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"The Unregulated Wild West": A Socio-Ethical Discourse Analysis of Direct-To-Consumer Genetic Testing

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"THE UNREGULATED WILD WEST": A SOCIO-ETHICAL DISCOURSE ANALYSIS OF DIRECT-TO-CONSUMER GENETIC TESTING

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ABSTRACT

More than 26 million individuals have submitted to direct-to-consumer genetic testing (DTCGT) services since the personal genomics industry gained traction in the late 2010s. Private firms AncestryDNA and 23andMe dominate the market, and as a result, hold ownership of some of the largest collections of human genetic data in the world. As a novel technology that analyzes consumer disease risk or genetic genealogy, DTCGT has emerged alongside a number of ethical, legal, and social implications that require scholarly investigation. This study places a critical eye on AncestryDNA and 23andMe to examine how DTCGT is contextualized in the news media. Using a Foucauldian discourse analysis, 50 articles from *The New York Times, The Wall Street Journal,* and *USA Today* were analyzed to capture present discourses and ethical critiques of DTCGT. Results of this study cast the genetic testing consumer as self-managing, datafied, and valuable. Consumers' quests to develop their genetic knowledge form the foundation of a bioeconomy that private firms and government entities use to advance research and innovation while implicitly reiterating neoliberal notions of autonomy, productivity, control, and individual responsibility. Issues of third-party sharing of genetic data, informed consent, risks and uncertainties about testing, genetic privacy, and more are discussed as they are presented in the news media. In light of these critiques, this analysis demonstrates a need for regulatory action and scholarly analysis on how DTCGT is contextualized as society becomes increasingly datafied and risk-aware.

Keywords: genetic data, datafication, biopolitics, governmentality, risk, discourse

DEDICATION

For my undergraduate genetics professors who instilled in me a passion for the molecular basis of life—

And to the political climate of the 2016 presidential election that motivated me to become a stronger advocate for the science I love—

This thesis is inspired by you.

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INTRODUCTION

The first direct-to-consumer (DTC) genetic tests hit the market in 1996, offering a mail-order option outside of a healthcare clinic that could help individuals tailor their diet based on genes linked to nutrient metabolism (Bowen and Khoury, 2018; Hogarth and Saukko, 2017). The genomics market at the time was small-scale and expensive: few diseases had well-known genetic associations, and labor-intensive testing procedures translated into tests that cost hundreds, if not thousands, of dollars for the consumer (Helgason and Stefánsson, 2010). In the following ten years, technology to discover disease variants improved with the emergence of the genome-wide association study (GWAS), an observational approach that examines the genomes of many individuals in order to associate specific genetic markers with a disease or trait. Under a GWAS, if one type of genetic marker is found more frequently in people with a disease, then that marker is thought to contribute to disease risk. The GWAS transformed human genetics of the early 2000s by allowing millions of genetic variants to be "read" at one time through the use of SNP arrays, single nucleotide polymorphism analyses that can pinpoint genetic diversity down to a single-letter difference in a person's genetic code (Genetics Home Reference, 2019). Common DNA variants that are revealed by GWAS then become the variants that consumer companies test for when they promise to deliver estimates of disease risk to consumers.

While GWAS and SNP arrays are two of many techniques that have advanced human genetics in recent decades, none have left as great a mark on the field as the Human Genome Project (HGP), an international, collaborative research endeavor that

aimed to sequence the entire genetic code of humanity over the course of a 15-year period from 1990–2005. Prior to the HGP, geneticists had a selective understanding of the human genome. Some gene families were better understood than others in terms of their sequence, function, and location alongside other genes in our chromosomes. But, it was not until the HGP that scientists were able to quantify just how many genes humans have (20,500) and what the exact sequence, or code, of those genes is (National Human Genome Research Institute, 2018). Completed two years ahead of schedule in 2003, the HGP resulted in maps of the human genome that provide the instructions as to how humans develop, how biological processes unfold, and how disease takes shape. We know now that the human genome is comprised of exactly 3.2 billion base pairs of adenine, cytosine, thymine, and guanine (ATCG), nucleotides in all of our cells that make up DNA (Chial, 2008). When even one of those nucleotides is mutated or missing, the code is thrown off, which can result in happy accidents like the ability to taste (and enjoy) cilantro but can also cause dangerous diseases if that mutation occurs in a gene that is vitally important. Thus, the ability to pinpoint exactly where in the genome mutations occur has transformed the possibilities of modern medicine and diagnostics. Another key finding of the HGP is that the genetic code of humans is 99.9% identical, i.e., my pattern of ATCG is 99.9% the same as any other human (Chial, 2008). The whole of human diversity can thus be attributed to a minute fraction of difference between us all, and it is that minute fraction that scientists spend most of their time trying to understand.

Organizers of the HGP had hoped to use the project to begin characterizing the function of each and every gene and the molecular mechanisms that contribute to each and every disease, but with the technology available at the time, it took 13 years solely to capture the sequence and map of the human genome. Much of the data analysis from the HGP has occurred in the 17 years since the project was completed as methods and diagnostic technologies have developed (National Human Genome Research Institute, 2018). The advent of these technologies—SNP arrays, GWAS, and other machines and protocols—has lowered the cost to conduct genetic analyses and quickened the pace at which results are disseminated. In a sense, technological development, information sharing, and laboratory analyses all enable each other in a cycle that allows the mass exploration of the human genome to occur.

Taken together, these advancements paved the way for a "second wave" of DTCGT that launched in 2007 with genetic testing firms such as 23andMe offering health risk testing for a variety of common diseases, such as asthma, diabetes, and stroke (Hogarth and Saukko, 2017). A rise in consumer interest in genealogy was burgeoning at the same time, and science rose to meet the demand: ancestry genetic testing found its own popularity in the 2010s for its ability to pinpoint a person's geographic and ethnic heritage and reveal a percentage breakdown to the age-old question of "What are you?" (Bowen and Khoury, 2018). As interest grew, technology advanced, and cost for both researchers and consumers fell, DTCGT boomed, and hundreds of firms began to join in on the personal genomics market in order to sequence, analyze, and interpret the genomes of individuals.

More recently, the *MIT Technology Review* marked 2017 as "the year consumer DNA testing blew up" (Regalado, 2018). With the industry reporting a commercial market of more than 26 million people, more consumers have purchased DTCGT in the past two years than all previous years combined (Regalado, 2019). Leading the personal genomics market are testing firms AncestryDNA and 23andMe, which together have some of the world's largest collections of human DNA stored on their databases (Crow, 2019). Further, researchers estimate that these two private firms are on track to own the genetic makeup of more than 100 million people within the next two years (Khan and Mittelman, 2018). While 23andMe began as a disease risk testing company and AncestryDNA as genetic test for consumer genealogy research, today both firms provide both ancestry and disease risk testing as they have risen in the testing market and emerged as leading competitors. As such, both firms wield influence over personal genomics as their popularity enables them to set precedence for how the market evolves and operates.

My interest in this topic began during my undergraduate education when I was a student of genetics. I fell in love with the science of the field, with how predictable our cells can be—an almost poetic assembly of genes, proteins, and enzymes that regulate our bodies and maintain our existence. One mistake in the replication of a gene can result in an onslaught of downstream effects that, with the right research question, can come to be treated with a drug or therapeutic gene editing technique in due time. I believe in the potential of what genetic research can do for an affected individual; yet, throughout all of my studies in genetics, not once did we have a substantial discussion about what it would

mean for that affected individual to receive therapeutic genetic treatment. In the context of this study, what does it *mean* to have the ability to unearth a person's family history or risk for disease? What are the individual and societal implications of such a remarkable technology?

I graduated from my genetics education in 2017 during a poignant moment not only for the development of consumer DNA testing, but for the advancement of science in general. The first half of 2017 saw the inauguration of Donald J. Trump as president of the United States, and with his transition into power, a shifting policy agenda that often felt as if it was targeting the sciences that I had just spent four years studying intently. For example, in week one of the Trump administration, an immigration ban was enacted "to protect 'the United States from foreign nationals entering from countries compromised by terrorism'", which resulted in international students from universities across the country being detained at airports or sequestered in their home countries, rather than returning from their winter breaks abroad to continue their studies here in the U.S. (Shear, Kulish, and Feuer, 2017, para. 33). Much of the scientific research that occurs at the university level is conducted by international graduate students who comprise 5.5% of American higher education, or more than one million students in 2019 (Institute of International Education, 2019). Yet, for a period of 90 days in 2017, their research and studies were stagnated and their character questioned in an executive order that burgeoned on unconstitutional and, at worse, xenophobic.

Still, the administration's policy changes did not stop in week one; they continued next by censoring the language used by federal agencies, including barring the words

"evidence-based," "science-based," "vulnerable," "entitlement," "diversity," "transgender," "fetus," and "climate change," in official documents and websites (Belluz and Irfan, 2018). Reportedly, the administration also de-staffed the science division of the White House Office of Science and Technology Policy, removed scientific advisory positions for the Environmental Protection Agency, and slashed research funding for a number of federal agencies, including the National Institutes of Health, Department of Energy, National Science Foundation, the National Oceanic and Atmospheric Administration, Department of Agriculture, and some programs at the National Aeronautics and Space Administration (Carter, 2017; Science News Staff, 2017). And, against the backdrop of the worst climate crisis society has seen in history, the administration withdrew the United States' from the Paris climate accord in June 2017 and has since rolled back nearly 100 climate and environmental policies aimed at conserving the planet for future generations (Shear, 2017; Popovich, Albeck-Ripka, and Pierre-Louis, 2020).

To be a graduate in 2017 when the headlines funneling from the White House appeared to dispute science and scholarly expertise was enough to embolden me to become an advocate for science in some way. My personality has always had a social justice edge; I have been concerned with society's unequal distribution of rights and privileges from the time I became aware of worldly happenings as a young teenager. In the landscape of 2017 American politics, I found a way to marry this edge with the sciences that I love—through a study of DNA testing that was exploding in a consumer market. In a large sense, I feel accountable for the genetics education I received over

those four years. I understand how a saliva sample travels from the home of a genetic testing consumer and into a diagnostic lab at one of these gentech firms; how it is mixed with chemicals, spun down and resuspended, and stripped of its properties until all that is left is human DNA, amplified hundreds of times over and analyzed on microchips, turning what was once material into something quantifiable: codified, digitized, and readable. I understand it, and so I feel a responsibility to be its gatekeeper. In the health, self-tracking landscape of 2020, much of that gatekeeping requires shining a light on the ways that a for-profit gentech company can utilize consumers' personal genetic data, especially when little to no governmental oversight is applied to the consumer genetics industry, with the hope that illumination will prompt more transparency from gentech companies and inspire more scholarly inquiry into this topic that is ever-present and continually developing.

As such, this study seeks to investigate what discourses of DTCGT are documented in journalistic reporting and the extent of which news media discourses make ethical arguments about DTCGT. I coin this a "socio-ethical discourse analysis" so as to keep attention on the ethical, legal, and social implications of DTCGT throughout this work. While an assemblage of relationships between government, technology (both gentech and biotechnology firms), economic, and political sectors is pronounced in DTCGT, my goal is to keep questions of ethics—S*hould we do this?Is it fair to do this?*—at the forefront in hopes of prompting further understanding on the issues raised in this thesis.

Therefore, throughout this work are framings of genetic knowledge that place personal genetic data in relief with understandings of digital data as something that is both "lively" and commodified, as something to be interpreted within a system of values and individual identity. Beginning from Deborah Lupton's research on the "quantified self," I use the framework of datafication to trace how DTCGT translates the corporeal body into a readable format of genetic data visualizations. In doing so, I aim to understand how genetic data have manifested as valuable sources for self-knowledge that hold the potential to influence humans' actions. This quest for genetic self-knowledge can be viewed through the lens of Michel Foucault's conception of "technology of the self," positioning DTCGT as a tool that consumers employ to deepen their understandings of their own identities and quests for self-improvement. This constant mode of health self-management is reaffirmed by Nikolas Rose's work on biocitizenship that prompts consumers to take charge of their own genetic health. Finally, literature on uncertainty and risk helps to contextualize the experience of being genetically at-risk for a disease revealed by the consumer testing experience. Through these frameworks, I will examine the translation of genetic makeup (in the physical) to genetic data (as the immaterial) as a concept that forms the basis of a successful business model that gentech firms have recognized and profited off of through a socio-ethical discourse analysis of DTCGT in news media discourse.

CHAPTER ONE

LITERATURE REVIEW

Eugenic beginnings

While scholars have theorized for decades about what the advent of personal genomics could mean for society, in a sense, the popularity of DTCGT took off before its ethical consequences could be widely investigated. The presence of consumer genetic testing technology now requires that ethical inquiry, especially in light of a history of genetic sciences that has almost always been wrapped in controversy. DTCGT does not represent the first instance in which the state—governments and private industry—has become intertwined in the corporeality of its citizens. The past shares multiple moments with the present when the health of a population was determined by the genetic "stock" of its people and was moderated by practices that sought to improve the biological quality of the population as a whole (Zimmer, 2018a). Coined "eugenics" in 1883 by Sir Francis Galton, the movement formed a set of beliefs and practices that encouraged healthy people to reproduce so as to maintain a fit, productive human race (Claude Moore Health Sciences Library, 2004). Termed "positive eugenics", the early movement focused on encouraging "physically and mentally superior members of the population" to choose partners who shared the same qualities as a way of selectively breeding a stronger human race (Aubert-Marson, 2009). Later, the writings and research of the "Father of Genetics", Gregor Mendel, paired with Galton's insights to explain how healthy traits are passed on in humans at a time when genetic inheritance was first being characterized and understood (Zimmer, 2018a). As the movement continued into the 20th century, its

messaging became more ominous through the oppositely termed "negative eugenics" that regulated the "weak" out of reproducing (Aubert-Marson, 2009). Government-instated policies attempted to eliminate disease, disabilities, and other qualities deemed undesirable via practices like the sequestration and sterilization of the mentally ill and restrictions on interracial marriage (Norrgard, 2008). The "feeble-minded," "morons," those who carried a low "intelligence quotient," or IQ—history painted them as having been failed by their heredity because their family's genes, when swapped together, resulted in mental illness and disability (Zimmer, 2018a). Women were blamed for having borne mentally ill or racially mixed children, that if only they would "conform to the conventions of society," or keep the company of "intelligent and humane people," their children would not be "degenerates" (Zimmer, 2018a, p. 85).

