AN ETHNOGRAPHY OF DIRECT-TO-CONSUMER GENOMICS (DTCG): DESIGN ANTHROPOLOGY INSIGHTS FOR THE PRODUCT MANAGEMENT OF A DISRUPTIVE INNOVATION

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Direct-to-consumer genomics (DTCG) health testing offers great promise to humanity, however to date adoption has lagged as a result of consumer awareness, understanding, and previous government regulations restricting DTCG companies from providing information on an individual's genetic predispositions. But in 2017 the broader DTCG market which also includes genealogical testing demonstrated exponential growth, implying that DTCG is starting to diffuse as an innovation. To better understand the sociocultural forces affecting diffusion, adoption, and satisfaction, qualitative ethnographic research was conducted with DTCG genealogy and health consumers. The data was qualitatively analyzed using thematic analysis to understand the similarities and differences in beliefs, attitudes, intentions, and mediating factors that have influenced consumers. Design anthropology theory and methods were used to produce ethnographically informed insights. The insights were then translated into actionable product management and business strategy recommendations.

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CHAPTER 1

INTRODUCTION

Genomics, or the study of all of the genetic information of a species, is a field of science that has far-reaching applications in medicine, biotechnology, anthropology and other social sciences (Barnes and Dupré 2008). Since the completion of the Human Genome Project (HGP) in 2003, genomics has been touted by the medical and biotechnology community as having the potential to "enable medical researchers to develop improved diagnostics, more effective therapeutic strategies, evidence-based approaches for demonstrating clinical efficacy, and better decision-making tools for patients and providers" (National Human Genome Research Institute 2015, para. 15). However, adoption within clinical settings has been slow given that most physicians have limited genetics and genomics education and training in their undergraduate and graduate educational programs and clinical training (National Human Genome Research Institute n.d.). To address this gap in the market, private companies have started to sell genetic testing directly to consumers. This model, known as Direct-to-Consumer genetics (DTCG), is progressing more rapidly than genomics in the clinical setting, but it too is still in its infancy.

In 2017 the number of people who have taken a DTCG test nearly doubled compared to 2016, pushing the total number somewhere close to an estimated 12 million (MIT Technology Review 2018). However, not all of the growth is for health purposes. In fact, the majority of the growth is happening for genealogical reasons led by Ancestry's DTCG test. AncestryDNA was released in 2012, and in the first three years of business within the genetic genealogy space, Ancestry sequenced over one

million partial genomes. Since 2015, AncestryDNA has grown exponentially. As of April 2017, Ancestry had reached 4 million users, with a fourth of the genomes being sequenced between January and April of that year (Ancestry 2017). On November 6, 2017, they posted on their website that they had reached 6 million genomes in the DNA database (Ancestry 2017). Then, as if the previous growth wasn't impressive enough, they sold roughly 1.5 million kits in quarter four of 2017, about triple the same period of the prior year, putting them somewhere above 7.5 million genomes in their database, which would represent about 62% of the total DTCG US market. (Forbes 2017).

But all of this growth, impressive as it is, does not help achieve the hopes and dreams of the medical community because only a fraction of the US population has taken a genetic health test. In fact, in a 2016 UBS Securities LLC survey of 1,000 people representative of the US population, they found that only 5 percent said they had been tested on their initiative, and 50 percent said they were likely not to get tested (UBS Securities LLC 2016). Similarly, in a 2016 Rock Health survey, 36 percent of consumer respondents stated they had not taken a genetic health test because there is "no need" and another 27 percent because they are "unaware or need more information" (Rock Health 2016, 21). However, the ever-increasing popularity of genealogy DTCG tests points seems to imply that there is a market in the making for genetic health testing. The question is, therefore, why, how, and when will consumers adopt DTCG health tests?

To explore this question, I conducted remote ethnographic research with consumers who have previously used DTCG genealogical tests, and those who have used DTCG health tests through Sequencing.com. The data was collected through

qualitative research sessions that involved phone-based semi-structured interviews for genealogical consumers and screen sharing-based interviews and observations for Sequencing.com users. The data was coded using thematic analysis and analyzed in the context of theories from anthropology, sociology, communication, and information systems that have been used historically to understand the diffusion and adoption process. The theoretical frameworks and models leveraged in this study include, but are not limited to, the Diffusion of Innovations Theory, the Technology Acceptance Model, communication flow models, and theories related to disruptive innovations.

The qualitative data was mapped to these theories to specifically understand the beliefs, attitudes, behavioral intentions, and other motivating factors that influenced adoption. The theories were also leveraged to gauge other dimensions of the diffusion and adoption process as it relates to perceived usefulness, ease of use, and risk. Furthermore, the research sought to build on these findings by defining the persona of current adopters. Finally, the research sought to identify gaps in the product offering, with the objective of developing some potential features for a product roadmap. The goal of these objectives was to produce actionable ethnographically informed insights that Sequencing.com can use to define their target market and create a whole product concept, that is mutually beneficial to their business model, as well the consumers that adopt the innovation.

