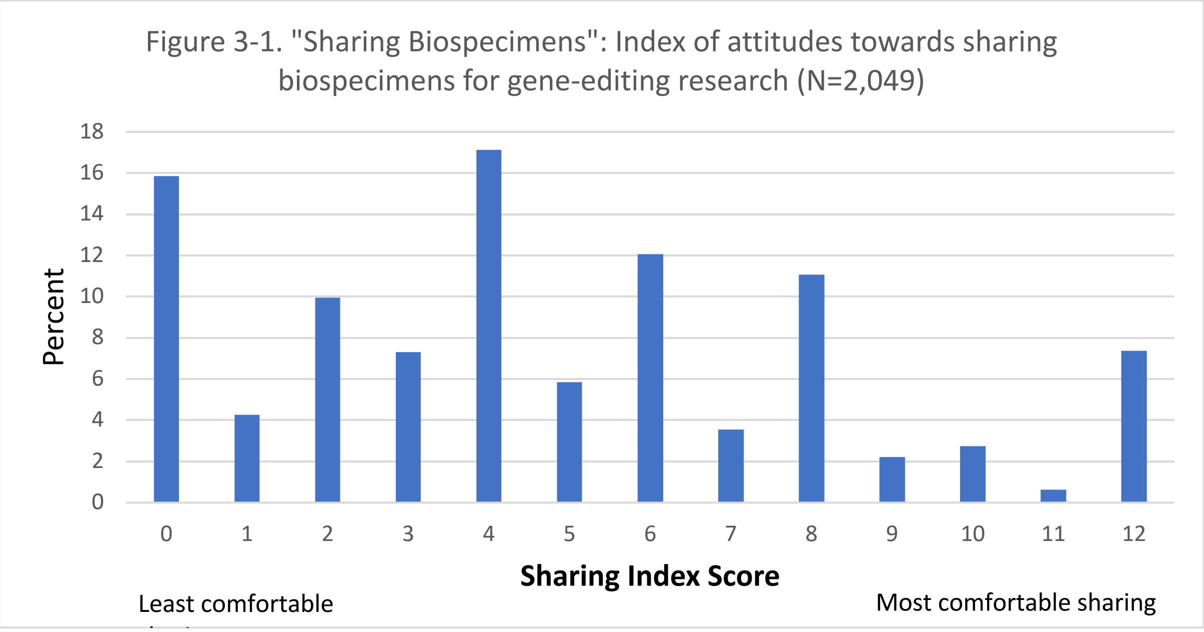

Figure 3-1. "Sharing Biospecimens" Index

3.3.2 Dependent Variable 2: Tax Support

The second outcome variable is comprised of a single survey item querying respondents’ comfort with their federal tax dollars being spent on research on gene-editing. We asked: “In the U.S., the federal government is a major funder of medical research using tax revenue. How comfortable are you with your tax dollars being used to support research on gene-editing?” Possible responses included “not comfortable” “somewhat comfortable” “fairly comfortable” and “very comfortable”. As a shorthand we will refer to this variable as “tax dollars” throughout. Figure 3-2 summarizes responses to this item.

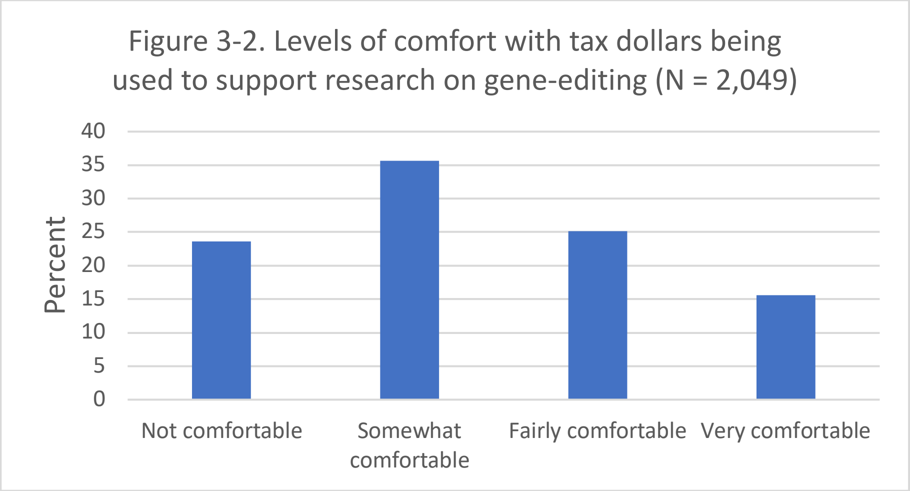

Figure 3-2 Comfort with Tax Dollars Used for Research on Gene-Editing

3.3.3 Dependent Variable 3: "Index of Optimism and Fear"

The final dependent variable was generated as a sum of responses to two sets of questions that ask about respondents' optimism about the future of gene-editing on the one hand and about their fear about the potential negative impacts of gene-editing on the other. We asked: "How optimistic are you that gene-editing will have a positive impact: a. on you; b. on your family; c. on society?" Respondents then were asked a parallel question: "How fearful are you that gene-editing will have a negative impact a. on you; b. on your family; c. on society?"

Thus, the "Index of Optimism and Fear" reflects a composite of 6 items from the survey (Table 3-3.) Each item response is a score 0-3 indicating respondents' level of optimism or fear regarding the future of gene-editing in the three cases of self, family and society. The fear responses were reverse coded. The final index ranges from 0 (very fearful / not at all optimistic) to 18 (very optimistic / not at all fearful.

TABLE 3-3. Dependent Variables Descriptive Statistics – "Index of Optimism & Fear" (N=2,049)
(% within category)

How **optimistic** are you that gene-editing will have a positive impact…	…on you	Not at all optimistic	35
		Somewhat optimistic	43
		Quite optimistic	14
		Very optimistic	8
	…on your family	Not at all optimistic	31
		Somewhat optimistic	46
		Quite optimistic	15
		Very optimistic	8
	…on society	Not at all optimistic	23
		Somewhat optimistic	48
		Quite optimistic	19
		Very optimistic	10
How **fearful** are you that gene-editing will have a negative impact…	…on you	Not at all fearful	34
		Somewhat fearful	44
		Quite fearful	12
		Very fearful	10
	…on your family	Not at all fearful	30
		Somewhat fearful	47
		Quite fearful	13
		Very fearful	10
	…on society	Not at all fearful	18
		Somewhat fearful	52
		Quite fearful	17
		Very fearful	13

Table 3-3. Dependent Variable 3 Descriptive Statistics - "Index of Optimism and Fear"

As is visually evident in Figures 3-3 and 3-4, the distribution of responses to the optimism and fear items for both self and family follow a similar pattern, with the greatest concentrations of responses in the "not at all" and "somewhat" true options. However, when respondents are asked specifically to consider the future of gene-editing for society, although the largest share of respondents remain "somewhat" optimistic or fearful, as compared with self and family, we observe movement towards both greater fear and greater optimism.

FIGURES 3-3, 3-4 – "Index of Optimism and Fear" Response variation within category (N=2,049)

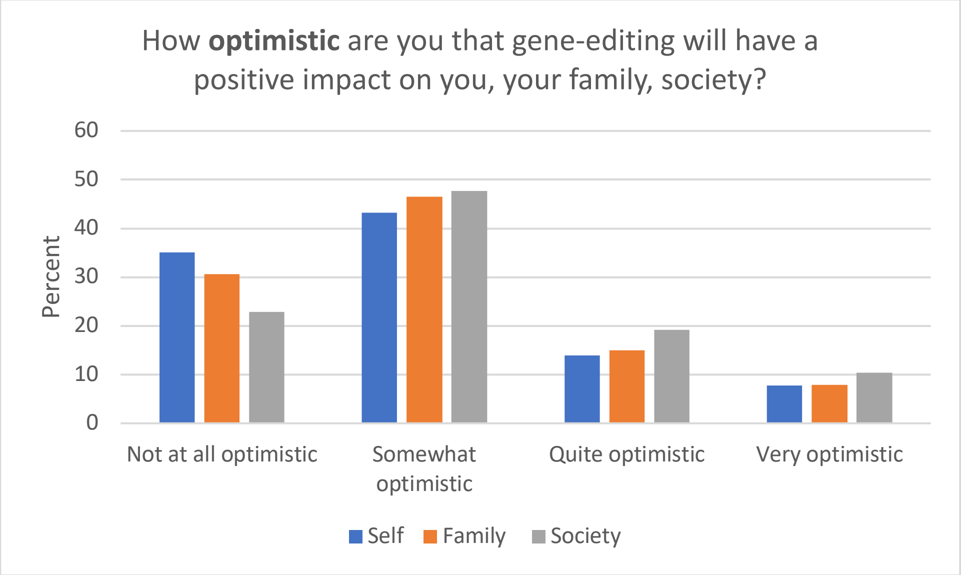

Figure 3-3. Variation in Optimism

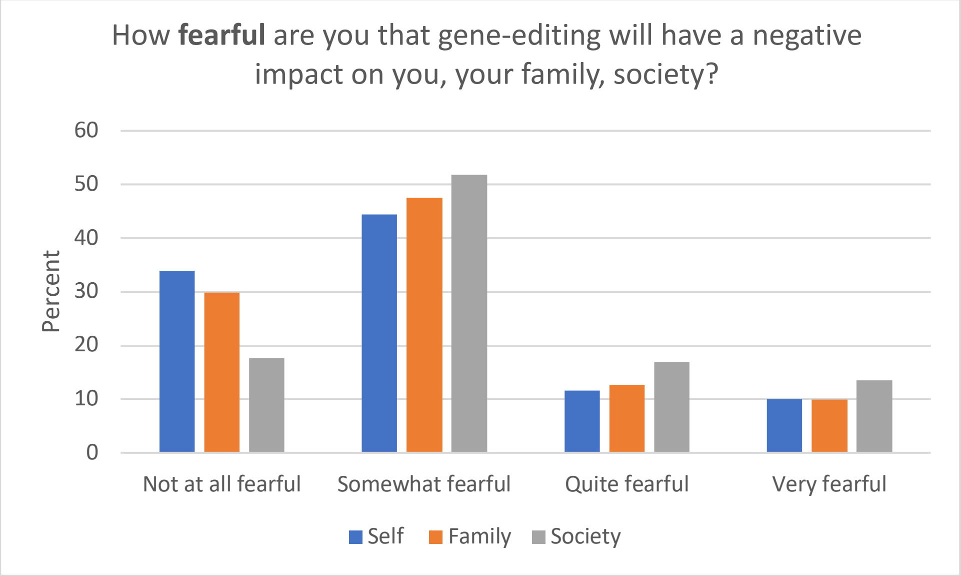

Figure 3-4 Variation in Pessimism

In sum, with the first two outcomes (i. sharing biospecimens and ii. tax dollars), we assess how the public views the investments (personal, biological and fiscal) required to create a CRISPR mediated-future. With the third outcome (iii. index of optimism/fear), we can assess *how participants view the future of this technology from a personal, familial and societal* *perspective*. Finally, we then ask what factors (demographic, experiential, attitudinal) help us understand the variation in respondents' views about these three outcomes of interest.