Scientific racism was another core tenet of 20th century eugenicists, who argued that African Americans carried a propensity for unintelligence and criminality. Crucial to the protection of white supremacist systems at the time was the "one-drop rule," which considered those with just one African American ancestor (or "one drop" of black blood) as racially black in the eyes of the law, leading to segregation and restrictions on voting in some states (Davis, 2001). Though it was not widely acknowledged across the country, the one-drop rule was founded on the backdrop of slavery and served as one of many cultural definitions of blackness in the U.S. in the early 20th century. Even poverty carried a hereditary stigma within the eugenics movement, the argument being that "the destitute didn't have the foresight to save enough money," and thus passed traits of penury and "feeblemindedness" onto their children (Zimmer, 2018a, p. 101).

Eugenics and its demoralizing policies began to lose popularity near the end of World War II when the liberation of Nazi concentration camps revealed the horrors of human experiments to a world formerly unaware that eugenic beliefs were being enacted in such ways. However, eugenics' stain on history lived on as it took decades for forced sterilization and discriminatory marriage laws to be repealed in the U.S.—a span of time that allowed social concepts of an idealized human race to persist, undoubtedly contributing to discriminatory stigmas that exist still today.

This recognition—that the health of a population can be (and has been) pinpointed to a hereditary component—is where this upcoming study finds its significance. Eugenics, at its core, was premised upon a desire to improve the human species, to make individuals healthier and more intelligent at any cost, and along the way, the movement wrapped itself up in dangerous discourses that hurt and demoralized many. While personal genomics technology (gentech) companies like 23andMe and AncestryDNA base their missions on acquiring genetic self-knowledge or taking a "genetic journey" for consumers to better understand themselves and their health, the implications of the technology tiptoe a line that could err toward eugenic tendencies if scientists and regulators are not careful. A consumer saliva test for health conditions could set precedence for a mandated genetic screening that stigmatizes the at-risk from the non-risk or reveals the haves from the have-nots if too much state intervention is allowed. The results of testing—currently sent to third-party biotechnology (biotech) companies for research to help identify genetic causes for traits and disease—could conjure up the question of therapy vs. enhancement. That is, at what point is a genetic intervention

bringing a patient to a comfortable level of function, as opposed to augmenting the human condition with elite capabilities? Critics, like those at the Genetic Literacy Project (2013) and geneticist and author Ricki Lewis (2014), would caution that these ethical scenarios are radical and that genetic technologies today should not be confused with eugenic practices of the 20th century. I propose that consumer genetic testing has invited novel inquiry that requires an analysis of its ethical, legal and social implications in order to put the best interests of the consumer first and also to establish a pretext for gauging how far we as humanity will go in our entanglements with the human genome.

Today's ethical, legal, and social implications

With the growing popularity of DTCGT comes an amplified discussion both in scholarship and the public discourse about the ethical, legal, and social implications of genetic testing from a number of angles. For example, researchers have raised questions about the effectiveness of the terms and conditions agreements or privacy policies that precede the purchase of consumer genetic tests in light of studies that show most users do not read the fine print of the services they are submitting to (Obar and Oeldorf-Hirsch, 2016) and that the specific policies distributed by DTCGT companies are often unclear and incomplete (Christofides and O'Doherty, 2016; Phillips, 2017). Other scholars have questioned the accuracy of genetic testing, given that companies all have their own unique algorithms and reference genomes for analyzing an individual's DNA, resulting in different percentage breakdowns depending on how diverse the reference genome is (May, 2018; Smart, Bolnick, and Tutton, 2017) and how the algorithm is designed (Tandy-Connor et al., 2018). Other authors asks whether it is appropriate to offer genetic

testing without supervision from a medical provider (Smart, Bolnick, & Tutton, 2017); whether genetic predispositions should be shared with health insurance agencies; and whether gentech companies should be allowed to sell consumer genetic data to advance research into disease and ancestry (O'Doherty *et al*., 2016) or share those data with law enforcement agencies in order to catch suspected criminals (Rothstein and Talbott, 2006). Permeating throughout the ethical discussion is the recognition that consumer-based genetic testing is an unregulated industry that is allowed to operate like the "Wild West" (May, 2018). As such, perhaps the most necessary lines of inquiry are those that ask how governing entities should instate policy to reel in an industry that has otherwise been able to evade oversight.

However, there is an important acknowledgement that needs to be made and examined before calls for regulation can be seriously considered, an acknowledgement that is often glossed over in the literature on the topic of DTCGT: The very act of spitting into a vial and shipping that saliva to a gentech company is political. The information contained within our saliva and the impacts that information can have on society may be thought of in terms of what Langdon Winner described more than 30 years ago as an "inherently political technology." That is, its application in the realm of DTCGT complements the conditions necessary for human associations (1980, p. 123). Humans are involved at every step of the testing experience: From the moment a consumer genetic test is manufactured, packaged, and shipped to a customer; to the moment a consumer collects their saliva and sends it back to the gentech firm; to the preparation of the sample and the analyzing of the consumer's DNA. All of these acts require the work of retail

workers, postal workers, consumers, lab technicians, and the web of corporate employees and executives who maintain the infrastructure and functioning of a gentech firm. Importantly, these human connections also represent the community who has invested interest in the culture that genetic testing has created: the family member on Facebook who "liked" their niece's status after she shared her AncestryDNA results, the friend who then went and bought his own ancestry test after seeing the same status, the journalists who have been documenting this phenomenon, and the government officials who have taken notice. DTCGT has created a technological system that maintains a cascade of human associations, and it has emerged as yet another outlet for humans to understand themselves on a deeper, more personalized level.

In this work, I align myself with Winner in that I believe it is "the things themselves" that can explain this cultural phenomenon (1980, p. 123). Rather than reducing the popularity of DTCGT to an assortment of social or technologically deterministic forces, I put my focus on genetic data themselves and the meanings and characteristics they enact. This focus, coined the theory of technological politics, can serve as a complement to other theories of social or technological determinism by taking "technical artifacts seriously" (Winner, 1980, p. 123). In doing so, it becomes possible to acknowledge the political-economical-technological ensemble of relationships that take place in a culture where technology is interwoven. Specifically, I traced DNA and its transition from "the carrier of genetic information" to its datafied articulation as a code that can predict a person's health risk or ethnic beginnings. Just as Winner (1980) showed for the atomic bomb, cotton-spinning mills, and other artifacts of the 20th century—

DTCGT exemplifies how "scientific knowledge, technological invention, and corporate profit reinforce each other in deeply entrenched patterns that bear the unmistakable stamp of political and economic power" (1980, p. 126) and it is the articulation of power that necessitates a deeper inquiry into DTCGT.

Thus far, I have reviewed the genetic sciences' roots in eugenics, how its advancement in the 1990s gave way to consumer genetic testing, and the varying ethical questions that arise from DTCGT. I will now turn to the theoretical frameworks that precede this study: those of risk and uncertainty, datafication, governmentality, and biopolitics.

Risks and uncertainties about testing

As a tool that conveys information to consumers that guides medical decision-making and develops genetic self-knowledge, DTCGT can yield insight as to how consumers receive risk information and manage uncertainty about genetic testing results. Uncertainty refers to situations in which the outcomes are unknown or ambiguous, due either to a lack of information or the inability to fully understand the information at hand (Brashers, 2001; Gesser-Edelsburg & Shir-Raz, 2016). DTCGT delivers predictive estimates of a consumer's disease risk or ethnic background that are based on statistical and probabilistic analyses; thus, reducing a genetic outcome to a perceived chance or likelihood of happening also confers a level of uncertainty with it. Consumer responses to genetic testing are experiential; as Brashers (2001) theorized, uncertainties play out amidst a web of multilayered, interconnected, and temporal contexts that make the risks conveyed by testing all the more complex to process. Consumers often experience their

uncertainty by questioning themselves, their ability to manage their disease risk, the effect of that risk on their families and relationships, and the relation of disease risk to other social contexts, e.g., "Can I pass this onto my children?" "Will I have to monitor this risk for the rest of my life?" "Can I afford the treatment if I get this disease?" "Is there even a treatment available for this disease?" Thus, engaging in uncertainty and risk management involves cognitive and emotional appraisals as consumers attempt to gauge what meaning and relevance the risk has for their lives (Oliveri *et al*., 2015). Risk experienced as a threat or danger to health might confer negative emotions of fear and anxiety, whereas mild to moderate risk might yield indifference or even inspire positive feelings of hope for a healthier future.

Following cognitive and emotional appraisals, consumers' responses to uncertain risks often include information-seeking behaviors that help to negotiate and manage what comes next after receiving testing results (Brashers, 2001). For consumers, "information gathering serves the purpose of differentiating options, finding options, and creating options" as a way to increase knowledge about an outcome and reduce uncertainty surrounding it (Langer, 1994, p. 45). As such, consumers may seek varying sources of information by consulting with their doctors, researching online, or joining support groups in order to interpret their testing results. However, for other consumers, avoiding information and maintaining uncertainty might serve as a better coping mechanism if a genetic testing result is too overwhelming to handle (Brashers, 2001). Consumers might also reappraise their situation and adjust the object of their uncertainty so as to minimize its effect moving forward, e.g., consumers at-risk for a disease with no treatment or cure

might abandon information-seeking behaviors and pursue other ways of accepting their diagnosis (Babrow, Kasch, & Ford, 1998). This process—of identifying an uncertainty, appraising it cognitively and emotionally, and then seeking information to negotiate a risk—can be affirmed by Affifi and Weiner's (2004) theory of motivated information management (TMIM) that situates uncertainty and information-seeking in three phases of evaluation, interpretation, and decision. A key feature of the TMIM is that anxiety is viewed a mediator that motivates a person to reduce uncertainty about a risky situation; this point differs from other communication theories that purposefully distance "anxiety" from "uncertainty" so as not to confuse the two experiences as synonymous (Brashers, 2001; Oliveri *et al*., 2015). Further, the TMIM focuses on self-efficacy, or the belief in the self to successfully attain an outcome, as an important mediator for decision-making. Thus, the TMIM proceeds as 1) identifying the uncertainty and the feeling of anxiety that follows, 2) assessing outcomes and negotiating efficacy beliefs, and 3) deciding on a strategy to seek information, avoid additional information, or reappraise the situation (Affifi and Weiner, 2004).

Just as uncertainty is experienced in regard to contextual and temporal qualities, Russell and Babrow (2011) contend that risk, too, is a "conceptual and experiential phenomenon" (p. 244) that is socially constructed and temporally located. The researchers argue that risk is shaped by the narratives that society shares about their experiences with risk, and as those stories are shared, the risk at hand is granted more agency, meaning, and context for others. This is how individuals develop their own "perceived likelihood that a particular event will lead to certain consequences" (Russell

& Babrow, 2011, p. 244). People judge for themselves how much weight to ascribe to risky events of the past in order to prevent undesirable events of the future. In the case of DTCGT, consumers must interrogate their family history of disease is in order to decide how meaningful a test for genetic risk might be. These interrogations with risk-making burgeon on what Brashers (2001) referenced as the divide between the "chronically ill and worried well" (p. 487). The more consumers track their digital and genetic data, the more salient "health" becomes on their minds and the more necessary it becomes to attain an idealized version of whatever "health" is. But in the quest to deepen genetic knowledge and adopt healthier habits comes increased anxiety about disease and illness in general, to the extent that society has developed its own a preoccupation with risk. The abundance of data technologies for monitoring health only heighten anxiety and uncertain, risky behaviors.

The datafication of genetic makeup

In 2020, data are seemingly everywhere, permeating throughout our lives in the social media we consume, the websites we visit, the apps we use, and beyond. We get in our cars and turn on our GPS to get to our destination; we swipe our IDs to access our office; we walk to our desk, the hallway illuminated by motion-sensor lights so as to conserve energy only when a human is in the room. At each point, data are being gathered, locating our driving routes and recording the time we arrive at the office or the number of times the lights are activated in a day. Authors have used the conceptual wordplay of "everyware" (Greenfield, 2006) and "everywear" (Gilmore, 2015) to describe the ubiquity of data-capturing technologies that exist in our spaces on our

bodies, respectively. However, the inclination to measure and record our everyday experiences is nothing new, as documented by Mayer-Schonberger and Cukier in their 2013 book, *Big Data: A Revolution That Will Transform How We Live, Work and Think*. While data are seemingly everywhere (everywear, and everyware), the modern "move to big data is a continuation of humankind's ancient quest to measure, record, and analyze the world" that is made more salient by the IT revolution and the last 30 years of the Internet's development (Mayer-Schonberger and Cukier, 2013, p. 76). Yet, datafying—quantifying that which is unreadable—can be traced back to the earliest civilizations around 3000 B.C. and the basics of counting and measuring lengths (Mayer-Schonberger and Cukier, 2013).