CHAPTER 2

BACKGROUND

The following chapter provides background information about the client, Sequencing.com, their need, the deliverables, the research process and how I came to work with Sequencing.com. I will then situate their need in the broader sociocultural context by discussing the history of DTCG market for both genealogy and health. I will close by discussing some of the concerns raised by the science community in the context of recent changes to the regulations that govern the DTCG market.

2.1 The Client: Sequencing.com

Sequencing.com is a software platform and application (app) marketplace that allows users to upload, store, and analyze genetic data, including partial and full genomes. Sequencing.com was created with the goal of making genetic information accessible to the world by making genetic code incredibly easy to work with and understand (Sequencing.com 2018). To accomplish this, the platform allows users to upload genetic data. The data can come from any DTCG testing service such as Ancestry.com, 23andMe, and FamilyTreeDNA, as well as from clinical labs.

Users are then able to analyze their genetic information using apps that were either created by Sequencing.com or other third-party app developers who have published their apps in the Sequencing.com app marketplace. The apps that Sequencing.com created produce results that are directly accessible from within the platform, while the apps that other developers created often require the users to create an account at the producer's website to retrieve their results. The apps are either free

or have a cost. The apps which have a cost associated with them may have a one-time fee or a per use fee. Costs range from $0.99 to several hundred dollars.

Currently there are 46 apps, making Sequencing.com the largest app marketplace for genetic testing. The apps are classified into eight categories: bioinformatics, clinical, enterprise and lab, research, mobile, app development, education, and wellness. The bioinformatics, clinical, enterprise and lab, and research apps are quite niche oriented as they are primarily targeted to individuals with a background in genetics. This is best illustrated by the names of the apps, which include examples such as Imputation Analysis, Convert rsids to Coordinates, Variant Effect Predictor, and BowTie2 Aligner. The apps in the mobile and app development category are targeted at app developers as proofs-of-concept (POC) for building apps on top of genetic data, but could be utilized by any user of Sequencing.com. The one app in the education category is a genealogy app, which again could be used by all users. Lastly, there is the wellness category which can easily target all users of the platform be it a bioinformatician, healthcare professional, or a consumer, but it is the most targeted to the consumer category. This is best illustrated by some of the app names which include Wellness and Longevity, Healthy Heart, Skin Health Optimizer, Age with Strength, Male Pattern Baldness, and Arthritis Prevention.

Some of the apps run directly within the platform such as those created by Sequencing.com, while others run elsewhere. For the apps that run elsewhere, they could be accessible as web apps or mobile apps for use on mobile devices, such as phones, tablets, or watches. When the apps are running outside of the Sequencing.com platform, they make use of the Real-Time Personalization™ (RTP)

technology which is an application programming interface (API) that allows app developers to pull genetic data from Sequencing.com, assuming an authorized purchase was made by a Sequencing.com customer. If RTP is used, app developers can simply analyze the genetic data to produce results, or they are able to combine other real-time data with the genomic data to produce customized recommendations to the consumer. This latter point is illustrated by one of the mobile app POCs Sequencing.com developed. The app is called Weather My Way + RTP, and combines real-time weather data with genetic data related to skin and cancer. The app works by locating the consumer geographically based on the geo-coordinates of their mobile device, checking the weather, comparing the weather against predispositions for skin problems like melanoma, and making suggestions for use of skin products such as sunblock (Sequencing.com 2018). This POC is of particular interest because it is essentially a smart app that is personalized to the user in an effort to create an easily actionable recommendation; and, as such, in many ways represents the future of genomics and the essence of why Sequencing.com was started.

Sequencing.com was founded by Brandon Colby, an expert and entrepreneur in the field of personal genomics. Dr. Colby holds an MD from the Mount Sinai School of Medicine, an MBA from Stanford University's Graduate School of Business and a BA in Genetics with Honors from the University of Michigan. Prior to the launch of Sequencing.com, Dr. Colby practiced personalized preventive medicine in Los Angeles. Dr. Colby is the author of the popular book *Outsmart Your Genes* and has invented numerous patent-pending technologies that improve the analysis, interpretation and actionability of whole genome sequencing data (Sequencing.com n.d.).

Given Dr. Colby's interest and vision, the growing market of genetic genealogy, and the recent FDA decision to allow 23andMe to sell genetic tests that advise consumers about their potential disease susceptibilities, Sequencing.com would like to pivot from their initial focus on academic researchers, healthcare professionals, bioinformaticians, and app developers to attract and retain consumers of the popular DTCG genealogical testing services. As a result of this, it is looking to understand better the beliefs, attitudes, intentions, and other motivating factors that may influence genealogical consumers to take health tests, as they represent potential customers of Sequencing.com. Furthermore, Dr. Colby would like to understand better what has or has not been working well for the consumers who have already adopted Sequencing.com, so that improvements to the product can be made.