3.3.4 Independent Variables: Demographics, Experience and Attitudes

We report the following demographic variables for our survey population, all of which are included in the analytical models: sex, age, race/ethnicity, educational attainment (binary BA or above), income (binary of >$50,000/annual income).

As discussed above, cultural factors including religion and politics have been found to be important predictors of attitudes towards gene-editing and controversial biotechnologies. We include a four-category indicator of religious affiliation (protestant, catholic, atheist/agnostic/none and other) and a measure of relative degree of religiosity (religious attendance). The "religious attendance" scale is a 9-point scale that captures the frequency that respondents attend religious services ranging from "never attend" (n=528) to "several times a week" (n=109). For politics, we include two items to capture respondents' political orientation; 'party id' and 'ideology.' The party identification item is a three-category variable (democrat, independent, republican) that condenses a seven-point scale into three categories (e.g. "strong", "moderate" and "lean" Democrat became "Democrat"). The ideology measure is a seven-point scale of ideology from "extremely liberal" to "extremely conservative" that also included an 8th option of "I haven't thought about it much". For this analysis, those in the 8th category were included in the "moderate" category and we treated this overall as a "conservatism" scale.

In surveys that address health topics, it is important to assess if the respondent's health status, experience with major illness (in this case cancer) and recent experiences with the health care system account for variation in attitudes towards health concepts at issue. Respondent's **experiences** related to their health status and healthcare seeking might explain the variation in willingness to participate in research and optimism for gene-editing. We include two items relating to respondents' personal health status, a five-item scale of "self-reported health status" which ranges from "poor" to "excellent" and whether or not a respondent has experienced a cancer diagnosis[15].

In addition to participants health status and experience with cancer, we include a measure of participants reported experiences with discrimination in seeking health care. Prior research has found that experiences of discrimination both in everyday life and in the health care setting can negatively impact healthcare seeking and treatment adherence (Casagrande et al. 2007; Hong et al. 2018), perceptions of quality of care (Sorkin, Ngo-Metzger, and De Alba 2010) and that these experiences are correlated with trust in physicians and the healthcare system (Glover, Sims, and Winters 2017). Less well understood, however, is whether the experience of discrimination corresponds with negative views of new, risky or controversial health care technology. Given prior associations, we hypothesized that the experience of discrimination would incline individuals to be less likely to support a frontier technology such as gene-editing, particularly when viewed in terms of the donation of biospecimens for research. We further hypothesized that respondents who report having a prior experience of discrimination in seeking health care will be less inclined to share their biospecimens for research on gene-editing and will be lower on the fear/optimism scale. (No hypothesis for the tax dollars outcome seemed warranted.)[16]

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[15] Chi-square tests of association between variables capturing respondents' recent experiences with seeking healthcare for themselves and loved ones did not appear to explain variation in respondents' views towards gene-editing, so they were omitted from further exploration for the sake of parsimony.

[16] We also considered the possibility that experience with discrimination in health care is a mediator or moderator of other direct effects that impact attitudes towards gene-editing. In particular, we tested whether, and to what degree, experiences and perceptions of discrimination in health care mediates the relationship between demographic characteristics and comfort with biospecimen sharing. These tests proved inconclusive (data not shown) and we could neither accept nor reject this hypothesis.

Related to the experience of discrimination, we hypothesized that respondents' trust in health care providers and trust in the healthcare system could impact their willingness to personally contribute to research with their biospecimens and tax dollars and their relative degree of optimism or fear about a gene-edited future. To assess this, we include a previously developed and validated index of "system trust" (Platt, Jacobson, and Kardia 2018; Platt and Kardia 2015; Raj et al. 2020) that captures respondents' assessment of the fidelity, integrity, competency and overall trust in the health care system. The items that comprise the "system trust" variable emphasize the context of the sharing and use of personal health information by diverse actors in the health system and query respondents' general trust in these system actors and institutions (Cronbach's $\alpha = 0.85$). In addition, we include a "provider trust" index comprised of items that query respondents trust in their own health care providers (Cronbach's $\alpha =0.70$)(Platt et al. 2018; Platt and Kardia 2015). We hypothesized that increased trust in both providers and the health system would positively correlate with positive attitudes towards biospecimen sharing and tax investments in gene-editing. We also hypothesized that increased trust would positively correlate with the index of optimism and fear.

Our model also includes an index comprised of four items assessing respondents' altruism, a composite measure that captures respondents' general views of societal harmony, disharmony and altruism (Cronbach's $\alpha = 0.70$) The index ranges from 1 to 4 with higher scores indicating more altruistic attitudes (Feldman and Steenbergen 2001; Platt et al. 2018; Platt and Kardia 2015; Raj et al. 2020).

We also include an item that is responsive to Faden and colleagues' (Faden et al. 2013) claim that sharing biospecimens and data with the research enterprise has become an obligation of participants in the health care system. We anticipated those who view the sharing of patient data and biospecimens as a moral obligation (health data altruists) would correspondingly hold more positive attitudes towards sharing of biospecimens for research and the use of tax dollars for gene-editing research (thus capturing a latent "pro-research" attitude) (Raj et al. 2020).

Finally, the emergence and popularity of direct-to-consumer genetics testing companies, along with the ample media coverage of these enterprises and the U.S. public's embrace of them, marks the current era of genomics and the period in which CRISPR and recent innovations in genome editing have entered into public awareness. We assess the extent to which respondents view the commercialization of DNA testing favorably with an item that captures their attitude towards Direct to Consumer (DTC) genomics companies such as 23andMe. With a four-point Likert scale from very unfavorable to very favorable for response, we asked: "Given what you know about companies like 23andMe and AncestryDNA, do you generally have a favorable or unfavorable opinion of these companies?" We anticipated that favorable attitudes towards these companies would be highly correlated with more supportive and optimistic views across all three of our dependent variables.

3.3.5 Analysis

In what follows we first report (i.) descriptive statistics for the core demographic variables and (ii.) outcomes of interest. Then we present results from a series of six OLS regression models as follows: first, we look at demographic variation in the outcomes of interest (Model 1a-c), and then explore a cultural attitudes model (religion and politics) (Model 2a-c), a health experiences model (Model 3a-c), a trust model (Model 4a-c), an altruism and health data altruism model (Model 5a-c) and finally, full models (Model 6a-c) encompassing all independent predictors. The purpose of the full models is to assess the relative salience of the various predictors net of all other effects. We estimate and report z-score standardized beta coefficients and robust standard errors to facilitate meaningful comparison of the independent variables within and across models.

Given the size of our final model (17 variables), we sought to minimize the possibility of Type I error with a Bonferroni correction. We define statistical significance at the alpha=.05 level. The Bonferroni correction suggests that findings with a p-value of .0029 or below are statistically significant.

3.4 Results

3.4.1 Descriptive Statistics

Table 3-4. presents the summary demographic statistics describing the analytic sample of our survey respondent population (N=2,049) and their measured political and religious attributes. The respondents to our survey were 51% female, 58% white, non-Hispanic, and 42% under the age of 45. Our S.E.S. indicators included education (68% do not hold a Bachelor's degree or higher) and income (48% report earning >$50,000/year). Our measures of cultural affinities included religion and politics. 50% of respondents claimed to be Protestant, while 24% identified as atheist/agnostic. The sample population as a whole is moderately religious (mean frequency of attendance of religious services = 3.94, SD 2.69 on a 9-point scale). As for politics, 32% of our respondents identified as Republicans, 18% as Independent and 50% as Democrats. Our respondents average ideological disposition was slightly left of center (mean=3.10, SD 1.58 on a 7-point scale, where 7 = most conservative).

Table 3-4. Respondent Demographics (N = 2,049)
% within category, unless otherwise noted

Sex	Female	51
Age	18-29	12
	30-44	30
	45-59	26
	60-64	32
Race/Ethnicity	White, non-Hispanic	58
	Black, non-Hispanic	16
	Hispanic and other, non-Hispanic	26
S.E.S	Bachelor's degree or higher	32
	>$50K/year	48
Religious affiliation	Protestant	50
	Catholic	19
	Atheist/Agnostic/None	24
	Other	8
Religious attendance freq. (Range: 1-9)	Mean = 3.94, S.D. = 2.69	
Political party identification	Democrat	50
	Independent/none/don't lean	18
	Republican	32
Conservatism scale (Range: 1-7)	Mean = 3.10, S.D. = 1.58	

Table 3-4. Respondent Demographics (N=2,049)

Table 3-5. presents summary statistics of the independent variables included in our models. While 69% of our respondents reported themselves to be in poor, fair or good health, 10% reported having a prior diagnosis of cancer. We queried respondents about their experiences of discrimination in the health care system and 22% reported having such experiences. We asked respondents if they believed that, generally speaking, people have an ethical obligation to share health data for research and found that 51% of our respondents believed that this was not true. As for attitudes towards Direct-to-Consumer genomics companies, we found that 62% of respondents held somewhat or very favorable views. Finally, our “provider trust” index found our respondents as a whole converged slightly above mid-range on a scale from 1-4, where higher scores indicate greater trust in healthcare providers (mean 2.21, SD =.46). For our “system trust” index (range 3-12), the mean score was 7.07 with a SD of 1.87. Finally, our respondents scored fairly high on our altruism index (range 1-4, mean 2.97, SD .66).

Table 3-5. Independent Variables (N = 2,049) % within category, unless otherwise noted		
Self-reported health status	Poor/fair/good	69
	Very Good/excellent	31
Prior cancer Dx	Yes	10
Experience of discrimination	Yes	22
Provider trust index (Range: 1 – 4)	Mean = 2.21, S.D. = .46, Cronbach's α= 0.6939	
System trust index (Range: 3 – 12)	Mean = 7.07, S.D. = 1.87, Cronbach's α= 0.8536	
Altruism index (Range: 1 – 4)	Mean = 2.97, S.D. = .66, Cronbach's α= 0.7093	
People have an ethical obligation to share health data for research…	Not true	51
	Somewhat true	28
	Fairly true	14
	Very true	7
Views of DTC genomics companies	Very unfavorable	12
	Somewhat unfavorable	26
	Somewhat favorable	52
	Very favorable	10

Table 3-5. Independent Variables Summary

Our respondents' reactions to the items that comprise the three dependent variables of interest in this study are summarized in **Table 3-6** (in addition to the aforementioned Tables 3-1 - - 3-3 and Figures 3-1 – 3-3)**.** Overall, respondents leaned towards being "less comfortable" with the idea of sharing their biospecimens for research on gene-editing (mean=4.72 on a 12-point scale), somewhat accepting of using tax dollars for research on gene-editing (mean=2.33 on a 4 point scale) and converging around not having strongly fearful or optimistic views of the future with gene-editing (mean= -.15 on a scale from -9 to 9).