The shift "from atoms to bits" reflects a tenet of datafication: that at one point in the now-present future, most anything that exists physically will have the potential for being digitized or datafied (Negroponte, 1995). The human body is no exception. With the prevalence of self-tracking health apps that can do everything from counting calories, to locating running routes, to measuring sleeping habits, the body is viewed as a source of information that people are tasked with interpreting independently. This tracking of personal information serves to develop a "quantified self" that helps users optimize their lives, their health, and their knowledge of themselves (Lupton, 2016, 2017). Self-tracking positions the body as a matter of big data to be read and analyzed, converting the body and its corporeal properties into digital texts "of which users are at the same time the content and the reader" (Turrini, 2018, p. 6).

Likewise, the translation of the body into information is an embodied practice; it is the physical manifestation of what was once undetectable grafted onto the human body. This liveliness of data is furthered by a community of consumers who have bought into (or downloaded into) the self-tracking health market. By sharing results online and discussing them with friends and family, digital data take on their own social lives, and our corporeal bodies break through into a "network society" where they circulate in their datafied form (Castells, 2012). As Levina (2010) writes, the network society is premised on the continual reengagement with genetic data in Web 2.0 social networking spaces, such as Facebook and Twitter, that emphasize virtual communities, user-generated content, and participatory culture with that content. Gentech firms promote this sharing of genetic information because sharing is precisely how the network society prospers—it "enables a fast and expansive network growth," by allowing more users to be reached by DTCGT, creating the potential for new consumers, (Levina, 2010, p. 2). Users' actions, or shares, gain value as more consumers purchase genetic tests; thus, users are participating in a realm of "citizen bioscience," in which their genetic data become the commodity on which the network society functions (Rose, 2007).

However, the sharing of data online—sometimes taking data tracked by one company and sharing it on the platform of another—opens the door to "dataveillance," in which users are constantly monitored on the basis of their online lives and digital data (Van Dijck, 2014). Herein lies the issue with datafication of genetic makeup—as found in the terms and conditions agreements of nearly any social app or website, once users post their data to a social feed, those data essentially become the property of the company and

the user loses rights to how their data are handled (Christofides and O'Doherty, 2016). Lupton (2017) purposed that users are often left in the dark about this process, unsure of how their data are generated, how they are being surveyed by data owners, or how their data are used and repurposed by data owners. Many users have reported feeling immobilized by data-capturing techniques and their particulars in a progressively tech-oriented world. The possibilities of what their genetic data can do for disease research or pharmaceutical development are enticing for consumers and thus provide incentive for purchasing DTCGT. In turn, the process of engaging with data and being surveilled is "pleasurable," as Whitson (2013, p. 164) describes, because the result is an entrepreneurial pat on the back for having donated data to a greater cause, all the while improving the self.

While digital and genetic data are themselves immaterial, they are predicated on material conditions of the self. Like digital data, genetic data cannot be heard, smelled, or felt—but they can be seen through data visualizations, such as graphs, tables, and reports that are generated by data owners, like 23andMe or AncestryDNA. Genetic data are synonymous with understandings of digital data, in that that the very act of spitting into a spittoon is "a culturally relevant instance of converting the body into information" (Turrini, 2018, p. 6). Much of the communication and sociological literature on self-tracking has concentrated on health apps and websites dedicated to movement, exercise, and general wellness; however, I am fascinated by the translation of genes contained within our physical bodies to traceable "raw" data, a digital sequence of the genetic code

that is homed on the Internet's cloud (Gitelman, 2013). As it relates to this work, the datafication of genetic makeup forms the foundation such that DTCGT is able to exist.

I draw a parallel to Lupton's literature on the quantified self to identify, indeed, that genetic testing consumers have become quantified by their genetic self-knowledge and that they have invested trust in what their genetic data mean for them. However, Lupton's quantified self does little to contextualize what is next. What can social science scholarship *do* to complement the quantification of genes? One possibility is Lupton's connection to digital biocapital: the deployment of personal data as a commodity. In Lupton's (2016) estimation, "Biocapital involves the derivation of value from biological entities such as human bodies" (p. 117). That is, in the quantification of genetic material, the body and genes themselves can be viewed as sources of value because the knowledge generated by analyzing them pays kindly for both the consumer and the state. The former benefits from a knowledge of self that helps to quell curiosity and uncertainty about family heritage or health predispositions, and the latter benefits from the purchase of goods (e.g., supplements, gym memberships, further diagnostic care) by the consumer to extend interactions with data. Both are positioned within a system of knowledge and power, which as Michel Foucault explains, reinforce each other. Knowledge is information gained through institutions, be it from books, school, or in this case, DTCGT; power is allowed to exist because of this knowledge, and it exploits knowledge in order to reimagine what knowledge can be (Foucault, 1977; Foucault, 1980). Thus, the power/knowledge couplet within DTCGT is premised upon a consumer who is

encouraged to engage with their data and a private gentech company that continually creates new opportunities for data engagement.

Before the datafication of genetic makeup, the sort of self-knowledge granted by DTCGT was not readily available to consumers without hundreds of dollars or the direction of a medical provider. For most, they could not fathom that within a few years, and for the discounted price of $49, they could receive their genetic profile as a Christmas gift. Consumers' progressively growing interest in DTCGT has placed a critical focus on the companies that store their data and just what, exactly, those companies intend to do with them. Just as health data are susceptible to dataveillance, so are genetic data; thus, I aim to draw a parallel between datafication research and the genetic testing experience to uncover what value DTCGT companies find in their users' genetic data and how that value translates into genetic data being commodified. The construct of the consumer, gentech companies, and the regulating bodies that oversee the testing experience forms a hierarchical system of relationships—micro, meso, and macro respectively—where data are valued and power is expressed from the top, down. The understandings mentioned here of biocapital, power/knowledge, and commodity are further explicated by Foucault's ideas of governmentality.

Genetic data as a form of governmentality

A cornerstone of Michel Foucault's concepts of governmentality and biopolitics is the premise that before individuals can be controlled or managed by a system of power, they must first know themselves in order to define their own identity (Foucault, 1988). Through the acquisition of self-knowledge, humans gain an ethical understanding of who

they are and what their standards are, and only once this self-knowledge has been obtained can the process for self-care begin. Upon the recognition of self, processes of human life become susceptible to management by a regime of authority, one that has control over knowledge and power—even going so far as turning citizens of the state into puppets of the state. Biopower, to Foucault, serves as a technology to manage large groups of people, allowing for the eventual control of an entire population. Managing biological lives and sorting people into categories stand as both economic and political strategies to ensure the welfare of the state, because if you can manage a human, you can make him/her/they a productive member of society (Foucault, 2010). Importantly, the meaning of "productivity" in Foucault's framework references the ability of a citizen to contribute to the economic well-being of the state. To foster that productivity, Foucault describes a collision of technologies of the market and technologies of the self—the first describing the things that we buy and sell to benefit our economy, and the second describing the things or practices that we individually adopt to better our quality of life and deepen our self-understanding (Foucault, 2010). These two technologies couple to produce a "technology of power" that serves as the basis for governmentality, in that, when individuals contribute to the economy and when they invest in the growth of themselves, they can be the most productive members of society, and thus those best suited for furthering the government's success.

Neoliberalism—a political/economic theory characterized by principles of privatization, individual autonomy, unencumbered markets, and free trade—has developed Foucault's technologies of power, market, and of the self by furthering the

concept of the individually responsible, self-managed consumer (Harvey, 2007). Neoliberalism gained popularity in the mid-20th century as a shift in economic ideology from classical liberalism, which many blame for the economic misfortune of the Great Depression in the 1930s (Dagger & Girvetz, 2020). As Foucault outlines, neoliberalism differs from classical liberalism in a few ways: 1) it dissociates "the market economy from the political principle of laissez-faire," emphasizing instead the constant intervention of the government in the construction of the market, 2) it moves from a "*homo œconomicus,*" as a person of exchange to one who is a person of enterprise, investing in themselves and striving for self-definition, and 3) it denotes power as exerted upon an entire population, rather than the normalization of the individual, i.e., biopolitics (Foucault, 2010, p. 147; Foucault, 1978; May, 2012). Neoliberal extensions of governmentality emphasize concepts of autonomy and subjectification to negotiate the ways in which individuals choose to regulate their health and well-being in response to efforts by the state to place responsibility on the individual, rather than society as a collective. Power, as applied to the population, asks the individual *homo œconomicus* to develop an entrepreneurial mindset and care for themselves, as care for the self directly benefits the population as a whole. Those who fail in their individualized endeavors toward optimization bear a responsibility for withholding society.

Biopolitical examinations into DTCGT emphasize neoliberal governmentality, with many beginning their discussions from Abby Lippman's 1992 "geneticization" thesis. This concept, devised by Lippman in anticipation of the rise of genetics as a field, refers to the ways that social and health-related activities would come to be defined by

genetic terms as genetic research progressed. Lippman predicted a tendency for human diseases, behaviors, and even differences between humans to be attributed solely to genetics at the expense of the role of environment in a person's development. While little of the geneticization thesis has been realized in the nearly 30 years since it was conceptualized (Weiner *et al*., 2017), sociological scholars point to DTCGT as a "vector of geneticization" that places a deterministic emphasis on a person's genetic identity (Hoover and Emerich, 2012, p. 32; Nelson, 2008).

Here enters the neoliberal term of "individual self-determination," in that, because DTCGT lacks medical supervision, consumers are charged with interpreting their own DNA test results and are thus responsible for developing their own genetic self-knowledge and identity. Users seek out DTCGT in order to optimize their health or deepen their understanding of their ethnic breakdown; therefore, DTCGT can be viewed as a "technology of the self" that presents a way for users to govern themselves and manage their own genes. The results of a genetic test serve as yet another tool for consumers to moderate their health behaviors or alter their identities, lending toward the creation of a more actualized self.

The landscape in which users can attain a personalized snapshot of their health is what Rose (2008) calls molecular biopolitics, the combination of the "molecular" features of humans and the "molar" questions of how to govern others and ourselves. Analogous to Foucault's technologies of power, Rose highlights the concepts of autonomy, control, responsibility, and prudence in describing the rise of personalized medicine that created DTCGT: "No more 'one size fits all', health is a personal matter—indeed a consumption

good," says Rose (2008, p. 437). His work denotes a shift from citizens as *patients* to citizens as *consumers* who actively choose medicine and treatments to enhance their own vitality and self-manage their health, denoting the creation of the biological citizen.

This biological citizen emerges from a long history of citizenship projects that sought to emphasize the ways that authorities envision potential citizens and the ways they tried to enact them, e.g., through biological terms of race, blood lines, and intelligence. The modern biological citizen diverges from racialized and nationalized citizenship projects to underline different ideas about the role of biology in creating a human's worth and different ideas of biological responsibility (Rose, 2007). Today's biological citizen is one who understands themselves at a genetic, molecular level and uses that understanding in a collectivized fashion to form biosocial groups around shared genetic identity. They are the parents in a Facebook group who support each other through the journey of a rare, genetic disorder; they are the activist patients who campaign for better access to health insurance or research into an under-funded condition. Each instance represents a citizen who has taken the search for scientific knowledge into their own hands amidst a bioeconomy that profits off of the generation of scientific knowledge. Importantly, "biological citizenship requires those with investments in their biology to become political," in ways that reinforce the market economy of health (Rose, 2007, p. 149). By linking to datafication of the body, Rose (2007) explains the rendering of bodily processes into economic value: genetic disease is viewed as a potential resource of economic opportunity for biotechnology companies through privatized funding for research practices and the patenting of inventions like diagnostic

testing methods and sequencing machines. These outlets present new possibilities for the generation of wealth premised on the body, and as Rose argues, even call into question the marketability of ethics that have emerged alongside genetic responsibility.

Delving further into a Foucauldian analysis of DTCGT, scholars usually take one of two directions, highlighting either the emancipatory effects of DTCGT or the disciplinary ones (Turrini, 2018). Emancipatory perspectives posit genetic testing consumers as "moral pioneers" who mobilize individually and collectively to learn more about their genetic health or ancestry without being prompted by a medical provider (Turrini, 2018; Rapp, 1988). Exemplified by Facebook groups and Reddit threads where users create community around their genetic testing results, this perspective touts "biological citizenship" (Novas and Rose, 2005) in which consumers take responsibility for their own self-discovery into their genetic makeup. The consequence of this perspective, Rose (2007) describes, is the classification of people into "families, lineages, communities, population, and races" that become susceptible to appropriation by "interested parties" (Turrini, 2018).

Alternatively, disciplinary perspectives refer to genetic testing consumers as "genetic entrepreneurs" that blend self-discovery with market capital. From this angle, empowerment is not the goal and genetic susceptibility is not a cause for alarm; rather, genetic testing results are viewed as information that consumers can use to maximize their well-being through "hard work as 'enterprising, self-actualizing, responsible' persons" (Novas and Rose, 2000). Disciplinary perspectives are rooted in market terms that view DTC genetic tests as transactional: the genetic entrepreneur purchases a good

that benefits the organization of the healthcare market. In this right, users buy into DTCGT in part to donate their DNA to advance research into disease, stating that the benefit to the "greater good" outweighs the potential costs of their data being sold to third-party entities (Halusker, 2019). Through this perspective, consumers are embodying the sacrifice of self for the progress of society at large, which is at its core a technology of power that assists the goal of governmentality.