Sequencing.com became the client of this project as a result of an existing consultative engagement between myself and the company. Previously I have conducted a heuristics evaluation of the website, and the opportunity grew out of that previous engagement. Like that previous engagement, this project worked quite well for both parties. Sequencing.com was very accommodating and supportive, and I have provided them with some early suggestions that they have implemented to their benefit already. One change that occurred throughout the process involved the recruiting. The research initially planned to recruit 10 participants for the health group, but given complications in attracting willing participants, the health group ended with nine. Another change involved a minor shift away from the research question related with behavior change, as it became apparent that unpacking that was difficult as the participants did not seem that willing to discuss that on a deeper level.

The deliverables provided to the client included a current model of adoption of DTCG health testing; a proposed ideal target market, as well as product management and business strategy recommendations. The model of adoption was mapped out across the five stages of adoption from the Diffusion of Innovations Theory and incorporated dimensions from the Technology Acceptance Model. It also incorporated influencing sociocultural variables uncovered in the course of the research. The model demonstrates how mediating factors across these theories affect the adoption process and lead to certain outcomes. The ideal target market was based on important factors that influenced diffusion and adoption, and led to positive user experiences. The business strategy recommendations involved short term objectives, and a long strategic intent. The short-term objectives were suggested in the spirit of creating a whole product concept that will serve the needs of different consumer groups as the product progresses along the adoption curve. The strategic intent recommended was to become the *hub of consumers' genetic life*.

2.2 DTCG Genealogy Tests

Direct-to-consumer genetic tests are marketed directly to consumers via television, print advertisements, or the Internet, and sold to them directly for use at home, typically without the involvement of a medical professional or an insurance company. The tests are often sold by companies that exist outside of the traditional healthcare sector. Upon purchase, a test kit is mailed to the consumer which allows them to collect a DNA sample. The sample can be collected many ways, but most often involves spitting saliva into a test tube or swabbing the inside of the cheek and then

placing the swab into a solution to transfer the cells. Either way, the sample is collected by the consumer in a sealable test tube which is typically placed in a biosafety bag that goes inside a pre-paid box and mailed back to a laboratory. At the lab, the DNA is sequenced, which usually takes between one month to a few months. When the results are ready, the company contacts the consumer, typically by email, and usually displays the results on a password protected website (US National Library of Medicine n.d.).

The rise of the DTCG health testing model is a relatively new phenomenon, only becoming a possibility for consumers in the late 1990s and early 2000s as sequencing and analysis costs started to drop. At this time, the first tests that became available, and popular, were genealogy tests. This process of creating awareness and popularization started with surname research by Bryan Sykes, a molecular biologist at Oxford University. His study sought to understand whether genetics could be used to assist genealogical research. The study, which looked at only four markers on the male chromosome, proved useful (Sykes and Irven 2000).

Following this, in March of 2000, Family Tree DNA (FTDNA) launched eleven marker Y-Chromosome STR tests and HVR1 mitochondrial DNA tests that expanded on the Sykes surname project (Wikipedia 2018). With this test, and FTDNA's online surname database, genetic genealogy research moved out of academia and into the publicly available commercial space of capitalism. This was followed the same year by Oxford Ancestors, a spinout from Oxford University, based on the Sykes surname project (Oxford Ancestors n.d., International Society of Genetic Genealogy 2017). These two publicly available tests marked a turning point, and after their release the flood gates broke open. By 2003, the field of DNA testing for genealogical purposes was

deemed to have arrived by Jobling and Tyler-Smith in the Nature Reviews Genetics that year (International Society of Genetic Genealogy Wiki 2015). They made this claim based on the fact that many more consumers were starting to buy tests, and more tests were becoming available from other private companies, a trend which would only continue.

By late 2007, there were many new private players in the industry such as the National Geographic's Genographic Project, African Ancestry, DNAPrint Genomics, Sorenson Genomics, Genomac, and Relative Genetics, as well as FTDNA and Oxford Ancestors. Together, these private DTCG companies had sequenced an estimated 550,000 to 650,000 genomes for genealogy purposes, with bullish estimates ranging between 600,000 to 700,000 (Bettinger 2007). Since 2007, this trend has continued, supported by ever decreasing costs in the sequencing space, as well as other technology costs associated with storing and delivering the results. For example, the cost to sequence a whole human genome in 2008 was almost $10 million. In mid-2015, it was just above $4,000, and by late in 2015 it had fallen below $1,500. Today it is close $1,000 (National Institute of Human Genome Research 2016).