Table 3-6. Dependent Variables (N=2,049)	
Sharing biospecimens index (Range: 0 – 12)	Mean = 4.72, S.D. 3.47 Cronbach's α = 0.8386
Supports use of tax dollars on gene-editing research (1 – 4)	Mean = 2.33, S.D. 1.00
Index of fear/optimism (Range: -9 – 9)	Mean -.15, S.D. 3.99 Cronbach's α = 0.8344

Table 3-6. Dependent Variables Summary

Reactions to the four items that comprise the "comfort with sharing biospecimens" index are summarized in Table 3-3 and Fig. 3-1 offers an "at-a-glance" view of the variation in responses by percentage across the complete 0-12 scale. Fig. 3-2 summarizes support for use of tax dollars on gene-editing focused research ("Tax dollars").

Figures 3-3 and 3-4 shows the variation in responses to all 6 items that comprise the “index of optimism and fear” and Fig. 3-5 displays the percentages of respondent scores across the complete composite index (range of -9 to +9). Those who score in the negative have registered greater fear overall, while those who score on the positive end of the scale have registered greater optimism about gene-editing across the six items comprising the scale. The notable concentration around “0” suggests to us that the largest portion of our respondents (~27%) have not yet formed strongly fixed views of gene-editing in these terms. Overall, the views of U.S. adults towards gene-editing technology do not yet appear to be strongly fixed either in favor or against as the most frequent response to both the fear and optimism options was “somewhat (fearful or optimistic)” for all six of the items in this index.

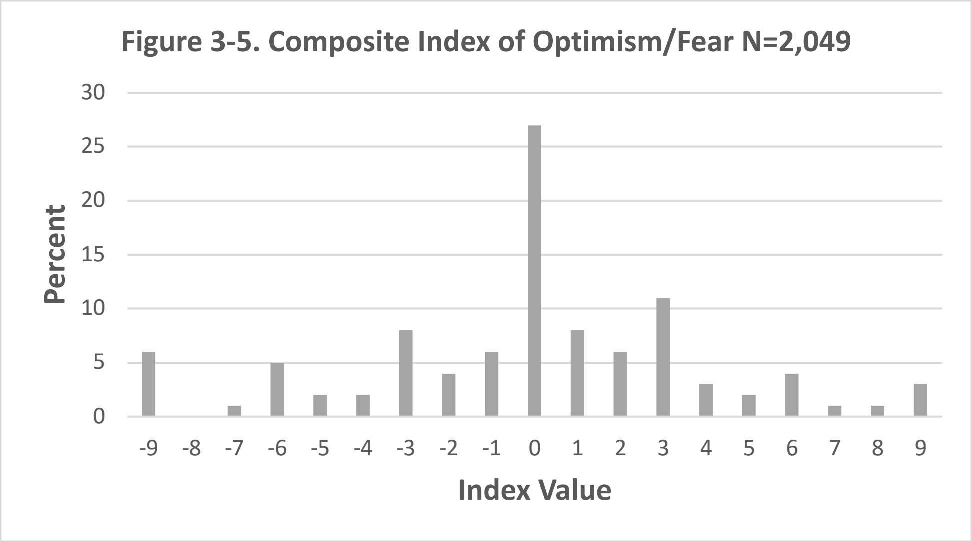

Figure 3-5. Composite Index of Optimism and Fear

To get an alternative view on the spread of respondents’ reactions to the optimism/fear items, we dichotomized the fear and optimism responses and placed them in a 2x2 table. Table 3-7 is the crosstab of a dichotomized version of the fear/optimism attitudes, combining “not at all” and “somewhat” fearful/optimistic responses on the one hand, and “quite” or “very” fearful/optimistic responses on the other. This cross tab is an indicator of the relative strength of attitudes towards the future of gene-editing. We see 67% of respondents aggregating in the “less fixed opinions about future” of gene-editing. This is another way to look at the concentration around “0” in Figure 3. Those with more firmly pessimistic attitudes towards the future of gene-editing represent a similar percentage of respondents with a firmly optimistic perspective (16% and 15% respectively).

Table 3-7. Crosstab of binary fear/optimism attitudes towards the future of gene-editing		Fear	
		Not at all/somewhat	Quite/very
Optimism	Not at all/ somewhat	Less fixed opinions about future with gene-editing 67% (n=1,375)	Stronger “anti gene-editing” opinions 16% (n=333)
	Quite/very	Stronger “pro gene-editing” opinions 15% (n=299)	Torn between fear and optimism 2% (n=42)

Table 3-7. Crosstab of Binary Fear/Optimism Attitudes

We would expect quadrant four here to be close to zero as it would reflect somewhat incoherent attitudes of great optimism and great fear regarding gene-editing. Only 2% of our sample responded in this way. The prima facia incoherence of this position might suggest a limitation of the survey format, such that these respondents may have been inattentive in their responses to these items and therefore we are cautious about interpreting this outcome.

We used paired t-tests to confirm that, with statistical significance, respondents are simultaneously more optimistic and more fearful about gene-editing for **society**, as compared with **family** and **self** (results not shown). Further, they are more optimistic and more fearful about gene-editing for **family** as compared with **self**. The step-wise increases in both fear and optimism, moving from self to family to society, represent statistically significant variation. However, when comparing across the optimism and fear responses, self and family are not significantly different, (i.e. the magnitude of fear and optimism are comparable for self and family) but reactions for society suggest that fear (mean = 2.26) is more intense than optimism (mean = 1.94). A paired t-test confirmed that respondents' fear about gene-editing's impact on *society* is statistically significantly greater (p<0.0000) than their optimism. So while the index reveals a vast number of less developed perspectives on gene-editing, when it comes to the impact of gene-editing on *society*, fearfulness appears to outweigh optimism at this point. This is consistent with the Pew Survey finding that, for most people in the U.S., caution is outweighing enthusiasm about gene-editing (Funk and Hefferon 2018).

3.4.2 Regression Models

Tables 3-8, 3-9 and 3-10 present the results of the OLS models (Models 1.a-c, - Models 6.a-c) for all three DVs and **Table 3-11** summarizes the results of the full models (Model 6.a-c) for the three dependent variables, indicating directionality and strength of association (p-value).

Demographics (Models 1a-c)

Among our control variables, we find that sex and educational attainment appear to explain some of the variation in attitudes across the three models, though only sex registers as a significant variable in all three sets. In our demographics only models, we found a consistent, though modest, correlation between being female and holding less supportive and optimistic views of gene-editing across all three dependent variables. This effect was largest for "tax dollars" ($\beta^* = -0.085$, $p<.01$). We conducted further analyses (not shown) to explore the interactions between gender and ideology and gender and religiosity to see if the gender effect could be accounted for by a block of strongly religious or conservative women impacting the overall main effect. These further tests did not support an interaction and so we conclude that female gender is consistently predictive of less supportive views of gene-editing across all three dependent variable constructs.

Having higher educational attainment (holding a BA degree or above compared with lower levels of attainment) appears to be a significant predictor of support for using tax dollars for gene-editing research when we model demographics only ($\beta^* = 0.092$, $p<.0025$). Notably, higher educational attainment was consistently significantly predictive of support for tax dollars in all 6 of our models (see below).

We find modest negative correlations associated with being in one of two older age quartiles (30-44 and 45-59) for both the sharing of biospecimens and the use of tax dollars for gene-editing research, all at the $p<0.05$ level. This negative association was only apparent for the 45-59 year old cohort for the index of optimism and fear (Table 3-10, cf. Model 1c and Model 3c).

Overall, demographics alone models were not particularly explanatory of the variation in support/comfort with gene-editing. The R-squared statistic across all three versions of Model 1 was quite low (0.025, 0.027, 0.013) suggesting that demographics alone are not able to account for much of the significant variation in the outcome variables. However, female sex was associated with lower comfort with gene-editing in all three sets of models and educational attainment appears to be a sound predictor of support for using one's tax dollars on gene-editing research.

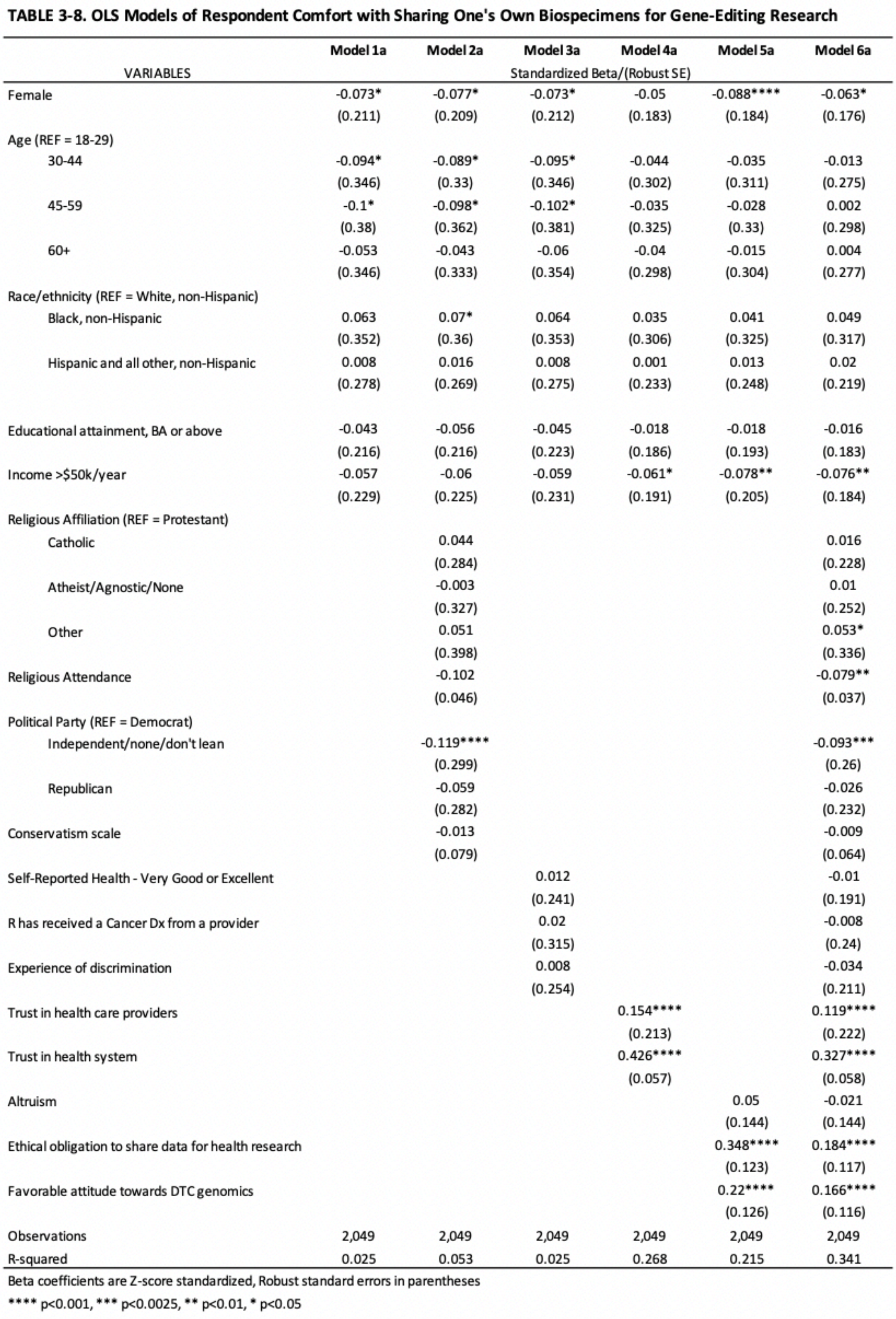

TABLE 3-8. OLS Models of Respondent Comfort with Sharing One's Own Biospecimens for Gene-Editing Research