My argument in reviewing this literature is that biopolitical analyses of DTCGT do not have an "either/or" outcome. Emancipatory and disciplinary understandings of personhood and subjectivity coexist in consumers' interpretations of their testing results, and both understandings should be considered alongside one another when putting a critical eye on the consumer genomics industry. Due to threats of commercial misuse, the emancipatory calls for appropriation of genetic knowledge must be heeded. With a technology that is based upon classifying oneself as "carrier" or "non-carrier," "European" or "African," the potential for reshaping identities in response to genetic test results is possible. The genetic options theory (Roth and Ivemark, 2018) explains just how this sort of genetic classification can transform social identity, causing individuals to selectively choose which part of their ancestral makeup they recognize. When considered in cohort with Foucault's ideas of governmentality, it becomes probable to envision a landscape in which a system of power—or a gentech company—can exploit racial divisions to politicize its people, rooting them deeper in their differences rather than uniting them in their similarities.

However, the disciplinary effects of DTCGT also hold merit. When an individual purchases a health genetic test, they do so under the notion that they will receive a result that can inform their future health regimen—that is, the knowledge of whether or not they are predisposed to a disease based on their genetic makeup will help them to decide how they should adjust their diet and/or lifestyle to remain as healthy as possible for as long as possible. Harvey refers to this quest for longevity as "enhancing one's vital capital," or working to ensure "the capacity of humans as living beings" (2009, p. 369). This sustained capacity is necessary for members of a society with capitalism as its economic system. The longer a human lives, the more opportunities he/she/they have to add to society's economic value. The very act of purchasing a genetic test to attain vital capital helps to benefit the economy, as do the subsequent actions taken to achieve a healthy outcome, e.g., purchasing healthier foods, dietary supplements, or a gym membership. Each choice made in response to a DTC genetic test represents a technology of the self and/or market that functions to insert able, productive bodies into the modern capitalistic system. However, "moral pioneers" of the emancipatory perspective are not excluded from the economic underpinnings of the tests they submit to, just as "genetic entrepreneurs" are no less biological citizens.

These emancipatory and disciplinary distinctions between Foucauldian perspectives of DTCGT are thin at best, and it is my intent to examine their blurred lines to unite these bodies of literature. Paired with datafication, I am interested in drawing a parallel between the collection of genetic data and the capability of those data to be manipulated by the "state"—a gentech firm, a health insurance company, or one of the

many other biotech companies who come to acquire genetic data through the sale of them. Using Foucault's ideas on biopower, I can trace the subjection that DTCGT consumers experience, consciously or not, when they lose ownership of their data by signing the dotted line of a terms and conditions agreement. Through this line of inquiry, I will attempt to answer the following:

RQ1: What discourses of DTCGT are documented in journalistic reporting?

RQ2: To what extent do these articles engage with issues of ethics, if at all?

CHAPTER TWO

RESEARCH METHOD AND DESIGN

Foundations and Approach

This study stems from a research question I had when I started graduate school in 2018: what motivates consumers to purchase genetic testing? When seeking graduate programs, I was eager for a social science that could equip me with the tools to answer this question, one that could serve to describe the phenomenon of DTCGT in popular culture. After all, the social sciences study people, and communication—the field where I landed—studies how people talk to each other and how artifacts convey a symbolic meaning that frame their conversations (Lindlof and Taylor, 2002).

Situated within the study of communication, this research utilizes a qualitative approach to elucidate the individual, organizational, and societal implications of DTCGT as reported by news media. A qualitative approach was chosen intentionally to answer the questions of this study, as I am not looking to impose theory upon the data; rather, I want the data to speak for themselves and for concepts to emerge organically. Issues of ethics are rich in contextual details; they are not simply black or white, cause and effect. "A circled number on a questionnaire is but the tip of the iceberg," as described by Baxter and Babbie (2003, p. 62). Thus, if I am interested in understanding the discourse clustering around DTCGT, I must honor the contextual details by using a method that helps to construct a qualitative social reality.

This research marks my second line of inquiry into the topic of DTCGT. The first occurred in Spring 2019 when I conducted a pilot study using the qualitative interview to directly ask consumers of DTCGT how they made meaning of their test results. I asked questions in order to capture what motivates individuals to know themselves at the molecular level, and I created scenario-based questions that tested consumer knowledge of real-world examples of ethically concerning misuses (or potential misuses) of genetic data. The results of this pilot study highlighted three leading motivations for participants who sought DTCGT: 1) curiosity, or the desire to take part in a newly available, state-of-the-art technology; 2) family, both using DTCGT to confirm familial relationships and to bond with family members over test results; and 3) an indifference to ethics, in that participants agreed that the benefits outweigh the risks when sharing their genetic data with a biotech company.

As the researcher, I was rather unsurprised by the results gathered. In approaching my pilot study, I suspected that testing consumers likely had not put much thought into the ramifications of a DTC genetic test, given previously referenced literature that most consumers do not read terms and conditions agreements before submitting their data (Obar and Oeldorf-Hirsch, 2016). I anticipated that, "It's just cool," would be the answer to the question of motivation, because, well, DTC genetic tests *are* cool. They utilize cutting-edge technology that was formerly inaccessible to the public, and they provide personalized analyses to an audience of consumers who are inherently self-curious. And, to the theme of "family," I could speak firsthand to the draw of learning about your ancestral history after having witnessed my dad's quest to track his own genealogy for

the better part of my life. So, I was not surprised by the themes that emerged from the data, but I was left wanting more.

Enter: this study, my second line of inquiry into this topic. This work utilized a different method—discourse analysis—to gain a more holistic understanding of the conversations and messages surrounding DTCGT beyond the scope of a small sample of participant interviews. In using a second method to expand on my Spring 2019 pilot study, I am attempting to triangulate and crystallize the data, two concepts described by Tracy (2010). The former represents when "two or more sources of data, theoretical frameworks, types of data collected, or researchers converge on the same conclusion" in order to generate a more valid study (Tracy, 2010). The latter encourages researchers to use multiple methods and sources of data, though not for the purpose of aiding validity; rather, the intent of crystallization is "to open up a more complex, in-depth, but still thoroughly partial, understanding of the issue" (Ellingson, 2008; Tracy, 2010, p. 844). Thus, by taking a multi-method approach through an interview study and now a discourse analysis, I am aiming to make my research more comprehensive while also deepening my understanding of the topic at hand and allowing for reinterpretation later on.

Discourse Analysis

As described earlier, users of health apps and software are often unsure of how their data are used and repurposed by data owners (Lupton, 2017), even though gentech companies outline the data's potential uses in their privacy policies. However, those policies are often jargon-filled and glossed over by consumers, which calls into question just how informed consumers are about the handling of their data (Obar and Oeldorf-

Hirsch, 2016; Christofides and O'Doherty, 2016; Phillips, 2017). Journalistic reporting serves as one way to elucidate the fine print of such privacy policies and other issues that stem from DTCGT. Investigative journalism and news media reporting are regarded for their emphasis on facts, truth, and reality, what Zelizer (2004) calls the "god terms" of the profession. A core principle of journalism relies on presenting an argument or issue from multiple vantage points with factual, informed evidence so as to give the reader a reliable account of the issue. The profession is also denoted by being "an independent monitor of power" to describe how power is executed in a society and what the effects of powerful entities might be for the public (Kovach & Rosenstiel, n.d.). It is these tenets that draw readers to news media as they search for an accurate and credible account of current happenings in the world, an account that is broken down and summarized for easy reading.

In this study, I looked toward journalism's capacity to provide information that is comprehensive, truthful, researched, and representative of varying perspectives in order to carry out a discourse analysis of news articles describing the advent of private firms 23andMe and AncestryDNA. As defined by Baxter and Babbie (2003), discourse analysis "is the qualitative study of constituent units of discourse and how they are arranged in a system, structure, or grammar," where "discourse" refers to language in context (p. 355). Rather than examining particular words or phrases in spoken language or written text, a discourse analysis considers the social and cultural frameworks in which language is enacted. It recognizes that trends in popular culture, such as the popularity of DTCGT, do not exist in a vacuum; thus, the conversations around a subject take place among

systemic and institutional practices that invoke meaning into dialogue. Just as this study attempts to place genetic data within a multiplicity of political-economical-technological relationships, the method of discourse analysis places language in context of a subject's history and the societal structures that contribute to it.

A Foucauldian approach to discourse analysis is amenable to this study of DTCGT because it contextualizes language through historical and cultural foundations. Importantly, Foucault's definition of "discourse" focuses on the rules, divisions, and systems that define how a particular topic is discussed; these rules and systems are the contextual component of language referenced by Baxter and Babbie (2003). Arribas-Ayllon and Walkerdine (2011) describe three broad qualities that further define a Foucauldian discourse analysis:

1) The analysis involves a genealogical inquiry into the subject of discursive practices, such that the subject can be understood in terms of its historical construction. When we describe how present discourses are shaped by poignant moments in history, we demonstrate that there are prior practices and relationships that serve as pre-conditions for how we understand discourse today and often, those pre-conditions are moral, political, economic, and technical events of the past.

2) The analysis stresses power relationships that are revealed through language and practices. Subjects are contextualized by the intervention of powerful entities, e.g., government, technological, or corporate entities that guide how discourse governs the self and others.

3) The analysis makes reference to subjectification by highlighting techniques for self-management and behavior modification. This point asks how an individual tends to the relationships and constructs surrounding them to develop their own attitudes and morals toward an object.

Choosing a Foucauldian approach represents an intentional practice of aligning this research with the theoretical frameworks of biopolitics and governmentality and the history of genetic sciences previously described here.

Data Collection

This analysis included articles from U.S. newspapers from 2017 through January 2020, corresponding with "the year consumer DNA testing blew up" (Regalado, 2018) and into the present, in order to document the current phenomenon of DTCGT. Articles were pulled from newspapers with the widest circulations—*The New York Times*, *The Wall Street Journal*, and *USA Today*—to gather an illustrative corpus of statements (Miaschi, 2017; Muck Rack, 2018; Pew Research Center, 2019).

Initially, I attempted to use NexisUni and Google News to collect the articles for analysis. NexisUni allowed for an advanced search option that limited the results to a date range, from selected sources, using a specific search term. However, the keywords "consumer genetic testing," only generated 12 results, all of which were from *The New York Times* despite a query from all three sources in this study. Only three of 12 results were news articles, while the rest were letters to the editor or articles covering unrelated topics. Querying with more specific keywords, such as "Ancestry.com" or "23andMe" rendered just as few results. It became clear then that NexisUni was not an appropriate

search engine to gather articles for this study. Google News was also limited, as the only way to search for articles by source is to use the source as a keyword, e.g., "consumer genetic testing" AND "NY Times," which allowed other sources to populate the results. Google News is also unable to customize searches by a specific date range; the most exact query I could run resulted in news articles published within the "past year" or "anytime," which made it tedious to search for articles published prior to 2019. I then decided to go to each news source's website to directly search their archives and gather articles for the initial sampling, having purchased subscriptions to *The New York Times* and *The Wall Street Journal* in order to conduct this study. (*USA Today* is freely accessible.)

Articles were then selected and organized based on the following criteria:

1. Only articles published between January 1, 2017 and January 4, 2020 were included in the initial sampling.
2. Articles were gathered using the keywords "consumer genetic testing," "Ancestry.com," and "23andMe."
3. Articles not specifically discussing DTCGT, Ancestry.com, or 23andMe were removed. Relevance was gauged by the article title, headline, and the first paragraph or so of copy that was visible without a publisher subscription.
4. Selected articles were numbered in an Excel spreadsheet and organized by article title, publisher, date published, and keyword.
5. Any articles that appeared in duplicate were removed.

84 articles resulted in this initial sampling: 38 from *The New York* Times, 30 from *The Wall Street* Journal, and 16 from *USA Today.* After paying for publisher subscriptions and getting past paywalls, I discovered that some articles in full were not relevant to the topic at hand and that some *Wall Street Journal* articles are still inaccessible, even with a basic subscription. This significantly impacted the number of articles from *The Wall Street Journal* that I was able to analyze in this study. To further narrow the articles for analysis, I used a random number generator to construct a final pool of 50 articles: 25 from *The New York Times,* 15 from *The Wall Street Journal*, and 10 from *USA Today.*

Data Analysis

I printed all articles and, for my initial round of coding, used hand-coding techniques and an arsenal of highlighters to begin analyzing the data. I employed the constant comparative analysis method (Glaser & Strauss, 1967; Charmaz, 2006) to identify common themes revealed in reporting about the personal genomics industry. Made known by Glaser and Strauss' grounded theory approach, the constant comparative method requires "an ongoing process of comparing units of data with each other," through the development of codes and categories, (Lindlof and Taylor, 2002, p. 250). I utilized open coding at the onset of my data analysis to interpret the articles I choose, reading them line by line and assigning categories to the data based on my initial thoughts and the coherent meanings that are conveyed at the surface-level of the data (Strauss, 1987).

After open coding, I took three weeks of time away from the articles before returning for a second round of coding, calling in the "constant comparative" aspect of this method. Walking away from the data, for any period of time, was a way of approaching this study with a fresh perspective so as to avoid becoming mired in the data. In the second round of coding, I grouped codes under a more generalized umbrella of topics, looking specifically for themes regarding neoliberal + governmental + bioeconomical understandings of the journalistic discourse on DTCGT (see *Table 1.*) Grouping the original codes in this manner calls in the Foucauldian approach of this study by specifically looking for power relationships within the discourse.