Making these tests even more affordable is the fact that a whole genome sequence is typically not carried out for genealogical purposes. In fact, a very small portion of the entire genome is often sequenced by one of the three common types of tests: mitochondrial, Y, and autosomal. Mitochondrial DNA (mtDNA) tests, trace a person's matrilineal or mother-line ancestry using the DNA in their mitochondria. Y-DNA tests, while more expansive than the mitochondrial tests, still only look at one chromosome, the Y chromosome, out of the 23 total human chromosomes. Autosomal

DNA tests look at any DNA that exists within the 22 non-sex chromosomes, as opposed to the sex chromosomes. Typically, these tests look at known single-nucleotide polymorphisms (SNP), which are changes to a single nucleotide in a DNA sequence. The number of SNPs reviewed differs by company, but is often in the range of 500,000 to 750,000 SNPs. (International Society of Genetic Genealogy 2017).

When taken together, the rapidly falling costs of sequencing, combined with the practice of carrying out only partial sequences, has led many more players into the market. In fact, by 2016 there were an estimated 74 companies providing DTCG tests for ancestry purposes (Phillips 2016). But despite there being an estimated 74 companies, only a few seem to be leading the way today based on acquisitions, diversification, partnerships, and/or venture capital. AncestryDNA for example, which only started its DTCG testing service in 2012, has since acquired other ancestry companies including Relative Genetics, GeneTree, and Sorenson Molecular Genealogy Foundation. These acquisitions, paired with the existing market share Ancestry had in the genealogical family tree space, allowed them to sequence over one million customers in their first three years, and 12 million by the close of 2017 (MIT Technology Review 2018).

Similarly, Gene by Gene, founded in 2000 as Family Tree DNA, later diversified to create the brands DNA Traits and DNA DTC for the purposes of offering other types of DTCG tests, such as a whole genome test. They have also acquired other ancestry companies along the way, including DNA Heritage and DNA-Fingerprint, and have partnered with National Geographic to provide testing for National Geographic's global genetic survey, the Genographic Project (Petrone 2015).

23andMe, a latecomer to the DTCG space like AncestryDNA, is also worth noting for it epitomes the Silicon Valley model of DTCG. Started in 2006 by Anne Wojcicki, an ex-investment banker looking to disrupt conventional business models of health care, 23andMe raised $8.95 million in 2007 from a number of high-powered investors, including the biotechnology powerhouse, Genentech in South San Francisco and Google, whose co-founder Sergey Brin, was married to Wojcicki from 2007 to 2015. Using this capital, 23andMe was able to rapidly scale with less concern for breaking even in their early years. In October 2009, two years after their first round of investment, 23andMe only had 30,000 active genomes in its database (Patch C 2009). But given their various rounds of funding, including their most recent raise of $250 million announced in September 2017, their database grew to include 2,000,000 genomes by October 2017, a change of 6566.66% over eight years (Hayden 2017).

The competition that these acquisitions, diversification, partnerships, and/or venture capital unleashed, has created a race to the bottom when it comes to the cost of selling genealogical tests. Whereas in the early 2000s, DNA tests were many hundreds of dollars, today you will often find an autosomal kit priced around $100 or less when on sale. In fact, during the 2017 week of Black Friday sales and the end of year holiday sales, when the DTCG companies are fiercely competing for business, most autosomal kits were selling near the $70 price point. This, in turn, has led to many more consumers buying the kits, across all 74 DTCG companies, particularly the leading brands of AncestryDNA, 23andMe, Gene to Gene (FTDNA), and National Geographic's MyGeno which is now powered by a recent startup, Helix.

2.3 DTCG Health Tests

Riding the wave of decreasing costs and building on the success of DTCG consumer genealogical testing, companies started to emerge to offer health testing outside of the clinical setting. The first wave of health tests that emerged primarily fell into the predictive category of DTCG health tests. At this time, there were three companies offering tests in that space (Williams-Jones 2003). Following this, in 2002 susceptibility tests started to hit the market providing information on gene variations that may predispose an individual to develop common health conditions or have certain traits. Common examples included genetic variation in drug response, clotting disorders, fetal sex, hereditary hemochromatosis and nutrition (McBride, Wade and Kaphingst 2010). Sciona, an example of a DTCG company focused on nutrigenetic testing, analyzed consumers' DNA to look for genes related to nutrient metabolism and provided personalized dietary recommendations (Hogarth and Saukko 2017).

Building on the success of these earlier companies 2003 to 2007 saw an explosion in the market with a fourfold increase (14 to 53 tests) in the number of available DTC genetic tests (Goddard, et al. 2009). Within this new group of companies were Navigenics and 23andMe. Both were very well capitalized compared to their competitors. Both were also respectively well aligned to the leading DNA sequencing chip companies, Affymetrix and Illumina, who produced chips that were used to rapidly sequence portions of genomes. These chips were helping to fuel genome-wide association studies in which hundreds of thousands of genetic variants are examined in large numbers to detect gene-disease associations, which in turn was fueling the ever-increasing number of susceptibility tests that could be offered to consumers. Given this

opportunity, Affymetrix and Illumina were also looking to move into this new DTCG space of commercial test to increase their market share.