	Model 1a	Model 2a	Model 3a	Model 4a	Model 5a	Model 6a
VARIABLES			Standardized Beta/(Robust SE)			
Female	-0.073*	-0.077*	-0.073*	-0.05	-0.088****	-0.063*
	(0.211)	(0.209)	(0.212)	(0.183)	(0.184)	(0.176)
Age (REF = 18-29)						
30-44	-0.094*	-0.089*	-0.095*	-0.044	-0.035	-0.013
	(0.346)	(0.33)	(0.346)	(0.302)	(0.311)	(0.275)
45-59	-0.1*	-0.098*	-0.102*	-0.035	-0.028	0.002
	(0.38)	(0.362)	(0.381)	(0.325)	(0.33)	(0.298)
60+	-0.053	-0.043	-0.06	-0.04	-0.015	0.004
	(0.346)	(0.333)	(0.354)	(0.298)	(0.304)	(0.277)
Race/ethnicity (REF = White, non-Hispanic)						
Black, non-Hispanic	0.063	0.07*	0.064	0.035	0.041	0.049
	(0.352)	(0.36)	(0.353)	(0.306)	(0.325)	(0.317)
Hispanic and all other, non-Hispanic	0.008	0.016	0.008	0.001	0.013	0.02
	(0.278)	(0.269)	(0.275)	(0.233)	(0.248)	(0.219)
Educational attainment, BA or above	-0.043	-0.056	-0.045	-0.018	-0.018	-0.016
	(0.216)	(0.216)	(0.223)	(0.186)	(0.193)	(0.183)
Income >$50k/year	-0.057	-0.06	-0.059	-0.061*	-0.078**	-0.076**
	(0.229)	(0.225)	(0.231)	(0.191)	(0.205)	(0.184)
Religious Affiliation (REF = Protestant)						
Catholic		0.044				0.016
		(0.284)				(0.228)
Atheist/Agnostic/None		-0.003				0.01
		(0.327)				(0.252)
Other		0.051				0.053*
		(0.398)				(0.336)
Religious Attendance		-0.102				-0.079**
		(0.046)				(0.037)
Political Party (REF = Democrat)						
Independent/none/don't lean		-0.119****				-0.093***
		(0.299)				(0.26)
Republican		-0.059				-0.026
		(0.282)				(0.232)
Conservatism scale		-0.013				-0.009
		(0.079)				(0.064)
Self-Reported Health - Very Good or Excellent			0.012			-0.01
			(0.241)			(0.191)
R has received a Cancer Dx from a provider			0.02			-0.008
			(0.315)			(0.24)
Experience of discrimination			0.008			-0.034
			(0.254)			(0.211)
Trust in health care providers				0.154****		0.119****
				(0.213)		(0.222)
Trust in health system				0.426****		0.327****
				(0.057)		(0.058)
Altruism					0.05	-0.021
					(0.144)	(0.144)
Ethical obligation to share data for health research					0.348****	0.184****
					(0.123)	(0.117)
Favorable attitude towards DTC genomics					0.22****	0.166****
					(0.126)	(0.116)
Observations	2,049	2,049	2,049	2,049	2,049	2,049
R-squared	0.025	0.053	0.025	0.268	0.215	0.341

Beta coefficients are Z-score standardized, Robust standard errors in parentheses

**** p<0.001, *** p<0.0025, ** p<0.01, * p<0.05

Table 3-8. OLS Models 1a - 6a "Sharing Biospecimens"

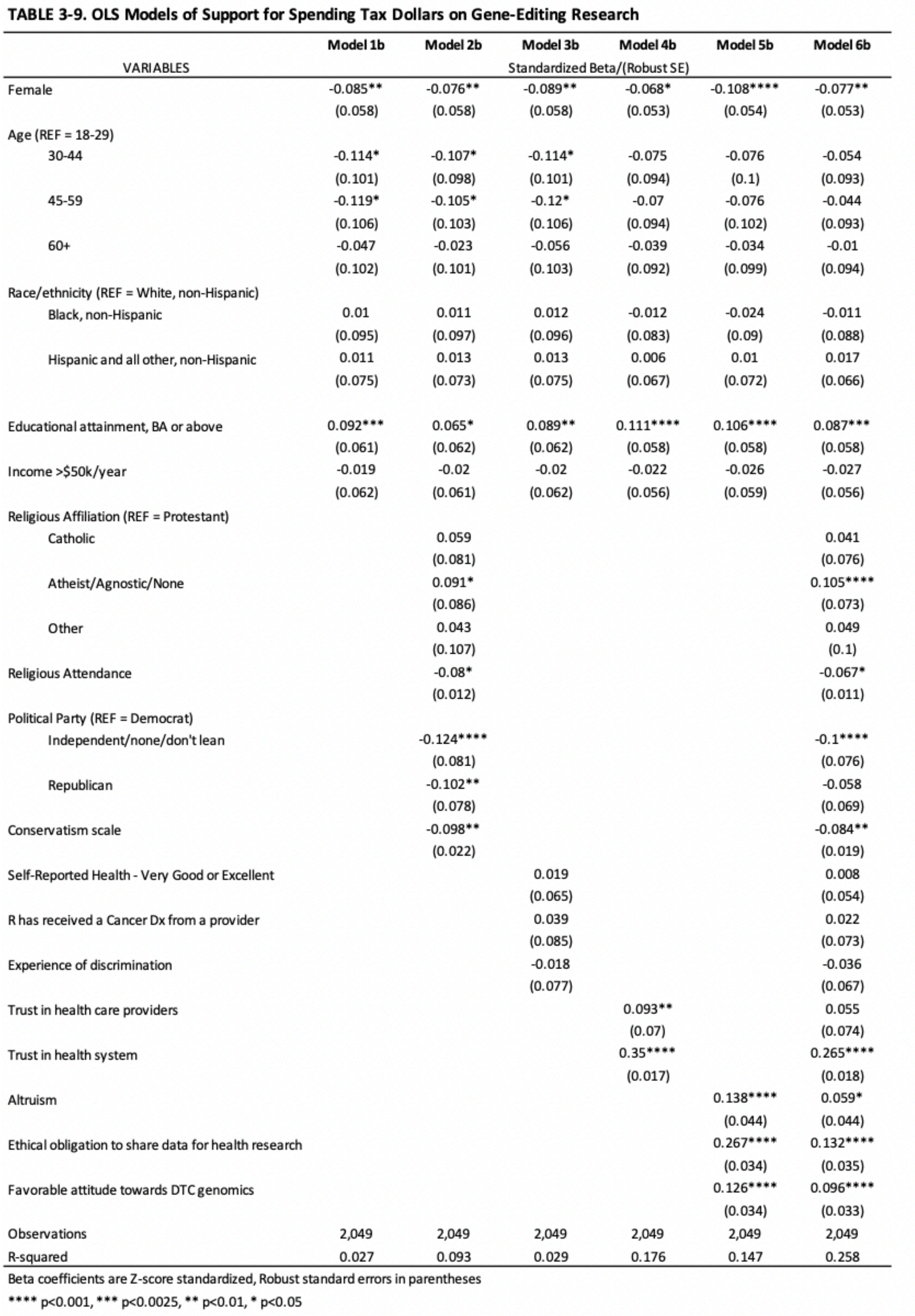

TABLE 3-9. OLS Models of Support for Spending Tax Dollars on Gene-Editing Research

VARIABLES	Model 1b	Model 2b	Model 3b	Model 4b	Model 5b	Model 6b
	Standardized Beta/(Robust SE)					
Female	-0.085**	-0.076**	-0.089**	-0.068*	-0.108****	-0.077**
	(0.058)	(0.058)	(0.058)	(0.053)	(0.054)	(0.053)
Age (REF = 18-29)						
30-44	-0.114*	-0.107*	-0.114*	-0.075	-0.076	-0.054
	(0.101)	(0.098)	(0.101)	(0.094)	(0.1)	(0.093)
45-59	-0.119*	-0.105*	-0.12*	-0.07	-0.076	-0.044
	(0.106)	(0.103)	(0.106)	(0.094)	(0.102)	(0.093)
60+	-0.047	-0.023	-0.056	-0.039	-0.034	-0.01
	(0.102)	(0.101)	(0.103)	(0.092)	(0.099)	(0.094)
Race/ethnicity (REF = White, non-Hispanic)						
Black, non-Hispanic	0.01	0.011	0.012	-0.012	-0.024	-0.011
	(0.095)	(0.097)	(0.096)	(0.083)	(0.09)	(0.088)
Hispanic and all other, non-Hispanic	0.011	0.013	0.013	0.006	0.01	0.017
	(0.075)	(0.073)	(0.075)	(0.067)	(0.072)	(0.066)
Educational attainment, BA or above	0.092***	0.065*	0.089**	0.111****	0.106****	0.087***
	(0.061)	(0.062)	(0.062)	(0.058)	(0.058)	(0.058)
Income >$50k/year	-0.019	-0.02	-0.02	-0.022	-0.026	-0.027
	(0.062)	(0.061)	(0.062)	(0.056)	(0.059)	(0.056)
Religious Affiliation (REF = Protestant)						
Catholic		0.059				0.041
		(0.081)				(0.076)
Atheist/Agnostic/None		0.091*				0.105****
		(0.086)				(0.073)
Other		0.043				0.049
		(0.107)				(0.1)
Religious Attendance		-0.08*				-0.067*
		(0.012)				(0.011)
Political Party (REF = Democrat)						
Independent/none/don't lean		-0.124****				-0.1****
		(0.081)				(0.076)
Republican		-0.102**				-0.058
		(0.078)				(0.069)
Conservatism scale		-0.098**				-0.084**
		(0.022)				(0.019)
Self-Reported Health - Very Good or Excellent			0.019			0.008
			(0.065)			(0.054)
R has received a Cancer Dx from a provider			0.039			0.022
			(0.085)			(0.073)
Experience of discrimination			-0.018			-0.036
			(0.077)			(0.067)
Trust in health care providers				0.093**		0.055
				(0.07)		(0.074)
Trust in health system				0.35****		0.265****
				(0.017)		(0.018)
Altruism					0.138****	0.059*
					(0.044)	(0.044)
Ethical obligation to share data for health research					0.267****	0.132****
					(0.034)	(0.035)
Favorable attitude towards DTC genomics					0.126****	0.096****
					(0.034)	(0.033)
Observations	2,049	2,049	2,049	2,049	2,049	2,049
R-squared	0.027	0.093	0.029	0.176	0.147	0.258