To assist in clarifying what those relationships might be, I employed LeGreco and Tracy's method of discourse tracing to more easily highlight the macro, meso, and micro levels of discourse that occur within the topic of DTCGT. Discourse tracing caters to critical-interpretative analyses of language, power, and context and seeks to make sense of the data gathered by clearly delineating the subjects who wield power within the discourse (LeGreco & Tracy, 2009). Micro-level discourse looks at how language is produced locally; meso-level discourse is broader, examining the entities and texts that organize local examples; and macro-level discourse encompasses even "broader social narratives and systems of enduring thought that shape and are shaped by micro and meso discourses" (LeGreco & Tracy, 2009). Thus, to elucidate how power is operationalized within DTCGT, I examined discourse through the interplay of government (macro), gentech company (meso), and consumer forces (micro). In the articles I studied, any mention of a government entity, e.g. the FDA, CDC, FCC, or law enforcement,

represented a macro-level attempt to regulate 23andMe or Ancestry. These gentech companies served as mediators between government and the DTCGT consumer. Through this lens, I was able to probe the dataset for power relationships, again, using the following research questions:

RQ1: What discourses of DTCGT are documented in journalistic reporting?

RQ2: To what degree do these articles engage with issues of ethics, if at all?

CHAPTER THREE

RESULTS AND ANALYSIS

Across the articles I examined for this project, I found that DTCGT was presented in terms of its accompanying ethical issues, as if the technology itself cannot be separated from the ethical questions that it raises. Not a single article in the dataset was able to present DTCGT without discussing at least one of the many problems posed by consumer genetic testing. RQ2 asks, "To what degree do these articles engage with issues of ethics?" and the answer is simply put: *entirely* or *completely.*

The articles chronicled the breaking news headlines of DTCGT over the past two years, from when the FDA first began to allow 23andMe to sell genetic tests for disease risk, to the tracking of the Golden State Killer using a consumer DNA database, to Elizabeth Warren's claim of her own Native American ancestry using genetic tests, and into more recent headlines, like AncestryDNA breaking into the health testing market and genetic testing's entanglements with child privacy laws. Below are the most salient themes found in the dataset, including the issues of ethics that marked each theme.

Biocitizenship: The self-managed consumer

> *Together, these tools [whole-genome scans, artificial intelligence, and targeted drug and gene therapies] can empower patients to become co-directors of their own medical destinies. In fact, the right to know the risks contained in your genetic code will likely become the most fundamental medical right of the 21st century.*

—Huber and Howard, *Wall Street Journal*

The framing of the genetic testing consumer as an enterprising biological citizen reverberated throughout the dataset. This theme was characterized by language that posited consumers as those who often seek testing without consulting with a doctor or genetic counselor because "…people do not always need the intervention of medical professionals and genetic counselors to learn their risk for certain diseases" (Kolata, 2017a, para. 8). For example, in 2017 when articles first began to document the advent DTCGT for disease risk, Kolata (2017a) presented the technology as an alternative to the clinical genetic test, stating, "until now, the only way for people to get such genetic tests was to see a medical professional" (para. 5) but the advent of a consumer option made the process all the more "simple" (para. 6). This claim by Kolata highlights the autonomy granted to consumers in figuring out their own disease risk or ancestral background by using privatized tests rather than clinical ones, an act that embodies neoliberal values of caring for the self and investing in one's own health. Self-investment strengthens the subject of the self-managed consumer, who is characterized in the discourse as one who seeks "control over their own health information" and uses DTCGT as a tool to "manage and monitor their health" (Huber & Howard, 2017, para. 4). As a result of learning their disease risks, some consumers manage their health outcomes by adjusting their lifestyles. One story from *The New York Times* spoke of 32-year-old Matt Fender who, upon learning from a 23andMe test that he had a genetic variant for early-onset Alzheimer's, sought "to improve his health through diet, exercise and supplements" (Hercher, 2018, para. 11). The process, of individually seeking a genetic test and then altering health

behaviors in response, demonstrates DTCGT as a technology of the self that consumers utilize to maximize their "vital capital" (Harvey, 2009). Micro-level discourses focus on the consumer who seeks healthier habits so as to stave off the likelihood that their increased genetic risks will be realized—but doing so implicitly reinforces the idea that "health" is the optimal state for which all citizens should strive. The healthy body is the morally acceptable body, and neoliberal principles encourage that the individual is responsible for attaining a state of health that ensures their ability to contribute to society. In responding to his genetic test with healthy behavior modifications, Fender exemplifies his own capacity for self-governance that in turn grants him more opportunity to be accepted and to participate our capitalistic system.

However, the story of Matt Fender also represents the opposing frame of the self-managed consumer that was presented in the discourse. While 23andMe told Fender that he was certain to develop Alzheimer's in his lifetime, AncestryDNA found no genetic marker indicating this outcome, leaving Fender "to grapple with the discordant results on his own. He felt more than ever in need of a doctor's advice" (Hercher, 2018, para. 23). Indeed, there were many more articles in the dataset that problematized the absence of medical supervision in DTCGT. For example, this frame "warns that some consumers may be led astray by genetic findings that are overblown or irrelevant" (O'Connor, 2017, para. 5) because "in a perfect world, a discussion with a medical provider would still happen first, before someone decides whether to get tested and what tests to take" (Painter, 2018, para. 11). Taken together, I argue that these articles present a consumer

who might misunderstand just how genetic tests achieve their accuracy and convey risks about disease.

Much of this frame implied that when medical professionals are left out of the testing conversation, consumers are granted total self-management of their genetic outcomes, because few consumers will cross-check their results with clinically proven genetic tests unless they receive a result that predicts an increased or almost-certain risk of acquiring disease later in life. Even still, several articles encouraged following up with a genetic counselor "before taking any action based on test results," so as to ensure that consumers can make fully informed decisions about their health outcomes (Marcus, 2018b, para. 12). I argue that this frame works to infantilize consumers by suggesting that they are not knowledgeable enough, nor do they have the agency, to make informed health decisions. Yet, the decision to include or exclude a genetic counselor in the testing conversation is *still* a choice made by the consumer; medical professionals serve as another source of information that the consumer can choose to include or exclude in order to better understand their genetic risks. If the self-managed consumer is defined by qualities of autonomy, self-determination, control, and responsibility over health outcomes, then the decision to seek medical advice—or even the decision to take test results at face value—are valid responses to DTCGT that do not diminish the agency of the consumer.

But, the accuracy of consumer tests is inherent to the genetic testing experience, and thus represents an important feature of genetic testing that the self-managed consumer must take into account. Accuracy of tests was a code that appeared repeatedly

across the dataset and was defined by its deep dive into the science of health and ancestry genetic testing. From the health perspective, clinical genetic tests are designed to be much more comprehensive in testing the genome than consumer tests are. For example, The Editorial Board of *The New York Times* contends that 23andMe "relies on much simpler technology than tests that you'd get at your doctor's office" (para. 2). Importantly, consumer tests from 23andMe and Ancestry only take into account "just a handful of places in the gene where mutations are known to appear" (The Editorial Board, 2019, para. 10). However, most diseases are complex and result from an interplay of multiple genetic mutations or even just one mutation in a gene that is not included in a consumer test. As Roni Caryn Rabin's *New York Times* article put it in the example of breast or ovarian cancer screening, "testing negative for the three [pathogenic] mutations does not mean someone is in the clear, as there are over a thousand BRCA mutations associated with increased cancer risk," and those thousand mutations are not presently included on the panel tested at 23andMe or Ancestry (Rabin, 2018, para. 5). Testing accuracy also takes into account the differences in algorithms and reference panels that each gentech company has to work off of. Marcus (2018b, para. 14) writes: "Companies rely on proprietary databases and algorithms to make their assessments. Results may vary depending on how many people a company has in its database, as well as how diverse their backgrounds are." For the ancestry testing consumer, one *USA Today* article posited that "ancestry testing is no exact science…data about your heritage are determined by comparing users to a reference database of other users. And each company has its own proprietary algorithm and dataset" (Farr, 2018, para. 10–12).

Accuracy of genetic testing and the potential for inaccurate test results is thus presented in the discourse as a risk that consumers need to be mindful of. For the self-managed consumer on a quest to deepen their genetic self-knowledge, accuracy is one of the more paramount risks to be concerned with. Being led astray by the tool you choose to use in monitoring your health or expanding your family tree could result in off-base health responses and unconfirmed familial relationships that invalidate the purpose of testing in the first place. Yet, accuracy is but one of many risks and uncertainties about the genetic testing experience that were documented in the dataset; phrases denoting risks and uncertainties about testing came up 20 times across the articles studied (see *Table 1*).

"Risks" presented in the articles were twofold: first, there is the inability of genetic tests "to describe a person's overall risk of developing the disease in question" (Burton, 2017, para. 4), as "diet, environment, lifestyle, family history and other factors play a role," too (Marcus, 2018b, para. 12); and second, the chance that tests might convey a false or inaccurate picture of disease or ancestry is a risk unto itself (Kolata, 2018). When consumer gentech companies "look for changes in tiny segments of genes, rather than examining the entire gene and looking for alterations," (para. 19) false-positive and false-negative results can occur, but unlike their clinical laboratory counterparts that are subject to regulations and quality controls to ensure error-free results, gentech companies absolve themselves of fault "because they make it clear that their data are not meant to be used for medical diagnoses" (Kolata, 2018, para. 29). Thus, the results received from 23andMe or Ancestry cannot "tell you much about your risk of developing the diseases in question" (The Editorial Board, 2019, para. 2). Clearly, the

results are an *estimate*, and proceeding with DTCGT carries with it its own risks and uncertainties about the results at hand. To the extent that discourses in these articles engage with scholarly understandings of risk and uncertainty, DTCGT serves as a testimony that the value of "risks" are to be determined personally, based on the lived experiences of the consumer. Participating in daily life where health is an ever-present goal means also participating in the constant construction and evaluation of genetic risk—taking a genetic test elicits information about risk, which produce actions that carry with them their own risks in a cycle that is ongoing.

For the self-managed consumer, the risk that results might not be as accurate or comprehensive as hoped for can prompt engagement with the uncertainty management process (Brashers, 2001) to question how worthwhile and meaningful results are in their broader health experience. In the earlier case of Matt Fender, who thought he was certain to develop Alzheimer's disease, news of his predisposition was "disturbing but manageable," (Hercher, 2018, para. 11) and his sensemaking process for his results meant consulting with a doctor to seek additional, clarifying information. However, for a disease that has no known cure or treatment, Fender's doctor responded with, "What the heck do we do about it, once we know, other than create high anxiety?" (Hercher, 2018, para. 13). Anxiety was therefore a mediator of uncertainty management in Fender's case, as it is a mediator in "dozens" of other instances when DTCGT reveals a high risk of disease. Reported by Sumathi Reddy (2019, para. 11) in the *Wall Street Journal,* also through the example of Alzheimer's disease, "the stress of knowing" your genetic predispositions presents its own consequences for risk management, as consumers have

to grapple with what their predisposition means for them and for their family, who might inherit the disease risk. The self-managed consumer, in this context, is presented in the discourse as one who is subject to the uncertainty and risk management process, having to ask themselves just how valuable the information stemming from DTCGT can be for their health journey.

Thus, the articles—especially those from 2017–2018 when consumer disease risk tests were first authorized by the FDA—spent much time advocating for doctors and genetic counselors to be involved in the testing process and for consumers to confirm their results using clinical testing if needed in order to ameliorate uncertainty posed by DTCGT. Not only did the articles present these recommendations, but gentech companies themselves include the recommendation for medical supervision and additional testing in their fine print. However, the acknowledgement was pervasive throughout the dataset that although these are the recommendations, most all DTCGT consumers proceed without heeding this advice and instead use genetic tests to satisfy their curiosity of the self.