Likewise, the market collectively diversified away from only the traditional biomedical space, and by the fall of 2007 there were 27 distinct online DTC testing websites offering 53 unique health tests in the price range of $90 to $5400 (McBride, Wade and Kaphingst 2010). Building on the advancements and collaborations within the genetic industry, Navigenics and 23andMe also formed collaborative partnerships with Microsoft and Google respectively (Hogarth and Saukko 2017). Together, this alignment between sequencing chip manufacturers, well capitalized DTCG startups, and tech giants capable of storing vast amounts of data helped to set the stage for a new era of DTCG.

Riding on the back of the confluence of forces that came together over the past few years to make health testing almost as approachable as genealogical testing, a second wave of companies such as 23andMe, Navigenics, and deCODEme began offering complex tests in late 2007 that cost in the range of $429–$1000. These tests, compared to some of the earlier tests which analyzed only a few hundred gene variants, were now analyzing thousands (McBride, Wade and Kaphingst 2010). Given this new opportunity, the testing companies began to expand their product offerings deeper into the wellness and medical market and started to advertise on social media actively. This series of events, along with media coverage like Time Magazine naming the Retail DNA Test the 2008 *Invention of the Year* led to an increase in awareness of DTCG health testing (Time Magazine 2008). However, with the growing awareness came increased scrutiny.

The scrutiny started in 2006 when the U.S. Federal Trade Commission (FTC), Food and Drug Administration (FDA), and Centers for Disease Control and Prevention (CDC) published an FTC Fact for Consumers report titled *At-Home Genetic Tests: A Healthy Dose of Skepticism May Be the Best Prescription*. The fact sheet stated consumers should “be wary of claims about the benefits these products supposedly offer,” and “while these tests may provide some information your doctor needs or uses to make treatment decisions for a specific condition, they are not a substitute for a physician’s judgment and clinical experience” (Federal Trade Commission Bureau of Consumer Protection Division of Consumer and Business Education 2006, para. 10, para. 13). This was followed by the U.S. Government Accountability Office (U.S. GAO) study of four nutrigenetic testing companies. The study found that the test results predicted the consumers were at risk of various diseases, even though the tests themselves carried disclaimers stating they were not intended for diagnosis (United States Government Accountability Office 2006).

By 2008, when the second wave of DTCG testing kits from 23andMe, deCODE and Navigenics were starting to gain market share, the FDA was debating whether or not they should start regulating a certain type of Laboratory Developed Test (LDT) known as In Vitro Diagnostic Evaluation and Safety (IVDMIA). The reason for debating the issue focused on concerns regarding analytic validity, the reliability of the actual genetic test and laboratory performance; clinical validity, whether the genetic variant corresponds to the condition or trait, and consumer comprehension (Curnutte 2017). The corollary to this FDA debate was whether or not the potential regulation of LTDs

should be extended to genetic tests. In the end, no decision was made, and DTCG companies continued operating relatively unencumbered.

As prices declined further, advertising and media coverage continued to increase, resulting in growing market share. These developments led other critical players outside of the regulatory agencies to get involved in the debate. Leading scientists such as the National Institute of Health (NIH) soon-to-be chief Francis Collins, and Craig Venter, one of the driving forces of the Human Genome Project (HGP) to speak up. They were calling for more transparency, which led Congress to request that the U.S. GAO launch a second study (Genomic Law Report 2010). This study sought to detail the reliability of the tests and company privacy policies. The findings were discussed in a 2010 Congressional hearing that involved experts testifying that the DTCG company information was not sufficient for medical use and was instead only "for entertainment purposes" (Spector-Bagdady 2015, 569).

Congress echoed the report findings and stated that the DTCG companies misled consumers and used deceptive marketing practices. The FDA then sent warning letters to 15 DTC firms to notify them that their tests were, in fact, medical devices, and therefore, under the jurisdiction of the FDA (Curnutte 2017). In the letter to 23andMe, the FDA stated “The 23andMe Personal Genome Service™ is a device under section 201(h) of the Federal Food, Drug, and Cosmetic Act (the Act), 21 U.S.C. 321(h) 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” thereby finally making it legally clear where the FDA stood on the matter (Food and Drug Administration 2010, para. 1).

Following this, some of the companies, led mainly by 23andMe, started working more closely with the FDA. However, in the case of 23andMe, which was the clear market leader for DTCG health testing at the time, this trend seemed to stagnate after they failed to deliver on a January 2013 promise that they would share more data with the FDA. In May of that year, 23andMe stopped communicating according to the FDA, despite the fact that 23andMe had recently launched a $5 million advertising campaign. This breakdown in communication led to the FDA sending a cease and desist letter on November 22, 2013, ordering 23andMe to stop marketing its product (Hayden 2017).