Beta coefficients are Z-score standardized, Robust standard errors in parentheses

**** p<0.001, *** p<0.0025, ** p<0.01, * p<0.05

Table 3-9. OLS Models 1b - 6b "Tax Support"

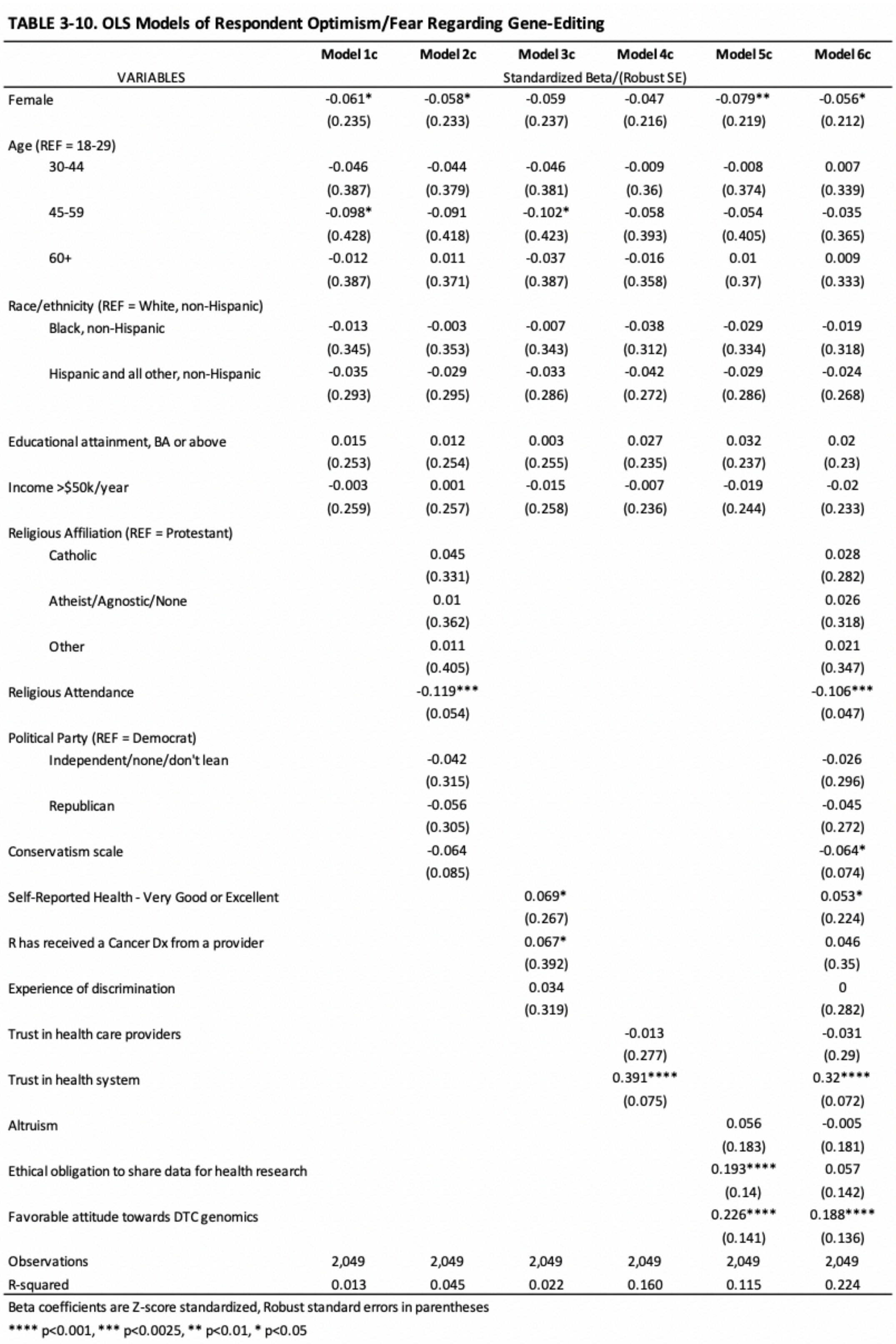

TABLE 3-10. OLS Models of Respondent Optimism/Fear Regarding Gene-Editing

	Model 1c	Model 2c	Model 3c	Model 4c	Model 5c	Model 6c
VARIABLES	Standardized Beta/(Robust SE)					
Female	-0.061*	-0.058*	-0.059	-0.047	-0.079**	-0.056*
	(0.235)	(0.233)	(0.237)	(0.216)	(0.219)	(0.212)
Age (REF = 18-29)						
30-44	-0.046	-0.044	-0.046	-0.009	-0.008	0.007
	(0.387)	(0.379)	(0.381)	(0.36)	(0.374)	(0.339)
45-59	-0.098*	-0.091	-0.102*	-0.058	-0.054	-0.035
	(0.428)	(0.418)	(0.423)	(0.393)	(0.405)	(0.365)
60+	-0.012	0.011	-0.037	-0.016	0.01	0.009
	(0.387)	(0.371)	(0.387)	(0.358)	(0.37)	(0.333)
Race/ethnicity (REF = White, non-Hispanic)						
Black, non-Hispanic	-0.013	-0.003	-0.007	-0.038	-0.029	-0.019
	(0.345)	(0.353)	(0.343)	(0.312)	(0.334)	(0.318)
Hispanic and all other, non-Hispanic	-0.035	-0.029	-0.033	-0.042	-0.029	-0.024
	(0.293)	(0.295)	(0.286)	(0.272)	(0.286)	(0.268)
Educational attainment, BA or above	0.015	0.012	0.003	0.027	0.032	0.02
	(0.253)	(0.254)	(0.255)	(0.235)	(0.237)	(0.23)
Income >$50k/year	-0.003	0.001	-0.015	-0.007	-0.019	-0.02
	(0.259)	(0.257)	(0.258)	(0.236)	(0.244)	(0.233)
Religious Affiliation (REF = Protestant)						
Catholic		0.045				0.028
		(0.331)				(0.282)
Atheist/Agnostic/None		0.01				0.026
		(0.362)				(0.318)
Other		0.011				0.021
		(0.405)				(0.347)
Religious Attendance		-0.119***				-0.106***
		(0.054)				(0.047)
Political Party (REF = Democrat)						
Independent/none/don't lean		-0.042				-0.026
		(0.315)				(0.296)
Republican		-0.056				-0.045
		(0.305)				(0.272)
Conservatism scale		-0.064				-0.064*
		(0.085)				(0.074)
Self-Reported Health - Very Good or Excellent			0.069*			0.053*
			(0.267)			(0.224)
R has received a Cancer Dx from a provider			0.067*			0.046
			(0.392)			(0.35)
Experience of discrimination			0.034			0
			(0.319)			(0.282)
Trust in health care providers				-0.013		-0.031
				(0.277)		(0.29)
Trust in health system				0.391****		0.32****
				(0.075)		(0.072)
Altruism					0.056	-0.005
					(0.183)	(0.181)
Ethical obligation to share data for health research					0.193****	0.057
					(0.14)	(0.142)
Favorable attitude towards DTC genomics					0.226****	0.188****
					(0.141)	(0.136)
Observations	2,049	2,049	2,049	2,049	2,049	2,049
R-squared	0.013	0.045	0.022	0.160	0.115	0.224

Beta coefficients are Z-score standardized, Robust standard errors in parentheses

**** p<0.001, *** p<0.0025, ** p<0.01, * p<0.05

Table 3-10. OLS Models 1c - 6c "Index of Optimism and Fear"

Religion and Politics (Models 2a-c)

In this model, we explore the explanatory role that religion and politics might play in attitudes towards gene-editing and find results that are broadly consistent with prior research, and that attitudes towards gene-editing seem to not be sharply divided by religious or political lines. Notably, political independents in our sample were less supportive of using tax dollars for research and less comfortable with sharing their biospecimens for research. We sought to understand if identifying as one particular religious denomination inclined respondents to be more or less supportive of gene-editing than another. Our results did not reveal evidence that, for example, Catholics are more supportive of gene-editing than Protestants. However, when it comes to supporting the use of tax dollars for research on gene-editing, those who identified as atheist/agnostic or none, were significantly more likely to be supportive than Protestants ($\beta^* = 0.091$, $p<.05$). This association held and increased in explanatory magnitude and statistical significance in our final model ($\beta^* = 0.105$, $p<.001$).

Increased *frequency of attendance* at religious services was *negatively* correlated with the index of optimism and fear ($\beta^* = -0.119$, $p<.0025$) and, less robustly, comfort with one's tax dollars being used to support gene-editing research ($\beta^* = -0.08$, $p<.05$). Although not significant initially in Model 2c, this factor emerged as a significant predictor of attitudes towards the sharing of biospecimens in the final model 6c ($\beta^* = -.079$, $p<.01$).

Political affiliation and conservative ideology have been found to be correlated with lower levels of support for gene-editing in prior work (Funk and Hefferon 2018; Scheufele et al. 2017). In our survey, this pattern held somewhat, though was less pronounced than the effect of identifying as a political independent or "non-leaner," as compared with identifying as a

Democrat. Identifying as an independent/non-leaner was significantly negatively correlated with attitudes towards sharing biospecimens for gene-editing research (β* = -0.119, p<.001). Further, political independents were significantly less likely to support the use of tax dollars for research as compared with Democrats (β* = -0.124, p<.001), as were those who identified as Republican (β*-0.102, p<.01). The effect of being a political independent retained significance in our full model (Model 6b) comprised of all controls and co-variates. Political party identification was not a significant predictor of respondents' placement on the index of optimism and fear (Model 6c).