Datafication: The datafied consumer

> *23andMe is among a crop of new services that have arrived to help us mine our genetic material for answers to questions we didn't even know we had. These services' ancestral algorithms are based on estimates and probabilities, not certainties, but they nevertheless claim to distill the self into a series of appealingly specific data points onto which personal narratives can be written.*
>
> —Hess, *The New York Times*

Acts of datafication were documented in the articles not only in the way that genes are translated into quantifiable records through DTCGT, but in the ways those data live on after being characterized. "Datafication" as a code that emerged from the dataset was most frequently marked by phrasing that describes how DTCGT takes place:

> The process for customers is simple. A customer spits into a tube and then mails it to 23andMe. The company's lab extracts DNA from the saliva cells and tests it with probes that find genetic markers using a special chip for genotyping. In about six to eight weeks the company sends the customer an email saying the results are in. By logging onto an online account, the customer can see the report and its interpretation. (Kolata, 2017a, para. 6)

The spitting, sending, and sampling of saliva was noted at least 10 times throughout the dataset as the catalyst that enables the genetic testing experience to occur. The genetic breakdown that ensues from "a simple saliva sample" can "provide people with information" (Kolata, 2017a, para. 1 & 7) or "unlock information in…DNA" (Marcus, 2018b, para. 2) that helps consumers understand their health or their relation to their family heritage. The very definition of datafication posits the physical body as something to be translated into immaterial information—and articles certainly did not fall short of referencing the "growing stream" (O'Connor, 2017, para. 5) or the "huge trove of genetic data" (Roland, 2019, para. 2) that results from DTCGT. The subsequent "genetic portfolio" (Daalder, 2018, para. 2) that users receive from 23andMe or AncestryDNA to visualize their results was framed in the dataset as a "roadmap to your genealogy and, in some cases, information about what diseases you're most susceptible

to" (Ravenscraft, 2019, para. 1). The "map" analogy was furthered for ancestry genetic testing in that 23andMe and AncestryDNA quite literally use a map of the globe to display ethnic breakdowns; in a *USA Today* article describing 23andMe's 2018 update to its genealogy algorithm, author Christina Farr writes, "The update will include 120 new regions across the globe. The product will be a lot more interactive, so users can zoom into their ancestors' geographic regions on a map" (Farr, 2018, para. 3–4). The invitation to interact with their own data supports the subject position of the datafied consumer—it posits consumers as the data points that they then get to interact with in visualizations that are easy to comprehend. Genetic data are granted meaning and sensemaking capabilities when presented in these visual formats that work to make data all the more lively for the datafied consumer. Especially in the instance of ancestry genetic testing, where genetic testing results are incorporated into a database accessible by members who pay for Ancestry.com subscriptions, genetic data help to elucidate familial relationships through the social media side of the company's website. Members are presented a virtual family tree based off their genetic testing results that link directly to social media profiles, where they can interact with family members who share an interest in furthering their family's genealogical research. As Krueger (2018, para. 9) writes in *The New York Times*, "The result [of ancestry genetic testing] is a more layered version of what happened when Facebook first emerged and out-of-touch family members found one another." In this right, genetic data develop their own social lives akin to the network society explained by Levina (2010). Data visualizations that are engaging, visually appealing, and easy to comprehend prompt the development of the social networking

experience. As social media networks grow, so too does the popularity of AncestryDNA and 23andMe as more consumers buy into genetic testing to expand their family trees. This notion provides further support that the datafied consumer is one whose data are commodities that propel the network society and establish gentech companies at the meso-level as being powerful entities that mediate between the state and the consumer experience of testing.

However, the liveliness of data and the ability to "see" it at all brings with it the ramifications of how data are handled, which were referenced abundantly in the dataset. A 2019 article from Edward Baig at *USA Today* framed the process of initiating a consumer genetic test as "surrendering" saliva to a gentech firm, rather than "sending" or "sampling" saliva, as if taking part in a consumer genetic test is a forced act commanded by another (Baig, 2019, para. 1). The article was written in reference to third-party sharing of genetic data, which implies that when the datafied consumer "surrenders" their saliva, they might also be forfeiting their last chance at genetic privacy and ignorance of their genetic underpinnings, i.e., consumers' notions of who they conceptualize themselves as, who they think they are, might be challenged once genetic testing results are received.

Third-party sharing of data represents the most documented code within datafication, counted at least 19 times in the dataset (see *Table 1*). Two of the more commonly referenced third parties where genetic data are shared are that of Promethease and GEDmatch, the former which "promises to do a more in-depth analysis for genetic mutations that cause disease" (Kolata, 2018, para. 3) and the latter that can "find

biological relatives or…construct elaborate family trees" (Murphy, 2018b, para. 2) beyond what 23andMe and AncestryDNA can provide. These third parties work through expanded reference populations, thanks to "publicly available data" and literature that details "gene variants reported to be linked to disease" (Kolata, 2018, para. 30 & 9) to send consumers updated reports about disease risk or ancestry periodically over time. However, just as 23andMe and Ancestry have their own algorithms for delivering results, so too do third-party companies, which adds another instance where data can be inaccurate and misinterpreted on the consumer's behalf. Promethease and GEDmatch face even less regulatory scrutiny than AncestryDNA and 23andMe due to their third-party status, which safeguards them from having to provide "conclusive" and clinically validated" results (Kolata, 2018, para. 1 & 22). The implications as such mean that the consumer will have to shoulder the worry and frustration that comes from a false-negative or false-positive result.

Across the articles on third-party sharing of data is a potential ramification that was referenced only three times across the articles under study: that when the third-party that obtains access to genetic data is a consumer's insurance company, the result could be an "insurance death spiral" that increases costs for consumers (Kolata, 2017b, para. 17). The Obama-era Genetic Information Nondiscrimination Act (GINA) protects consumers in the event they have a genetic predisposition for a disease such that employers "cannot ask employees to take gene tests and cannot use any such results in employment decisions; insurers are not permitted to require gene tests or to use the results in coverage decisions" (Kolata, 2017b, para. 11). However, long-term care and life insurers are

exempt from GINA and are able to inquire about health status in order to make coverage decisions. If patients decide not to report their genetic risks for fear they will be denied coverage, premium prices will skyrocket as policyholders get sicker. “Increasing numbers of people at low risk might decide the insurance was not worth the rising price. Even many at high risk would eventually find the policies unaffordable,” Kolata (2017b, para. 17) explained. Members of the military, veterans, Native Americans, and small business owners with fewer than 15 employees are also not protected by GINA, leaving their genetic information subject to insurance discrimination (Genetic Alliance *et al.,* 2010). The notion that consumers might conceal their genetic predispositions in the pursuit of long-term care insurance is supported by a study done by Dr. Robert C. Green from Harvard University, which “found that those who learned they had a gene variant…were nearly six times more likely to buy long-term care insurance than those who did not. […] Many thought there was no need to tell the insurer why they suddenly wanted the policy” (Kolata, 2017b, para. 22–23; Taylor *et al.,* 2010).

Finally, third-party sharing of data goes beyond that of gentech DNA databases to include the ways that gentech firms share data for their own research gains. Meso-level discourse describes how gentech firms have contracted with “[research] companies” (Marcus, 2018b, para. 18) and “drug giants” (Roland, 2019, para. 2) to share consumer genetic data in an effort to accelerate drug development, conduct research into the genetic basis of disease and lifestyle factors, identify candidates for clinical trials, and more. Several articles in the sample served to describe what consumers should know before they submit their data for a DTCGT by reiterating that “customers are free to opt out of

the research option at any time or delete their data" (Suppe, 2018, para. 27) and they should also "read the company's privacy policy" (Ravenscraft, 2019, para. 6) in order to develop informed consent. Contained within those privacy policies are 23andMe and Ancestry's claims that all consumer data shared with another entity is "de-identified and aggregated" (Suppe, 2018, para. 13; Ravenscraft, 2019, para. 13), meaning a consumer's name and personal information are stripped from their genetic data, and those data are then combined with data from the millions of other consumers who have submitted to DTCGT in an effort to maintain a consumer's privacy to third-party companies. However, glossed over in policies on de-identification and aggregation is the latent understanding that all DNA can be traced back to a consumer, no matter any attempt to anonymize it, because DNA is a personal map and genetic fingerprint that is unique to each person.

This review of the third parties mentioned in the dataset, i.e. Promethease, GEDmatch, health insurance providers, and biotechnology and pharmaceutical companies, serves to position the datafied consumer in regard to the entities that hold power over consumers' personal genetic data. When juxtaposed beside companies that collect, mine, and disseminate genetic data, the individual testing consumer can be viewed as the "data poor" who is in opposition to the "data rich," which implies a certain level of value that consumers' genetic data must hold if testing companies are so motivated and eager to maintain and advance the genetic testing experience (Ruckenstein and Schull, 2017). The datafied consumer is subjected as a form of biocapital for companies to extract profitable information from, eluding to Rose's (2007) concept of the

bioeconomy and neoliberal principles of a market that creates biologically informed, productive citizens. However, a caveat of the biological citizen, referenced in literature and in this dataset, is the potential for data to become tracked and monitored by those entities who store and share genetic data.

Consumer privacy thus marked another code found in the dataset; in fact, it was the second-most frequently documented code of all the articles read (see *Table 1*). How gentech companies are seeking to protect consumer data represents possibly the greatest challenge to DTCGT and is made more difficult by the fact that "it's impossible to fully anonymize such intrinsically personal data like DNA" (Suppe, 2018, para. 13). As mentioned, consumer companies rely on deidentified, aggregate data which claim to make DNA untraceable "back to the individual" (Suppe, 2018, para. 11); however, researchers have shown that it is possible to identify testing consumers by using predictive analytics to ascertain familial relationships through mining genetic data (Erlich, Shor, Pe'er & Carmi, 2018; Kim, Edge, Algee-Hewitt, Li & Rosenberg, 2018). Further, Ravenscraft (2019, para. 2 & 15) highlighted that genetic data "can become difficult to track" and are "difficult or impossible to delete" once they are shared with gentech companies. Suppe (2018, para. 17) also went on to present the divide between consumers' opinions on privacy concerns by framing those who are "supporters of research" and have therefore consented to sharing their data to inform medical knowledge against those like 38-year-old testing consumer Drew Olanoff, who closed his 23andMe and "asked to have his data deleted" because "he never opted in to donate his data for research in the first place" (para. 31). Additionally, authors Marcus (2018c, para. 21) and

Murphy (2018a, para. 2) presented the popularity of DTCGT as a threat to consumer genetic privacy because "databases are growing so rapidly" that "already, 60 percent of Americans of Northern European descent…can be identified through such databases whether or not they've joined one themselves." This possibility makes it even more difficult "for individuals to retain any anonymity" (Murphy, 2018a, para. 2) in their testing experience and calls for "'a re-evaluation of the status quo' when it comes to genetic privacy, especially in the U.S., where genetic testing is increasingly accessible" (Marcus, 2018c, para. 22).

These codes—of overt instances of datafication, third-party sharing of data, insurance discrimination, and privacy concerns—are grouped together because they represent illustrations of how the physical become the datafied and are then mined for further information. The articles highlight that genetic data are valuable sources of information that gentech companies can (and do) use to prop up their research agendas, therefore increasing opportunities for market collaboration that increases the monetary value of these companies. Consumer data were not presented as a simple exchange between two entities; rather, data live on beyond the gentech firm's laboratories and take on new purposes as they are shared. From a technological sense, data are presented as the crux upon which predictive analytics function to mine data for information; without data, algorithms used by gentech firms to draw connections between genes would not have a purpose. Thus, a latent feature of the datafication theme in these articles is that third parties will continue to develop new ways to use and understand genetic data; new companies will continue to establish with the sole purpose of developing novel avenues

for studying consumer-provided data. Consumers, being the sources of information, are again the data points in the scenario. With growing interest from the biotechnology industry in the use of those data points, consumers as generators of bio-value, searchable by "the state" i.e., governments and private industry, is the final important theme of this study.

Power: The valuable consumer

The pitch for home DNA testing could not be more succinct: know thyself, for a fee.

—Herrman, *The New York Times*

Referring back to LeGreco and Tracy's discourse tracing, government agencies and law enforcement were identified in this study as the macro-level entities that create and participate in the web of scientific-technological-economic power relationships surrounding DTCGT. This web is nuanced; it includes not only the regulations set forth by the government that permit the sale of consumer genetic tests, but the ways that government can benefit and extract value from databases of genetic data. As data live on and become repurposed by third-parties, opportunities arise for powerful entities to use genetic data to reinforce longstanding social divisions, to interfere in the personal privacy of citizens, and to fuel the continuation of individuals as productive citizens who serve the overall well-being of the state and corporate interest. Power is nuanced because it is often implicitly wielded, and the articles studied did not fall short of exemplifying that. Codes relevant to the theme of power and biocapital were recorded more often than the other codes in this study (see *Table 1*).

The conversations surrounding power over genetic data were established in the dataset beginning in 2018 when the "Golden State Killer", Joseph James DeAngelo, was apprehended by law enforcement using the newfound method of genetic genealogy and familial DNA searching. The method allowed law enforcement to reverse-engineer DeAngelo's family tree by first taking DeAngelo's DNA collected from a crime scene and converting it into a digitized format suitable for GEDmatch. Once uploaded, GEDmatch's algorithm connected law enforcement to 10-20 of DeAngelo's distant cousins. Genealogists traced those cousins back to a common ancestor—DeAngelo's great-great-great grandparents—and then laboriously traced every branch of those grandparents' offspring until they had 25 distinct family trees and 1,000 possible suspects. After narrowing down the search to family with ties to Sacramento in the 1970-80s, only two suspects were left: DeAngelo and one other, who was later eliminated through a relative's DNA analysis. DeAngelo was apprehended after law enforcement tested his DNA—gathered from trash he disposed of at his house—against DNA from the 1980s crime scene (Jouvenal, 2018; McMahon & Harris, 2019).

Law enforcement's use of DNA databases is nothing new; state law enforcement has their own DNA database—the Combined DNA Index System (CODIS)—which aggregates genetic profiles of any person convicted of certain crimes or DNA profiles found at crime scenes. What makes the Golden State Killer case different was the use of the public, open sourced, consumer-provided database of GEDmatch, because, "while safeguards exist to make sure the information uncovered from criminal databases isn't misused or disclosed improperly by police, none of those regulations exist for

commercial databases" (Yancey-Bragg, 2019, para. 8). The overarching, deeply ethical concern brought about by the Golden State Killer case was that very first step in tracing DeAngelo's family tree: that law enforcement took a DNA sample from a crime scene and uploaded it to GEDmatch, technically, as a fake identity. When doing so, detectives on the case certified "that the DNA was their own or belonged to someone for whom they were legal guardians, or that they had 'obtained authorization' to upload the sample" (Kolata & Murphy, 2018, para. 11).