In the letter, the FDA stated: "even after these many interactions with 23andMe, we still do not have any assurance that the firm has analytically or clinically validated the Personal Genome Service (PGS)" (Food and Drug Administration 2013, para. 6) The FDA statement was made based on 23andMe's "health reports on 254 diseases and conditions, including categories such as carrier status, health risks, and drug response, and specifically as a first step in prevention that enables users to take steps toward mitigating serious diseases" (Food and Drug Administration 2013, para.2). After this, 23andMe was able to operate still and provide trait and ancestry tests, but the medical tests that the FDA had classified under medical devices could no longer be sold.

But determined to get back to selling their health tests, 23andMe, under the guidance of a legal team, began cooperating with regulators. Through the process, the regulatory environment that was to govern the DTCG industry going forward gradually came into focus for all parties, and controls were detailed by the FDA to make it more transparent what steps needed to be taken to provide adequate assurances of safety

and efficacy. DTCG companies wishing to sell over-the-counter (OTC) tests would need to give consumers information about the biological sample collection device itself, which must get FDA clearance and the details about the test's analytical performance. The FDA also wanted to see documentation on other instrumentation and software used in the testing process.

With these new guidelines in hand, 23andMe began the process of obtaining approval for a DTCG health test, and at the end of 2014, asked the FDA to approve one such test. The test was for Bloom Syndrome and was intended to inform consumers if their children might inherit a genetic risk for the disease. 23andMe seemingly started with the Bloom Syndrome test because it is a carrier screening test, which implies the test informs consumers if they are carrying one or more copies of a gene, but does not necessarily mean that the disease will be inherited. Therefore, the tests results do not provide a disease diagnosis. This point was critical, as demonstrating the validity of identifying a single gene disease is much easier than a polygenic disease. As part of the approval process, the FDA also required 23andMe to address utility concerns, requiring them to test users for comprehension, requiring a score of 90% or greater for each comprehension concept (Curnutte, 2017). 23andMe complied, and with all of the requirements met by early 2015, the FDA approved the test in February 2015, making it the first FDA approved DTCG test in the United States available for sale to consumers.

In their approval letter to 23andMe, the FDA stated “The FDA believes that in many circumstances it is not necessary for consumers to go through a licensed practitioner to have direct access to their personal genetic information. Today’s authorization and accompanying classification, along with FDA’s intent to exempt these

devices from FDA premarket review, supports innovation and will ultimately benefit consumers. These tests have the potential to provide people with information about possible mutations in their genes that could be passed on to their children," and a result, a near fifteen-year period of uncertainty had seemed to come to an end (Reuters 2015, para. 6).

Following this, 23andMe once again took the lead, and by April 2017, through cooperation with regulators, they were approved for another ten disease-related susceptibility tests, which they achieved by conducting "extensive validation studies for accuracy and user comprehension that met FDA standards" (23andME 2017, para. 5). As a result of this process, they have helped prepare the way for many other DTCG companies, and in the process helped to push the FDA to articulate the required controls. The question now is when, why and how will the majority of consumers adopt DTCG health tests?

CHAPTER 3

LITERATURE REVIEW

In this chapter, I look at existing literature from anthropology, sociology, communication, information science, and business management to help us understand why DTCG testing is adopted and how it spreads. I also document some of the larger social forces at play that relate to its adoption, and then discuss how the use of design anthropology represents an ideal theoretical and methodological toolkit for intentionally designing product and business strategies which are culturally aware and sensitive of all stakeholders.

3.1 Design Anthropology

Design anthropology is a form of applied anthropology that it is reflective, yet given its design orientation, also deliberately and openly prescriptive. Moreover, design anthropology is adept at solving modern complex problems given its ability to understand the problem by conducting applied research which is framed through the theory and scholarship of cultural anthropology, linguistic anthropology, and archaeology (Wasson 2016).

Design anthropology grows out of the confluence of multiple disciplines which include design and anthropology but is by no means limited to them. This trend of blending disciplines seems to have arisen in its modern context with information technology in the early 1990s as a result of the new challenges it presented. At that time, design consulting firms like IDEO, Fitch, and frog were starting to bridge industrial design and engineering. Similarly, larger research labs like Xerox PARC, Microsoft

Research, and Bell Labs technologies had been bringing together communication designers, usability and human factors engineers with social scientists from anthropology, linguistics, and sociology. The goal was to "understand how people thought machines worked, to understand the interactions between people and technology, and the reciprocal impact of organizations, practices, and technologies on one another" (Clarke 2017, 57).

Building on the foundations of these earlier movements, pioneering design firm E-Lab helped to bring design anthropology into its own right by fostering a model of collaboration between designers and anthropologists, thereby bringing together design and ethnographic practice (Wasson and Metcalf 2013). E-Lab is important because it fostered an equal partnership between research and design, with teams of roughly equal representation and influence, and ethnographic methods were the core of their research methods (Wasson 2000).