A separate indicator, "conservatism scale", revealed, unsurprisingly, that those higher on the scale (i.e. more conservative) were less supportive of the use of tax dollars for gene-editing research, although increased conservatism did not, contrary to our hypothesis, correspond with attitudes towards sharing biospecimens for gene-editing research. In our final model of the optimism and fear index, increased conservatism was associated with a less optimistic view overall towards gene-editing, although only at the p<.05 level.

Health and Health Care Experiences (Models 3a-c)

We anticipated that people with experience of a cancer diagnosis would be more supportive of uses of gene-editing because of the therapeutic potential of this technology and prior work that found treating severe illness was generally more acceptable among possible applications of gene-editing. However, none of our three indicators of health experience (self-reported health status, having received a cancer diagnosis from a provider, having experienced discrimination in seeking health care) were found to be significant predictors of willingness to share biospecimens or support for spending tax dollars on gene-editing research. We did find a modest association between being in very good or excellent self-reported health (compared with fair or poor), and holding a more optimistic view of gene-editing overall (β* = .069, p<.05), which retained the same significance, though less explanatory power in the final model. Having received a cancer diagnosis in the past was also modestly predictive of increased optimism about gene-editing, however, this effect disappeared in the final model.

Trust in Providers and Trust in Health System (Models 4a-c)

Models 4a-c examine the hypothesis that increased trust in providers and the health system overall will be positively predictive of respondents support for sharing their biospecimens and tax dollars for gene-editing research, as well as more optimistic views of gene-editing overall. Notably, these models, comprised of the two trust indices and the demographic controls, resulted in the best model fit (highest R-squared statistic) of the five partial models for all three of the outcomes of interest (.268, .176, .160). To unpack this, Model 4a allows us to account for ~27% of the variance in attitudes towards sharing biospecimens for research on gene-editing, whereas the first three models (Models 1a – 3a) were all below 10%.

Scoring higher on the index of "provider trust" (composed as the sum of means of four items that assess respondent trust in their health care providers) was positively correlated with willingness to share biospecimens for gene-editing research ($\beta^* = .154$, $p<.001$) and with comfort with use of tax dollars for gene-editing research ($\beta^* = .093$, $p<0.01$). In the final models, having higher levels of provider trust remained a significant predictor of willingness to share biospecimens ($\beta^* = .119$, p<001).

Recall that the "system trust" index is the sum of three smaller indices assessing respondent views of the health system's *fidelity*, *integrity*, *competency* and indicators of respondent "*global trust*," captures respondents' views of the trustworthiness of the health system taken as a whole. Increased "system trust" was associated with greater willingness to share biospecimens for gene-editing research ($\beta^* = .426$, $p<.001$), greater support for use of tax dollars for gene-editing research (β* = .35, $p<.001$) and greater optimism about a future with gene-editing (β* = .391, $p<.001$). The strength of this association remained large and statistically significant in the final models for all three outcomes (β* = .327, β* = .265, β* = .32). The Z-score standardized beta coefficients enable us to quickly see that system trust is the single variable that accounts for the most variation in the three outcomes, whether as part of the partial model (Model 4a-c) or the full multivariable model (Model 6a-c).

Altruism, Ethical Duty to Share Health Data, DTC Genomics (Models 5a-c)

Model 5 incorporates three variables (along with demographic predictors) that indicate respondents' general levels of altruism, support for the claim of an "ethical obligation for patients to share their data for health research" and respondent views of DTC genomics companies. As with Models 4a-c, Models 5a-c realized significant improvements in model fit as compared with Models 1 through 3 across all three outcomes of interest with the ability to account for ~22%, 15% and 12% of the variation in the three outcomes (r-square statistics of .215, .147 and .115).

Respondents with higher scores on the altruism index were more likely to be supportive of spending tax dollars on gene-editing research in model 5 (β* = .138, $p<.001$), however in the full model, this association was diminished (β* = .059, $p<.05$). Contrary to our hypothesis, altruism was not significantly associated with willingness to share biospecimens or position on the optimism/fear index.

As expected, those agreeing with the idea that patients do have a *positive ethical obligation* to share health data for research (health data altruists) were significantly more likely to express willingness to share their biospecimens for research to develop gene-editing (β* = .348, $p<0.001$), a finding that held in the final model as well (β* = .184, $p<.001$). Further, those who agreed with this principle were more likely to support the expenditure of tax dollars for research on gene-editing (β* = .267, p<0.001; final model: β* = .132, p<.001). Holding this ethical stance was statistically significantly associated with one's position on the index of optimism and fear in the partial model only (β* = .193, p<.001). Recall that only 21% (Table 2b) of our respondents viewed the claim that "people have an ethical obligation to share health data for research" as either fairly or very true.

Respondents' views towards gene-editing were consistently, and predictably, positively correlated with those who held favorable attitudes towards direct-to-consumer genetics companies such as 23andMe or Ancestry.com. The popularity of DTC companies has grown alongside the emergence of CRISPR gene-editing and we hypothesized that those who have favorable attitudes towards DTC genomics would be more inclined to support developments in genomic technology and capability. Holding a more positive view of DTC genomics companies was positively correlated with support for sharing biospecimens to develop gene-editing (β* = .22, p<0.001), with willingness to support the expenditure of tax dollars on gene-editing research (β* = .126, p<0.001) and with being more optimistic than fearful of a gene-edited future (β* = .226, p<0.001). These associations held in all three full models (β* = .166, .096, .188) at the p<.001 significance level.

Full Models (Models 6a-c)

Table 3-11 summarizes the direction and magnitude of all significant variables from the three full models. The model fit for the three full models indicates that we were able to explain 34% of the variation in respondents attitudes towards sharing biospecimens for gene-editing research, 26% of the variation in respondents support for spending tax dollars on gene-editing research and 22% of the variation in respondents relative optimism and fear about the future of gene-editing.

TABLE 3-11. Comparison of Significant Predictors from Full Models

VARIABLES	**DV 1 - Sharing biospecimens**	**DV 2 - Tax dollars for G.E. research**	**DV 3 - Index of Optimism/Fear**
Female	**- ***	**- ****	**- ***
Age	----	----	----
Race/ethnicity	----	----	----
Educational attainment, BA or above	----	**+*****	----
Income >$50k/year	**-****	----	----
Religious Affiliation (REF = Protestant)			
Catholic	----	----	----
Atheist/Agnostic/None	----	**+******	----
Other	----	----	----
Religious Attendance	**-****	**-***	**-*****
Political Party (REF = Democrat)			
Independent/none/don't lean	**-*****	**-******	----
Republican	----	----	----
Conservatism scale	----	**-****	**-***
Self-Reported Health - Very Good or Excellent	----	----	----
R has received a Cancer Dx from a provider	----	----	----
Experience of discrimination	----	----	----
Trust in health care providers	**+******	----	----
Trust in health system	**+******	**+******	**+******
Altruism	----	**+***	----
Ethical obligation to share data for health research	**+******	**+******	----
Attitude towards DTC genomics	**+******	**+******	**+******

+/- = connote positive/negative correlation

**** p<0.001, *** p<0.0025, ** p<0.01, * p<0.05

Table 3-11. Comparison of Significant Predictors from Full Models (6a, 6b, 6c)

3.5 Discussion

3.5.1 The U.S. Public and Gene-Editing

Our survey finds that the U.S. public is not yet firmly set in its views on gene-editing and their willingness to participate in building this technology. This ambivalence is evident in the 55% of respondents who are fairly or very comfortable with sharing their biospecimens for gene-editing research in the least controversial case (developing disease treatments using de-identified biospecimens). This ambivalence turns negative when the goal is "enhancement," (we find a 23% increase of respondents who are *not comfortable* sharing de-identified biospecimens when the research is focused on enhancements.) Additionally, levels of comfort with sharing biospecimens drops further when the context involves using "identified" biospecimens, suggesting that this common approach to the use of biospecimens and health data may be relevant context for how the public perceives the pathway towards a future of gene-editing therapies.

This ambivalence towards gene-editing is furthermore apparent in the 60% of respondents who are only somewhat or not at all comfortable with using tax dollars to support gene-editing research. Finally, this ambivalence is evident in our third dependent variable, the index of optimism/fear, where we found that >65% of our respondents were neither strongly optimistic nor fearful for themselves, their families or society. Perhaps the public has appraised the situation and are generally reserving judgment until the gene-editing revolution bears fruit in the guise of clinical breakthroughs or investment windfalls. We suspect that it is more likely that this somewhat ambivalent perspective suggests that, for many in the U.S. public, gene-editing has not yet emerged as a salient matter on the issue agenda. This is an important finding for those engaged in science communication, for those seeking to either enhance public support or to raise alarm bells of risk or concern among the public.

This chapter contributes a novel finding to the growing body of research on public attitudes towards gene-editing. Namely, when the issue of supporting the future of gene-editing is posed in terms of making personal contributions of biospecimens or tax dollars, the U.S. public is equivocal in its enthusiasm. Furthermore, this equivocation is bound up with personal factors, cultural attributes and attitudes towards institutions. Future research can build on this work to try to deepen and sharpen our understanding of the trade-offs in personal and societal commitments that people in the U.S. are willing to make to bring about a gene-edited future. Given the variation in levels of support or enthusiasm for gene-editing we found in our survey, our analytical approach enabled us to identify factors that account for the variation in these attitudes. Chief among these explanatory variables was "system trust".

3.5.2 Trust as a Key Predictor of Views Towards Gene-editing

We find that trust in the health care system was the variable that best explained variation in attitudes towards gene-editing, linking support for new technology (and our study of this domain) to the body of work on trust and trustworthiness of the healthcare system. For those respondents who were disposed to trust the health care system, the prospects of supporting the future of gene-editing through donating biospecimens, using tax dollars for research were more welcome. That trusting attitudes predict more positive attitudes towards gene-editing suggests that as translational efforts are made to move CRISPR into clinical trials, background trust levels of prospective patients and research participants ought to be taken into account. Furthermore, research should interrogate how prior attitudes of mistrust in the health care system impact willingness to participate in research and support expenditures towards new health technologies.

3.5.3 Demographic Variation in Attitudes is Modest

Among our control variables, we found that sex, education and income explained only a small amount of the variation in attitudes towards gene-editing. In particular, female respondents were less likely to support gene-editing across all three of our dependent variables. This finding is consistent with prior survey work that has explored variation in support for gene-editing; however, deeper explanations for this effect are still needed. The coefficients for gender barely change across models including our other covariates, suggesting that women's lower levels of support cannot be explained by religion, politics, health and healthcare experiences, trust, or altruism. Future work should consider other potential mediating variables. Additionally, it may be helpful to rephrase the question; rather than seek to account for why females appear to be less comfortable with the prospect of gene-editing, a fruitful path for future work might be to try to understand why males are so comfortable with it.