Besides a glaring violation of the site's intent, the case raises a whole set of ethical questions that were well characterized in the articles studied. First, the case of the Golden State Killer—a serial rapist and murderer—provided one of the first high-profile investigations using genetic genealogy, and police have since used the method to convict other crimes, such as assault and battery. This questions the limit on the types of crimes investigated through genetic genealogy: "If the police felt free to use it in an assault case, why not shoplifting, trespassing or littering?" (Joh, 2019, para. 8). And just because police can use DNA technology in this way, should they be able to? Secondly, the case tiptoes around informed consent for DTCGT consumers. As one *USA Today* article characterized, consumers who submit their DNA to GEDmatch might as well consider themselves "genetic informants" on their relatives, given genetic genealogy's ability to trace family trees (May, 2018). While the consumer themselves might consent to use their genetic profile in a criminal investigation, their relatives have not, and there is no way for those relatives to opt out of the method. "You may never commit a crime. But

how should you feel if your DNA was used to locate a distant relative who did?" (Kolata & Murphy, 2018, para. 19).

Taken together, the concept of individual genetic privacy seems all but abandoned in police's unregulated use of public genealogy databases. Power is taken very literally in this sense: "there aren't strong privacy laws to keep police from trolling ancestry site databases" (May, 2018, para. 14) and in turn, consumers who have participated in GEDmatch and other public genealogy databases are putting "really revealing genetic information...in the hands of law enforcement with no restrictions whatsoever" (Yancey-Bragg, 2019, para. 19). Without court orders and established precedent on how to handle genetic and digital identities, there is little consumers can do to protect their data, and thus "the limits on Americans' genetic privacy are being fashioned by private entities" (Joh, 2019, para. 10). This unregulated point of the consumer testing experience relates back to the biopolitical concept of dataveillance in which interested parties seek to track consumers in order to monitor and modulate consumer behavior. In the case of law enforcement use, data-tracking helps delineate between the criminal and the innocent and represents a practice that macro-level governing entities can employ to control the micro-level consumer.

Genetic genealogy presents an entry point to an entirely different reality of DTCGT, that of minority underrepresentation and race classification. Minorities are "disproportionately represented in state databases" like CODIS and could be targeted by law enforcement through the search of public databases (Hernandez, Kanno-Youngs, & Elinson, 2018, para. 11). However, what law enforcement will find in the search of those

public databases is likely an underrepresentation of minority genetic profiles. Five articles studied in the dataset expressly discussed "the need for more genetic diversity" in DTCGT as more people from minority backgrounds seek to participate in commercial testing that is presently primarily comprised of DNA profiles of European ancestry (Marcus, 2018a, para. 4). A history of scientific racism once disincentivized minority populations from participating in genetic research out of "concern about potential misuse of DNA results and mistrust of health research" (Marcus, 2018a, para. 5). Marcus referenced the "past wounds" that genetic research reopens for minority populations, noting that the history of unethical studies in underrepresented groups requires more dedication now to reassure minorities that it is safe to participate in research and that their data will be cared for properly. The benefit of participating, for gentech companies, means that more tests will be sold and more profit is garnered; for minorities, more testing means more accurate results as more minorities are added to the companies' reference datasets.

Yet, as previously described, invitations for law enforcement to surveil minorities as possible criminal suspects will become more frequent as more profiles are added in the public genealogy sphere. Further, as more consumers buy into DTCGT, the attempt of gentech companies to characterize the social conception of race will become more prominent. At least three articles studied directly questioned whether or not genetic tests for ancestry are "meaningful" or "instructive," because "genetic data is technical and identity is social" (Kolata, 2017c, para. 24; Nelson, 2018, para. 2). At the core of it, ancestry tests are misinterpreting the ways that we as a society discourse about race and

are irresponsibly erring onto and past scientific controversies that claimed race as a genetically determined feature. Genetic reductionism, or the understanding that genes alone are enough to describe human behavior and traits without consideration for environmental or societal influences, is what occurs when "race" and "genes" are conflated with one another (Carter, 2007). Articles in the dataset—especially those written by Kaplan (2019), Zimmer (2018b), Hess (2018) and Kolata (2017c) from *The New York Times*—did well to note that at the deepest, most scientific breakdown of who we are, all humans are comprised of the exact same 99.9% of DNA. What sets us apart is a negligible fraction of genetics that can be traced back to our countries of origin thousands of years ago. This definition represents ethnicity, or the geography of where we came from, and while ancestry genetic testing returns results that claim to dictate ethnicity, "public airings of DNA results often read as an attempt to transcend race by revealing hidden, scientific-seeming insights that expose our 'true' origins" (Hess, 2018, para. 8). The ensuing consequence of these tests, noted in the articles, is a society of consumers who are sure of themselves and their ancestral roots, but are more easily divided when race is politicized in the news headlines. Power/knowledge is therefore exercised over genetic testing consumers who have ascribed their ethnicities to be their identities to create an us vs. them mentality when it best serves the state's agenda. And, from a racialized vantage point, genetic testing strengthens the deployment of race categories by biologizing the conception of race to a purely genetic component that gentech firms embolden in their formations of genetic knowledge. The danger in equating ethnicity and race as the same, or race in a geneticized basis, is the reemergence of a

"new truth about human identity" that errs on a reemergence of scientific racism (Carter, 2007).

Additionally, paying for service represents another code documented in the dataset that establishes the power and biocapital theme. This code was noted in the study any time an article mentioned the financial costs associated with DTCGT: On an everyday basis, "many [genetic tests] are available for under $100, making genetic tests increasingly affordable for greater numbers of consumers" (Marcus, 2018b, para. 3) and especially around the holidays when "some [tests] are going for as low as $49" (Pitzl, 2017, para. 13). The monetization of the genetic testing experience is inherent to the power + biocapital theme, as it reinforces the concept of the bioeconomy. Pay-for-service models are what bolster gentech companies like 23andMe and AncestryDNA in consumer markets; money is what wields prominence and allows companies to develop partnerships that establish influence. A 2019 article from *The Wall Street Journal* exemplified this relationship: "23andMe signed a $300 million agreement last year giving the pharmaceutical company GlaxoSmithKline rights to use genetic data for drug discovery" and it was that "drug development pipeline" that CEO Anne Wojcicki hoped would "power" 23andMe in its 2019 profits (Winkler & Marcus, 2019, para.10 & 1). The partnerships created and the products that stem from those partnerships are what gentech companies use to incentivize consumers' continual engagement with their companies; the offerings represent "a broader, growing marketing strategy" that intends to "tap into the idea that DNA is deterministic, that genetic differences are meaningful" (Herrman, 2018, para. 13).

For example, Herrman writes about AncestryDNA's 2018 partnership with the music streaming app Spotify to create playlist that supposedly delivers the "sound of your DNA"; songs are chosen for the playlists based on the top 5 regions of the world where a consumer's DNA can be traced. Attributing a sonic ability to the very biological property of DNA represents a marketing attempt by gentech firms to make genetic testing into a compelling, personalized form of entertainment; but more critically, it represents a very clear example of how "everything in the world is getting biologicalized" (Herrman, 2018, para. 9). Music is inherent to our cultural identities, and it exists as a form of expression of our innermost thoughts and feelings. We make sense of ourselves often by connecting with the lyrics of songs, and we connect with others through instances when music is a shared experience. To compile the results of an ancestry genetic test into that of a Spotify playlist "provides a free and easily accessible way to experience the limits of DNA testing in the pursuit of self-knowledge" (Herrman, 2018, para. 17). For the subject of the datafied consumer, Spotify-AncestryDNA playlists are like souvenirs of the genetic testing experience that relate back data's liveliness and sensemaking capabilities. From the vantage point of the valuable consumer, playlists also represent how AncestryDNA will "trade in the prestige of genomic science…in order to sell more stuff" (Herrman, 2018, para. 13). Consumers' data, their money, and their human DNA are situated in the genetic testing experience as the biocapital that gentech companies leverage to strengthen their market positions through attractive products and offerings that compel consumers.

The final code contained within the theme of power and biocapital is that of government involvement in the DTCGT experience. This code was characterized by the

ways that articles under study referenced government entities, e.g., the military, IRS, the FDA, and law enforcement, and the regulations and/or policies they instate to wield control over 23andMe and AncestryDNA. This code was established from the very first article studied, which highlighted the FDA's 2017 decision to "for the first time…allow a company to sell genetic tests for disease risk directly to consumers" (Kolata, 2017a, para. 1). The decision represented "a turnaround for the agency, which had imposed a moratorium in 2013 on disease tests sold by the company 23andMe" (Kolata, 2017a, para. 2). The moratorium referenced had ordered 23andMe to stop the sale of their DTCGT until the technology had received marketing authorization from the FDA. At the time, the FDA considered DTCGT to be an unclassified medical device, and they had questions about the "analytical and clinical validity" of the tests. For the four-year period from 2013-2017, the FDA and 23andMe worked in cohort on the regulatory premarket review process until the FDA was satisfied with the data provided by 23andMe and deemed that the tests "can be used safely without professional supervision" (Yim and Chung, 2014). In 2017, as news of FDA approval made its way throughout media, *The Wall Street Journal* picked up the story and announced the FDA's decision as "a turning point in the democratization of personalized medicine" (Huber & Howard, 2017, para. 1).

A year later, in March of 2018, the FDA extended its approval of 23andMe to offer home tests for three breast cancer mutations—a position that just one year earlier, the FDA said they would not allow as "diagnostic tests [such as a genetic test for BRCA] are often used as the sole basis for major treatment decisions" for which a medical provider was required to initiate with a patient (U.S. Food and Drug Administration,

2017). Although a switch in positions, *The Wall Street Journal* reported that because of the FDA's rigorous review of 23andMe from 2014-2017, it was able to "more quickly approve the cancer risk tests" because it had "assessed the scientific precision of 23andMe genetic work in general" and deemed it to be "safe and effective" (Burton, 2018, para. 6 & 12). As Burton went on to describe, the presidential election of 2016 was also a significant catalyst to the FDA's decision to allow 23andMe limited medical testing, given the shifting regulatory agendas between Presidents Obama and Trump: "Under the Obama administration, the FDA had focused its concern on lab-test accuracy and safety…The emphasis has shifted now toward simplified approvals of innovative tests. After President Donald Trump's election, the Obama FDA backed off from lab-test regulatory plans," which therefore spurred 23andMe's FDA approval as it exists today (Burton, 2018, para. 14–15).

The transition between presidents demonstrates the power of changing leadership and policy agendas, as well as the power that both the executive and legislative branches of government hold over regulatory entities who are involved in DTCGT policymaking. This was furthered in the dataset by mentions of the Federal Trade Commission, which "has the ability to police unfair and deceptive business practices across all industries" in the event that consumers question "how to protect and delete [their] data" if they suspect a gentech company has misused or improperly shared with third-parties (Ravenscraft, 2019, para. 5 & 1). And, the 2019 decision by the IRS tax agency to "greenlight tax breaks for buyers of 23andMe genetic tests" represents again how consumers are provided with incentives to engage with the consumer genetic testing industry (Rubin &

Marcus, 2019). The IRS ruling determined that the "health portion of 23andMe's test is medical care for tax purposes" meaning that "people with tax-advantaged flexible spending accounts or health-savings accounts…can use that money to purchase the kits" (Rubin & Marcus, 2019, para. 5 & 7).

These examples of government involvement in the testing experience are significant to the subject position of the valuable consumer because they situate the consumer as a source of free, clinical labor for the powerful entities that oversee DTCGT. 23andMe and Ancestry rely on consumers to purchase their testing so that they can source more genetic data to conduct research and broker research partnerships. Governing entities, too, have a vested interest in privatized technologies so that they can get more for less; partnering with private industry allows government to delegate their research agendas while lessening the burden of research costs on their budgets. For this purpose, consumers and the genetic data they provide stand as the commodities of exchange that ensure the consumer testing experience and enable these entities to progress. Technically, consumers are research participants who contribute to the advancement of genetic knowledge, though they are not credited for their contributions *and* they have to pay to participate in the research experience—two qualities that distinguish privatized science from traditional tenets of academic research.

CHAPTER FOUR

DISCUSSION

The intent of this study was to examine the discourses that are present in the news media on DTCGT, with special attention paid to the ways that news articles engage with issues of ethics in consumer genetic testing technology. The findings show that DTCGT is, indeed, the "unregulated wild west" (Yancey-Bragg, 2019) due in part to the novelty of consumer testing technology, but also due to the privatized nature of testing that thrives on corporate profits. DTCGT is riddled with unique scenarios that push the bounds of self-curiosity in order to deepen consumers' understandings of themselves, their health, and their ancestral roots, but that curiosity does not come without equally as many scenarios that cause me to pause and ask how gentech companies can support consumers' genetic journeys while also helping to safeguard the testing experience.

When I first set out to complete this study, I did not know what themes and discourses I would find in the articles studied. Being a former student of genetics, I was personally concerned about the ramifications of DTCGT, but even I did not expect for these ramifications to be highlighted as frequently as they were in the sample studied. Ultimately, RQ1 (what discourses are present?) and RQ2 (to what extent are ethics represented?) reaffirm one another, in that, discourses on DTCGT in news media are defined by the social, political, and technological constructs that precede (and become emboldened by) genetic testing technology. When we ask whether medical professionals should be included in the consumer testing experience; whether tests are "clinically and

analytically valid"; whether the risk of knowing our genetic predispositions is worth the ensuing anxiety; whether data should be shared with other for-profit companies; and so on, we are engaging in critical dialogue that attributes meaning to genetics as a science and DNA as the carrier of information that dictates how humanity evolves. For consumer genomics companies to continue operating without engaging in these discursive practices would be a disservice to the history of geneticists and scientists who first characterized DNA and its tangential biological mechanisms. It would also be a disservice to the self-managing, datafied, valuable consumer at the center of the testing experience.