This was important because before ethnography being used, cognitive psychology as the social science research model of choice (Norman 1988). The problem with this previous model was that it mostly accounted for what the user was thinking, and often failed to understand the larger institutional and cultural contexts that the use was embedded in (Robinson 1993). Furthermore, before the greater degree of equality between research (anthropology) and design that E-Lab promoted, anthropology was often just a complementary practice to design or usability testing, as opposed to "informing design to re-framing social, cultural and environmental relations in both design and anthropology" (Kjærsgaard 2011, 9).

Despite the advances E-Lab had achieved in realizing a higher degree of equality between the disciplines, not all design anthropology is created equal. Some theorists have argued that there are three models: dA, Da, and DA.

- *dA* – The theoretical contribution is for anthropology rather than design. Design follows the lead of anthropology in terms of adopting theoretical understandings, or becoming the subject of anthropological study" (Gunn and Donovan 2012, 12).
- *Da* – Fieldwork is in the service of design. Framing originates from problem orientated design approaches rather than engagement with peoples. Anthropology is put in service of design for example ethnographic studies are used for establishing design requirements" (Gunn and Donovan 2012, 12).
- *DA* – Disciplines of design and anthropology are engaged in a convergence of efforts each learning from the other each learning from the other" (Gunn and Donovan 2012, 12).

These models are important to keep in mind because I do not seek to simply contribute to the theory of anthropology or improve the user experience of Sequencing.com. No, I seek to ensure that we are designing an ideal future state of DTCG, because whether we like it or not, with every object, technology, or system we create, we are designing cultures of the future (Balsamo 2011).

Likewise, this thesis aimed to produce actionable product management insights that Sequencing.com could use to achieve competitive advantage, but, and this is critical, it must not be done at the expense of consumers. An innovation as disruptive and personal as genomics needs to serve consumers because it, possibly even more than other designed artifacts, will define what it means to be a human (Tunstall 2017).

To produce the actionable insights, let us first look back at how ideas and innovations spread. From there, we will move on to factors that influence adoption, and

finally we will look at some ethical concerns that we need to design for if we are to produce DTCG that positively influence what it means to be human.

3.2 Diffusionism and the Spread of Cultural Traits

Given anthropology's focus on culture, there is a long-standing tradition of trying to understand the origins of cultures and how they spread (Univerisity of Alabama Department of Anthropology n.d.). The collective body of this work falls under the broad theories of diffusionism. Diffusion research gained its foothold in a time in which the theory of evolution, colonialism, and industrialism where all on the rise in the middle of the nineteenth century.

At this time, European and American anthropologists were seeking to understand how humans progressed in development from a primitive culture, to an advanced culture, such as those found in Europe. Of course, today, this perspective is widely understood to be Eurocentric and inaccurate, but at the time, anthropologists were still trying to understand if human culture evolved similarly as biological evolution, or whether culture spread in a diffusion process from innovation centers (Hugill 1996).

One such model for the latter perspective came from the German diffusionist school known as the *Kulturkreise* (culture circles). The *Kulturkreise* school, led by Fritz Graebner, sought to explain the spread of culture as a process of by which traits radiate out from one or more central seed cultures (Univerisity of Alabama Department of Anthropology n.d., para. 1, para. 2. para. 3). He believed that cultural traits were borrowed through processes such as marriage, trade, war, and communication. He felt that once these new traits were encountered, they were adopted by the new culture,

and applied to the new context, thus making them at once similar, yet culturally distinct (Harris 1968).

Also working around this time, Gabriel Tarde, a French sociologist, theorized that significant sociocultural change requires the diffusion of innovations, and believed these innovations, which were infrequent moments of genius, required the support of key social members to help the ideas spread. Support came in the form of belief and adoption of the innovation. The diffusion process involved key social members communicating their support, which would in turn be mirrored others people who imitate the beliefs (Kinnunen 1996).

3.3 Diffusion of Innovations

Building on the synergy between these theories, numerous models have been created to explain diffusion in a modern global context. One of those, aptly named the Diffusion of Innovations (DOI) theory by Everett Rogers, attempts to explain why, how, and the pace at which new ideas and technology spread. In his 1962 book titled the *Diffusion of Innovations*, and the four subsequent additions which included substantial cross-cultural data from around the world, Rogers argued that diffusion is the process by which an innovation is communicated between people within a social system. Since the initial publication of his book, this particular type of diffusion research has been applied by scholars across the globe, in diverse disciplines such marketing, public health, economics, sociology, communication, geography, management, education, public administration, political science, and information systems, to understand the adoption and diffusion of ideas.

To better understand factors influencing adoption, Rogers focused on five key elements of the process: the adopters, the innovation, communication channels, time, and the social system. Adopters are the individuals or groups such as businesses and governments which make decisions to adopt something. The innovation is any new idea, practice, or object that could be adopted. Communication channels are the means by which new information is transferred. Time is the period in which the adoption occurs. The social system is the interconnected web of relationships that influence an adopter's decision, be it mass media or direct social relationships. (Rogers 2003).