Respondents with a higher level of educational attainment were more inclined to support tax expenditures on gene-editing (Models 1b-6b) and this held across all six models of this outcome. That educational attainment did not predict greater comfort with sharing biospecimens or greater overall optimism however is inconsistent with other work that has found education level to predict levels of support for gene-therapy (Delhove et al. 2020).

3.5.4 Religion and Politics Capture Some Variation in Attitudes

It is political independents, not republicans, in this survey who appear to be most reluctant in their support for gene-editing. Political and religious identity (cultural schemas) do appear to account for some of the variation in attitudes towards gene-editing (especially religious attendance and political party) across all three dependent variables. However, the interpretation of these associations is somewhat less obvious. There seems to be a political effect at work, but the positions are not highly polarized along the ideological spectrum or by party identification.

The negative reaction to using tax dollars to fund gene-editing research among conservatives is consistent with other recent survey research on views on spending priorities for the federal government in the U.S. For example, a March 2019 Pew survey of the U.S. adult population found that Republicans (and those who lean Republican) were less supportive of increasing federal spending on health care (27% vs 73%) and scientific research (40% vs 62%) than Democrats (and those who lean Democrat) (Pew Research Center, 2019).

Unfortunately, the survey design does not enable us to disentangle the net effect of spending tax dollars specifically on gene-editing technology, as compared with generic use of tax dollars for scientific research or health care. Conservatives prior views towards taxation may be determining their reaction to the question of tax dollar spending on gene-editing research, thus it is difficult to specify the extent to which this item is confounded by other attitudes. However, one way to think about the lack of support for tax investments in gene-editing research here is to reflect that whatever enthusiasm conservatives in this sample have for gene-editing was insufficient to overcome their aversion to tax spending.

3.5.5 Health Status and Experience of Discrimination

We anticipated that those in poor health and those with the experience of a cancer diagnosis would perceive something like gene-editing positively and be interested, even eager, to support the development of this technology. To the contrary, in this study, these factors did not appear to account for the variation in attitudes towards gene-editing. Those in very good or excellent health held more optimistic views of gene-editing overall. One possible explanation is that respondents are not reacting to the prospect of gene-editing technology in an instrumentally rational fashion, seeking maximize personal well-being, but rather are reacting from other heuristics (religion or politics) or deeper-seated trust attitudes. Another possible reason for this finding, discussed above, is that the association between gene-editing and "technologies specifically being developed to improve the health of individuals" has not been robustly made. Rather it seems that people in the U.S. do not yet have strong fixed ideas that gene-editing would be a path to improve health.

Those who reported in the survey to have experienced discrimination in the past when seeking medical care were not significantly associated with any particular direction of attitudes towards gene-editing. We expected that those reporting experiences of discrimination when seeking health care might be less optimistic about a future with gene-editing. Even though the coefficients in all six models were negative, none were statistically significant.

3.5.6 Altruists, Health Data Altruists and the Personal Genomics Revolution

We found that our generic measure of altruism predicted increased support for using tax dollars for research, however, being a health data altruist (those who supported the idea of a duty to share health data for research) was a particularly significant predictor of support for the sharing of biospecimens and tax dollars for gene-editing research. Given the provocation of scholars who argue that patients ought to be understood to have a positive duty or obligation to participate in research in order to promote the ideal of a learning health system (Faden et al. 2013), we queried respondent's views of this notion. This view is seen as controversial because while many patients are indeed altruistic when it comes to sharing their samples or data, or in terms of participating in clinical trials or general research, such altruism has typically been deemed optional and wholly voluntary in nature. By identifying a positive duty, Faden and colleagues challenge the notion that the exchange of information in health care is unidirectional (doctor cures patient, patient pays doctor), but rather cyclical (doctor cures patient, doctor and system learn from the encounter which informs care of patient 2 etc.).

We also found that holding favorable views of direct-to-consumer genomics companies was highly predictive of support for (or having a positive view of) gene-editing across all three dependent variables. As we expected, we found that higher levels of health data altruism and holding more positive views of the companies leading the personalized genomics field would indeed predict positive attitudes towards a technology like gene-editing. This cluster of supportive attitudes towards the expansion of genomics in research, clinical applications and personal uses suggests a latent disposition among a subset of our respondents that might be thought of as “pro-genetics” and thus, by negation, a subset of dissenters. Future work could examine these broad dispositions and their relation to support or dissent for adoption of new medical innovations.

3.6 Limitations

Although our OLS models help identify potential explanatory factors in the variation in attitudes towards gene-editing, as this is a cross-sectional analysis, we are not able to make extrapolations about causality. Due to space limitations, we were unable to query participants prior knowledge or familiarity with gene-editing, which other research has found to correlate with attitudes towards gene-editing. Future work to examine the relationships between attitudes towards biospecimen and health data sharing and leading-edge technologies such as gene-editing should interrogate prior awareness and knowledge of the technology. In addition, qualitative studies that seek to further personalize and contextualize the personal and societal investments needed to bring about a gene-editing revolution in clinical care should be pursued to understand the values and commitments that shape public perspectives in this complex area.

3.7 Conclusion

We used a nationally representative survey of the U.S. adult population to examine three dimensions of the issues surrounding gene-editing. The donation of biospecimens for research on gene-editing in contexts with different applications and privacy measures in place revealed that the public is somewhat ambivalent about contributing personally to this research infrastructure. Likewise, we found sources of variation in the public's support for using tax dollars to support this research, which was also somewhat ambivalent overall. Finally, we explored the public's relative levels of optimism and anxiety around the future of gene-editing and found that most respondents are simultaneously "somewhat optimistic" and "somewhat fearful" about the implications of this technology.

Our results show that people's feelings about CRISPR are bound up with other feelings and institutions - their religiosity, their trust in the health system, their attitudes about DTC genomics - and that there is a persistent gap in enthusiasm between men and women, as other research has also found. Future efforts to engage the public can build on the factors we found to be predictive of support for building a future of gene-editing including: medical altruism, favorable views towards genomics, trust in the health care system. Further, engaging skeptical populations should include more than just outreach promoting the benefits of CRISPR technology itself, given how correlated acceptance of this new technology is with trust in the health system overall, as well as deeply personal factors including sex, religion and political ideology.

Demographic, attitudinal and experiential factors associated with dissent or support for gene-editing should continue to be taken into account when taking steps to engage the public. In spite of its limitations, survey research is an important way to continue to inform the ongoing debates around the implementation of CRISPR and gene-editing. Surveys can inform the direction and scope of deeper qualitative engagement. For example, this study suggests that connecting patient trust in the health care system to trust issues surrounding gene-editing would be a productive way to orient engagement efforts as efforts to engage the public around gene-editing move forward.

Conclusion

This dissertation set out to answer three questions: How was CRISPR framed and discussed in the U.S. news media between 2012 and 2018? Who is participating in public discussions about CRISPR and why is there so little room for public perspectives and involvement? What does the U.S. public really think about gene-editing?

Chapter 1 analyzed the state of the discourse about CRISPR as it appeared in the U.S. news media between 2012-2018. I found that the media discourse has replicated certain tendencies found in previous research including a tendency to primarily frame the story of genetic technologies in terms of progress, profits and potential cures. The dominant master-frame of "cautious optimism" combines this positive outlook with concerns about medical and scientific risks and some attention to ethical concerns. I also found a significant strain of "boosterism" which likewise emphasizes progress, profits and potential cures, but sheds concerns about risks and downsides. Boosterism also reverses the usual ethical concerns by suggesting that timidity could lead to the moral harm of depriving humanity, and future humans, of a life-improving (maybe life-saving) intervention. Conveniently for advocates of the mainstream view, the existence of boosterism enables cautious optimists to take refuge in the reasonableness of their position, acknowledging both risks and ethical questions as needing to be taken very seriously. Finally, I identified the "critical frame," posing harder and broader sets of concerns about the implications of gene-editing than the cautious optimism or boosterism frames, but largely relegated to a small number of articles. The most cited proponent of the critical narrative was largely ignored by the prestige press and instead was cited in the more ideologically pronounced outlets. This marginalization of critical voices suggests that the news-consuming public was left unaware of important questions about gene-editing, including implications of gene-editing technologies for constituencies like the disabilities community. These concerns were generally left aside in favor of discussions of risks and benefits for individual patients.

Chapter 2 looked at the question of what role, if any, the public has played in the media discourse about CRISPR and how expert communities sought to define those roles for the public . Experts in the agricultural sector seemed to view the public as potentially adversarial, adopting a public relations approach that emphasized differences between CRISPR and earlier genetic modifications of crops (GMO 1.0). In contrast, when discussing CRISPR applications for humans and human health, the scientific community initially made ambitious invitations to the public to participate in building “consensus” around the contentious and divisive issues that gene-editing provokes. Later, the scientific community called for “engagement,” “dialogue,” or “discussion” with the public, but the means and ends of such efforts were left undefined, unfunded and largely unclear. Throughout, the dynamics of “urgency and deferral” allowed experts to proceed without ever taking concrete steps to foster public engagement. In some of the coverage there seemed to be an urgent need, often suggested by quoted experts, to get the dialogues with the public going and to understand where the public stands on the contentious issues surrounding CRISPR. At the same time, experts sought to assuage public fears about science run amok, offering reassurances that there really is plenty of time for the public to be consulted, particularly since the science is still in an early phase of development. But when a crisis arose, experts suddenly suggested that it was too late to wait for public debates. Experts rallied to the defense of the field when a rogue actor, He Jiankui, used CRISPR and IVF to edit the embryos of several children and then implant them in their mothers. This quick response further alienated the public from the challenging questions surrounding gene-editing: no public constituencies were sought to make meaningful contributions to the discourse as this affair unfolded. Ultimately, I argue that between the use of public relations by some expert communities, the confusing nature of the calls for public inclusion in debates about CRISPR by other experts, and the intense crowding out of publics that occurs in moments of crisis, the public is left in a paradoxical position: it is always too soon to debate the issues surrounding CRISPR until it is too late.