Therefore, an obvious outcome to this study would be a call for regulation on personal genomics companies to address issues of consumer privacy, law enforcement use, third-party sharing of data, and others highlighted here. The reality is that 23andMe and AncestryDNA function in a novel, loosely defined market that creates regulatory challenges. Is DTCGT a wellness product? A medical device? A technological innovation? The FDA's premarket review of 23andMe treats DTCGT as a medical device because "it is intended for use 'in the diagnosis of disease or other conditions or in the cure, mitigation, treatment, or prevention of disease, or is intended to affect the structure or function of the body'" (Yim & Chung, 2014). But, what about ancestry genetic testing that serves the purpose of recreation and entertainment or of quelling the consumer's interest in non-medical properties of their DNA? There is a great need for clarification on how this technology should be defined if any policy progress is to be made on issues of ethics. Although I will be the first in line to advocate for greater transparency and

protections on what testing is and how data are handled, until DTCGT can be defined among stakeholders, its regulatory pathway remains unclear.

Still, for all the ethical lines of inquiry that this study takes, there is a tantamount acknowledgement to draw from the data: that is, DTCGT has placed genetics on the agenda, in public life and in consumers' personal lives. The explosion of the personal genomics industry in the late 2010s garnered interest from millions of people across the world about their genetic selves: the health that they inherited from their families and the geographic locations from which those families began. While the accuracy of DTCGT is contested—because of proprietary algorithms and genome panels that provide only a snapshot of all the possible genetic markers for a trait—the benefit of DTCGT for genomic literacy is something to be celebrated. Never before have humans been so engaged with the science of genetics—how traits are passed down through generations, how mutations arise, or how DNA can be traced geographically—for no reason other than sheer interest. It should be an endeavor of private testing firms to harness interest into campaigns for genomic literacy awareness that not only make their practices more transparent to the public but continue to persuade and educate consumers on genetic sciences.

Theoretical Contributions and Implications

The framing of DTCGT in the articles studied helps to garner insights that further the theories and frameworks outlined in this study: those of risk and uncertainty, datafication and the "quantified self", and governmentality and biopolitics. As a technology premised on testing for genetic predispositions to disease, DTCGT is riddled

with contexts that create uncertainty for the consumer. Brashers (2001) theorized uncertainty as a multilayered, interconnected, and temporal experience that prompts various considerations from the person at the center of the uncertain outcome. The articles studied nodded to this notion, as DTCGT elicits questions from the consumer about genetic risk, accuracy of results, and informed consent throughout the testing experience and, in some cases, even before testing has been ordered. In the example of health genetic testing, consumers are charged with considering whether it is beneficial to their well-being for them to know about their genetic predispositions in the first place or whether ignorance really is bliss and the choice to remain uninformed will give them greater peace of mind. Yet, if a consumer does proceed with testing, results might conjure up feelings of anxiety or worry for themselves as the at-risk individual or for their loved ones who might inherit the same predispositions. The process of receiving risk information, appraising the results to gauge their meaning and significance, and deciding a planned behavior to negotiate those uncertainties affirms Brashers (2001), as well as Affifi and Weiner's (2004) theory of motivated information management. The understanding that DTCGT is an uncertain experience should only heighten calls for private gentech firms to be more transparent and instructive in how they analyze and convey genetic risk information.

Additionally, this study supports theories that genetic risk is socially constructed and that it perpetuates society's divide between the chronically ill and the worried well. Consumers that are drawn to genetic testing for health reasons are participating in the present model of healthcare that prompts the continual, constant search for disease and

any symptoms that might cause disease later on. If we are always on the lookout for a danger to our health, there is a greater likelihood that we will find something to worry about—and risk assessments provided by DTCGT are no exception. Before DTCGT was available to consumers, genetic testing as a health mediator was mainly reserved for conditions and symptoms that stumped medical professionals. Genetic testing was not regular procedure; but now, more than 26 million consumers have received risk information from private gentech firms, which places "risk" in a more salient context. The focused emphasis on genetic risk in light of DTCGT stands as an example of how advancing technologies—and societal discourses about those technologies—can amplify the significance granted to "risk" in health decision making, which supports its social construction. Moving forward, there is a need for scholars to theorize realistic ways to help consumers process genetic risk information, given that DTCGT is present and ongoing. Arguing for greater methods of uncertainty reduction or information seeking can be problematic because more information might be overwhelming, and excessive explanations of risk could snowball into heightened feelings of anxiety. As such, it is important that risk be conveyed responsibly at the first instance when a consumer receives their genetic testing results, so as to quell any negative emotions after the fact.

The consequences of the datafied consumer represent another implication for theories that engage in the liveliness of data (Lupton, 2017), the network society (Levina, 2010), and acts of dataveillance (Van Dijck, 2014). Articles here presented clear descriptions of the transformation of saliva into genetic data. The possibilities of what those data can reveal—in research, as things to be experienced recreationally, and as

commodities that further corporate profits—are possibilities that that preceded critical thought on how genetic data should be handled. In the future, theories would benefit from inquiry that imagines datafication as a central precept of the DTCGT experience and works to explicate the meanings of data in all the spheres they end up in, e.g. social networking websites, law enforcement investigations, and third parties like Promethease, Spotify, and GEDmatch. There is a need to understand how consumers derive their identities at least in part from their understandings of their genetic data, and how identities are further challenged when genetic testing results do not align with their conceptions of self. And, there is especially a need to lessen the possibility of surveillance of genetic data for nefarious purposes by powerful entities.

Finally, to the extent that the articles positioned DTCGT as a newfound tool for monitoring health, this study engages in biopolitical understandings of DTCGT as a form of governmentality. Neoliberal extensions of Foucault's (2010) work on governmentality demonstrate that individuals must be in pursuit of healthy bodies in order to maintain moral order within a society. As a topic described in the articles, DTCGT was framed as a technology of the self that consumers employ to attain healthy status by adjusting their behaviors in response to testing results. Yet, to what degree consumers actually make those behavior modifications was not clearly presented in the articles and thus elicits further inquiry. Relating back to the uncertainty management process, consumers might choose not to ascribe meaning to testing results if risks are mild to moderate; therefore, the extent of the self-managed consumer depends on a construction of risk that is too dangerous not to ignore. The threshold for ascribing action to testing results could further

resolve the concept of the biological citizen in DTCGT. Additionally, the lack of minority representation in consumer genetic databases signals to a disconnect between the state and its minority community. Scholars would do well to focus more attention on how lower-income and culturally marginalized individuals are affected by a history that has excluded them from scientific research—one that disproportionately affects them now when law enforcement gets involved in work with genetic testing. Finally, the power asymmetry denoted here between macro governing bodies, meso corporate testing firms, and micro-level consumers is a relationship that cannot be diminished as DTCGT advances in the coming years. Relating back to Foucault's power/knowledge concept, the discourses contained in this study do more than explicate the varying nuances of DTCGT; they also serve as examples of how power can be distilled hierarchically and how, in the establishment of consumer genetic testing firms, knowledge can be gained from entities that hold power. AncestryDNA and 23andMe have created a baseline for knowledge of genetic traits that millions of people have encountered for the first time through the establishment of DTCGT. The charts, graphs, and interactive maps provided by these companies to display their results helps consumers to understand how DNA translates into diseases and ancestral relationships; the companies have, at once, analyzed very personal information given freely by testing consumers and also repurposed that information as a field of knowledge. For Foucault, power/knowledge is an inseparable couplet because power and knowledge reinforce each other in continually developing constructs, of which, DTCGT is one.

Likewise, power/knowledge and the historical and cultural foundations on which DTCGT is built cannot be separated from the conversations had about genetic testing. The discourses studied in this thesis are productive not only because they highlight the varying ramifications of DTCGT that require careful thought and consideration, but because they highlight how powerful entities can foster qualities of self-management and control in the pursuit of healthy lives and citizens. Discursive practices help to shape the subject of the genetic testing consumer not as passive objects of biopower, but as consumers who have wielded knowledge at their fingertips to make informed choices for their genetic health. There is an agency to the genetic testing consumer that is underscored by the discourses on DTCGT. The marketability of health will only continue to develop as technology advances; thus, emphasis must be given to narrow the divide between the data rich and the data poor to ensure more transparent discursive practices.

Limitations

This study sought to investigate two research questions that aimed to capture both the discourses and ethical issues of DTCGT that are present in news media. While I believe this study achieved what it set out to do, it is not without its limitations or areas for improvement. First, this study was narrowed down to news media from just three sources, *The New York Times, The Wall Street Journal,* and *USA Today*. While I certainly feel as though I reached theoretical saturation in the 50 articles I examined, this study excludes a number of other possible news sources that could have expanded the topic of DTCGT even further. As an entrance to understanding DTCGT, I believe the three sources chosen served their purpose and provided a comprehensive sampling of the

varying issues of ethics that stem from consumer testing technology; however, other accounts provided by technology and popular news media, podcasts, documentaries and more could work to further triangulate and crystallize the data provided. Additionally, the coding process employed here presents another possible limitation to this work. I used the constant comparative method to identify the themes outlined here, but these themes only tell part of the story of DTCGT. In line with the tenor of qualitative work, this study describes only the themes that emerged to *me* as the researcher; others who review these news articles might capture other features from the data.

Future Directions

As evidenced by the limitations, this study serves as just one way to engage with data on DTCGT. In my work, I have now completed an interview study with genetic testing consumers to gauge their motivations and understandings of testing risks, as well as the present discourse analysis to better capture what those risks and ethical issues of testing are. An interesting follow-up to this study could shift the testing conversation to other subjects involved in the personal genomics industry, such as the medical professionals and genetic counselors who help consumers interpret testing results or the policymakers that set the regulations on DTCGT. Participant interviews with genetic counselors could illuminate how medical professionals help their patients make sense of consumer genetic data, whereas a content analysis of policy briefs, governmental press releases, and legislative rulings could highlight the varying perspectives and considerations that policymakers include when instating regulations on the testing industry.

Furthermore, the more concerning outcome of this present study are the findings on consumer genetic privacy and third-party sharing of genetic data. More work needs to be done by ethicists, law scholars, geneticists, and social scientists to determine recommendations for policymakers and corporate entities in order to protect consumer data once it is shared with a gentech company. De-identification and aggregation of genetic data is not enough; allowing police unregulated reign over public genealogy databases is not okay; contributing consumer genetic data to a greedy pharmaceutical industry is unprincipled; discriminating against the genetically at-risk through insurance coverage is unacceptable—and more studies are needed to help shape the course of DTCGT and reel in these concerns in the future.

Finally, at the outset of this thesis project, the COVID-19 viral pandemic emerged, and scientists across the globe responded by opening their labs and transitioning their research agendas to studying the coronavirus' transmissibility, biology, and epidemiology. 23andMe and AncestryDNA have joined in on COVID-19 research by offering to analyze consumers' DNA for genetic differences that determine why some COVID patients get sicker than others (Robbins, 2020). The two private firms are seeking to assemble a vast trove of study participants in order to contribute to a worldwide genome-wide association study of COVID-19 to search for genetic markers that might be key in treating the virus or developing its vaccine. Given that 23andMe and AncestryDNA represent the corporate arm of a broader scientific community of research hospitals and academic labs, their participation in COVID-19 research presents a fascinating line of inquiry for future studies to addresses. Namely, the assemblage of

relationships between privatized science, medical settings, academia, and government organizations demonstrates a powerful moment in scientific discovery when research agendas merged, and scientists worked in cohort to resolve an emergent threat to public health. Examining the impact of DTCGT in how COVID-19 research progresses could deliver insights into how necessary (or not) private gentech firms are to the advancement of science.

CONCLUSION

DTCGT has emerged over the past 5-10 years as a "technology of the self" that consumers seek to deepen their genetic self-knowledge. The ability of consumers to submit saliva samples to private gentech firms for analysis into their genetic makeup represents a modern instance of datafication in the conversion of DNA to genetic data. As genetic data are analyzed, shared, and repurposed in the consumer testing environment, there exists opportunities for powerful entities to derive value from those data for uses in drug development, disease research, law enforcement investigations, and the creation of products that enhance the consumer testing experience. 23andMe and AncestryDNA represent two of the fastest growing private gentech companies that have established the personal genomics industry through tests that characterize disease risk and genetic genealogy. Using a Foucauldian discourse analysis of news articles about 23andMe and AncestryDNA, this study demonstrated that genetic testing consumers seek to develop their genetic knowledge through neoliberal perspectives that position consumers as individually responsible for managing and understanding their genetic outcomes. To the consumer, genetic data are viewed as a sources of information, but to private gentech firms and government entities, data are forms of biocapital that sustain a bioeconomy, of which, consumers form the foundation. The advent of the consumer genetic test highlights the need for greater studies into the communication of genetic risk and uncertainty, as well as policy work that articulates the extent of consumer genetic privacy and third-party sharing of genetic data.

APPENDIX

Constant Comparative Codes and Themes

Broader Theme	Code	Prevalence
Biocitizenship	Lack of medical supervision	19
	Accuracy of tests	17
	Risks and uncertainties about testing or disease	20
Datafication	Datafication of genes	13
	Third-party sharing of genetic data	19
	Life insurance / long-term care discrimination	5
	Privacy concerns	28
Power + Biocapital	Law enforcement use	15
	Minority underrepresentation / race	16
	Paying for service	11
	Government involvement	36

Table 1. The initial round of open coding generated the codes denoted in column 2 and their prevalence, i.e., the number of times the codes appeared across 50 articles, in column 3. Broader themes in column 1 represent how codes were grouped in the second round of coding.

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