In Chapter 3, an analysis of new survey data contributes to our understanding of what the public really thinks about gene-editing. We posed the question of support for gene-editing in terms of respondents' comfort with sharing their own biospecimens for research on gene-editing. This framing of the question changes the nature of the ask from a generic question of personal attitude to a specific question about personally supporting the infrastructure needed to create a future with gene-editing. Likewise we sought such specificity with the second dependent variable, asking about preferences concerning the use of tax dollars for gene-editing research. Our third dependent variable asked respondents to think about the future of gene-editing on three levels (self, family and society) and to gauge their level of hope and fear in relation to each. We found that across all three variables, the public was more supportive than not, but that this was somewhat ambivalent. Our study suggests that when the question of supporting gene-editing is placed in terms of making a more personal commitment (in biospecimens or tax dollars) to realizing the technology, then support softens and Americans equivocate. Through OLS regression models, we revealed several factors that appear to correspond with different attitudes towards these outcomes. Trust in the health system was the single variable that offered the most explanatory power. We concluded that future efforts to engage the public can build on the factors we found to be predictive of support for building a future of gene-editing including: medical altruism, favorable views towards genomics, trust in the health care system. Further, engaging skeptical populations should include more than just outreach promoting the benefits of CRISPR technology itself, given how correlated acceptance of this new technology is with trust in the health system overall, as well as deeply personal factors including sex, religion and political ideology.

CRISPR in 2020 and the Road Ahead

After the tumultuous events surrounding He Jiankui and the Chinese twins in 2018, the cadence of coverage of CRISPR in the U.S. news media decreased through 2019. For advocates of CRISPR, getting out of the spotlight for a time was probably viewed as a welcome development. By the end of 2019 and into the early months of 2020, the emerging story of COVID-19 and the global pandemic quickly made the stories surrounding CRISPR and gene-editing a lower priority for health and science reporting. CRISPR appeared again early in the pandemic, however, as a potentially important tool for developing techniques to better characterize, diagnose and possibly figure in treatment of COVID-19. Teams at both UC Berkeley (Innovative Genomics Institute) and Harvard/Broad Institute were involved in efforts to apply what they had learned in the realm of gene-editing to the exigencies of the moment. In addition, a triumphal good-news moment for the gene-editing community emerged later in the year when Jennifer Doudna and Emmanuelle Charpentier were awarded the Nobel prize in bio-chemistry for their discovery of the CRISPR-cas9 gene-editing platform in 2012.

By mid-June of 2020, media stories reported seemingly divergent paths for clinical applications of CRISPR. On the one hand, NPR reported on June 23 on the continued positive trajectory of Victoria Gray, the first person to be given a CRISPR-based treatment for Sickle Cell disease, nine months after receiving treatment. Gray, along with a small cohort of patients being treated using a similar protocol for beta thalassemia, expressed her delight at the effectiveness of the treatment which she credited with affording her the strength and well-being needed to cope with the demands of solo parenting during the COVID pandemic and the social upheaval following the murder of George Floyd (her husband is a deployed member of the military). Sickle Cell and Beta Thalassemia are both diseases for which new and effective treatments have been few and far between and have long been identified, given their monogenic etiology, as likely candidates for CRISPR-based therapy. NPR's coverage of Victoria Gray's journey through treatment was personal and emotional, often featuring her voice, "We need this right now more than ever, you know? It's a blessing," she said. "It gave me hope when I was losing it. So I feel joy, you know, knowing that there is hope."

On the second path, anxieties around the prospects for CRISPR for germline editing were being reported. During one week in June 2020, three preprints were released on the bioRxiv pre-print server that demonstrated the great uncertainty and risk associated with the use of CRISPR to edit embryos. These were follow up studies on earlier experiments with CRISPR on human embryos that were both covered in the press, and all three studies found highly damaging on-target effects occurred in significant percentages of the embryos that were part of these experiments. The risk of off-target effects (the prospect of making unintended modifications to distal parts of the genome) was always a concern with gene-editing, but these studies reveal the risk of "on-target" effects occurring much closer to the target sites of the gene-editing process. A prominent gene-editor from UC Berkeley, Fyodor Urnov, reacted to these pre-prints in a OneZero article, claiming:

> "There's no sugarcoating this...this is a restraining order for all genome editors to stay the living daylights away from embryo editing." (Mullin, 2020)

He also was quoted in a Nature (2020) article reporting on the three studies:

> "If human embryo editing for reproductive purposes or germline editing were space flight, the new data are the equivalent of having the rocket explode at the launch pad before take-off."

These findings underscore the ongoing uncertainties surrounding CRISPR applications, particularly in the case of editing embryos and making germline modifications. Set alongside the apparent success story unfolding around the Sickle Cell Disease and Beta Thalassemia trials, and with the long shadow of the He Jiankui controversy still looming, clinical applications of CRISPR appeared to be most likely to find fertile ground in the somatic treatment of monogenic disorders and as a highly adaptable set of tools for understanding and characterizing the genetics of viruses.

Amidst these twin storylines of promising success and clear failures, the bioethical debates over CRISPR continued apace. A panel discussion at the ELSI world congress in June 2020 focused on heritable gene-editing and the topic was regularly discussed in academic journals, at conferences and in several monographs released by prominent bioethicists and scientists. But this was largely a debate taking place among members of the bioethics and scientific communities, the broader public remained on the sidelines of the CRISPR debates as the pandemic surged.

Finally, a third key story that featured CRISPR was also in the news media that same week of June 2020. A Boston Globe commentary reported that a bio-engineering company, Oxitec, was moving ahead with getting local approval to release over 1 billion CRISPR-modified mosquitos into the wild in Florida and around Houston, with the goal of diminishing the aedes aegypti population (Kofler and Kuzma 2020). This would be one of the first “wild” tests of the gene-drive technology and it sparked renewed calls for greater FDA oversight and more transparent risk assessment protocols.

These stories of early success with treating sickle cell, the potential derailment of germline editing due to massive errors in the process, the role of CRISPR as a tool to address the COVID-19 pandemic and ongoing efforts to use CRISPR to modify the ecosystem all suggest a technology that occupies a central role in a variety of fields and that has not been slowed down by the upheaval brought on by the revelations surrounding He Jiankui’s experiments. As CRISPR and gene-editing continue to find their way in these disparate domains, the goals of increasing public awareness, involving publics in forging the narratives of CRISPR and engaging with diverse publics to better understand the underlying values, needs and expectations of the public on how this technology will advance all remain unfinished work.

The consequences of broad and deep fissures opening up between scientific and medical experts and segments of the public have been brought into stark relief during the COVID-19 pandemic. With uncertainty, unclarity and mistrust impacting the effectiveness of public health mitigation strategies such as mask use across the U.S., we have seen the deleterious impact of these gaps impacting the health and lives of thousands of people. With the emergence of vaccines in 2020, there was hope that the country, positioned as it was with a great deal of vaccine pre-purchased, would be able to relatively quickly begin to mitigate the spread and severity of the pandemic. Instead, a number of factors have kept the rates of vaccination much lower than expected and needed to achieve “herd immunity.” One key factor is the emergence of conspiracy theories about the origins and safety of the vaccine which have spread over social media networks and kept some segments of the population avowedly opposed to the vaccine. Meanwhile medical and scientific professionals struggled with their messaging and the competing pressures to "return to normal." Vaccine hesitancy was not only driven by conspiracy theories and misinformation. Legacies of medical racism and racially stigmatizing medical research compounded ongoing challenges in distributing the vaccines equitably among racially marginalized populations. Developers of gene-editing techniques for clinical or reproductive uses would be misunderstanding the lessons of the COVID-19 pandemic if they assumed that the technology would somehow avoid entanglements with the complex social realities that have surrounded the pandemic.

The politicization and weaponization of misinformation is made possible when the gaps between expert and lay publics remain deep and wide and there are no bridges being built from either side. The COVID-19 pandemic highlights the ways in which these dynamics can have very real impacts on health outcomes. In the case of an emerging technology like CRISPR, the potential for such gaps to emerge and for conspiracies to gain traction seems equally plausible even if the impacts of such gaps may be less obvious than in the case of a pandemic. The failure to effectively engage publics about matters of science, technology and health has very real repercussions. The scientific community should think carefully about how to respond to such views and how to proactively work towards building trust. More top-down education along the lines of the deficit model is perhaps necessary, but likely not sufficient to bring the public along with the CRISPR revolution.

A key issue moving forward with public engagement will be the work to include marginalized and vulnerable populations in the efforts to elucidate a richer and comprehensive understanding of how the public views the prospects of a CRISPR-mediated future. Such efforts will have to contend with the eugenic legacy of genomics, which inflects the bioethical debate to this day (Agar 2019; Lombardo 2018; R. Pollack 2015; Sparrow 2010) and the ways that racism impacts efforts to build a just system of access and inclusion in societal discourse around the future of technologies like gene-editing (Creary 2021; Creary, Thiel, and Eisen 2017). As noted above, some efforts have been undertaken to engage with patient and caregiver perspectives on CRISPR among people with sickle cell disease (Hollister et al. 2019; Persaud et al. 2018), autosomal aneuploidies (Snure Beckman et al. 2019) and Down syndrome (Michie and Allyse 2019; Riggan et al. 2020). However, this work must expand to include not only a broader swath of patient communities, parents and caregivers, but also members of the disabilities community, couples undertaking genetic screening for reproduction or those seeking to use assisted reproduction techniques and even representatively selected “mini publics” to consider the impacts of this technology on their communities and society overall. Such efforts will have to be mindful of the legacies of inclusion and exclusion in scientific research and the ongoing disparities in access to the benefits of new scientific knowledge and technologies. As I found in my media analysis, the relative absence of critical voices (Chapter 1) and the inability of the public to yet gain a serious foothold in the discourse around CRISPR (Chapter 2) suggests not only the urgency with which these efforts must be undertaken, but the wide terrain in which this can and should cover.

While efforts are underway to consider needed oversight and governance mechanisms and reforms across sectors, and possibly to launch a “global observatory” (Arguedas-Ramírez 2020; J. Benjamin Hurlbut, Jasanoff, Saha, et al. 2018b; Jasanoff and Hurlbut 2018a; Parthasarathy 2015b; Saha et al. 2018) to coordinate research and regulatory measures across national borders, complementary efforts to build robust streams of policy-relevant and policy-informing public input should be undertaken, funded and pursued. Obstacles remain, not the least of which are the deep fissures and strains within and among societies that were revealed by the COVID-19 pandemic. Public health, health care and political systems all continue to strain to meet the needs of society in an equitable fashion, and the weaponization of mistrust in science and public health have revealed and exacerbated the already significant gaps in expert/lay divides.

Even with such challenges, the public has an important role to play in shaping the future of CRISPR and gene-editing. Efforts to build infrastructure to facilitate this engagement that may have been stalled by the pandemic should be taken up anew. The revelation of the depths of mistrust, ambivalence and uncertainty many in society harbor about scientific and medical experts compounds the challenges of developing meaningful public consultations, but having these dynamics laid bare might also prove to be an asset moving forward. I hope that this dissertation can contribute towards getting such engagement moving in a productive direction. Understanding the nature of the past and ongoing discourse around CRISPR, breaking out of the "too soon / too late" paradox, and taking stock of the variation in attitudes towards gene-editing in society are important steps to make future public engagement and consultation possible and fruitful.

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