For Rogers, diffusion transpires as a result of a five-step decision-making process that occurs through communication channels over time within the social system. The five steps are knowledge, persuasion, decision, implementation, and confirmation. The knowledge step involves individuals first being exposed to the innovation but not yet interested in it. In the persuasion step, an individual becomes interested and seeks out more information. This is followed by the decision stage where an individual either decides to adopt the innovation or not. In the implementation step, an individual makes use of the innovation and makes a subjective decision about its usefulness. Finally, in the confirmation step, an individual will decide whether or not to keep using the innovation, which is based both on their own beliefs, as well as social norms (Rogers 2003).

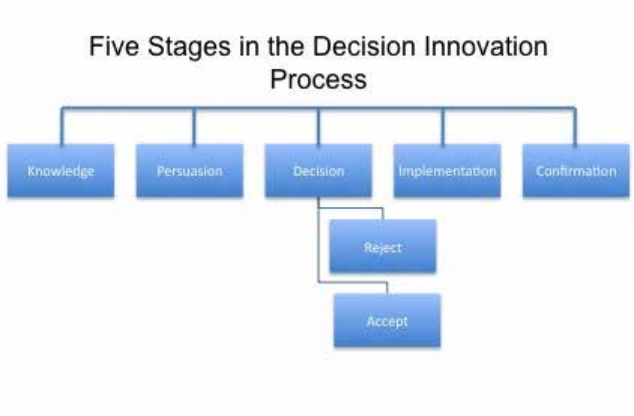

Figure 1: Five Stages in the Decision Innovation Process (Wikipedia 2009)

Building on the five-step decision-making process individuals use in deciding to adopt an innovation or not, Rogers also classifies adopters into five groups: innovators, early adopters, early majority, late majority, and laggards. Innovators are the first group to adopt, and they are more apt to take risks, have greater financial resources, and often the highest social status. They are followed by early adopters who are similar to innovators in that they usually have more financial resources and higher social status. However, they are slightly more risk-averse than innovators and make choices about adoption based on that perceived risk. They also have the highest degree of opinion leadership out of the five groups. The early majority have above average social status, but take considerably longer to adopt the innovation, and have less opinion leadership than the early adopters. The late majority typically adopt an innovation after the mean of the population, based on a high degree of skepticism, and/or lack of financial resources. They also often have lower social status and little opinion leadership. Finally, the laggards are the last group to adopt an innovation. They have minimal social status and opinion leadership. They often also lack financial resources and social connections and may be considered very traditional in their worldview (Rogers 2003).

To better understand the time component of adoption, the DOI plots the adoption groups through time along the adoption curve, which mirrors the bell curve, to indicate when those groups adopt a new idea or technology and in what percentage. As time advances and the more groups adopt, a point of saturation is achieved in the market. This process of saturation maps to an S Curve which is overlaid on the adoption curve. The relationship between data points demonstrates that as the late majority starts to adopt the technology, the rate of adoption drastically speeds up, reaching a point that Rogers calls the critical mass. At this point, the adoption has become widespread, and is almost self-replicating, with little to no need from those with greater social status to spread the innovation, as it has become a social norm (Rogers 2003).

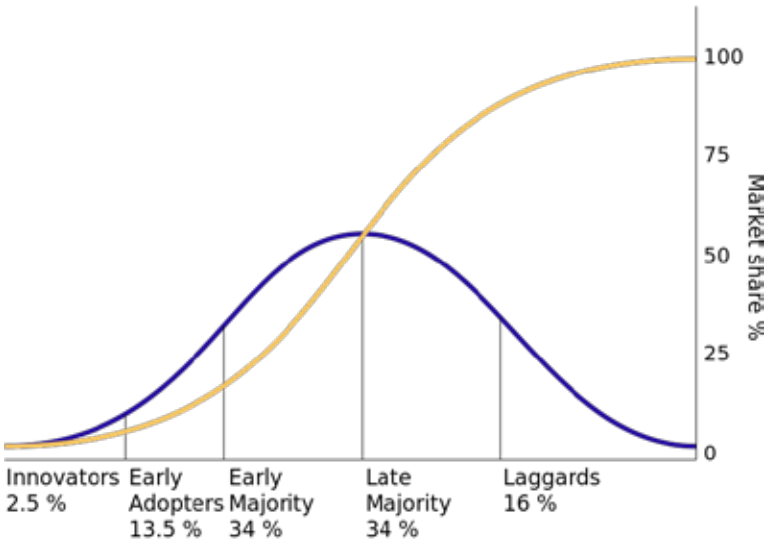

Figure 2: DOI Adoption and S Curves (Wikipedia 2012)

The power in the Rogers framework of diffusion research is that it has been systematized, which makes it easier to understand and study the broad constructs such as the elements, process, and the time component. However, DOI can benefit from the addition of other theories to help develop a deeper understanding of various dimensions

such as the innovation, communication channels, the social system, and even the adopters.

3.4 Technology Acceptance Model

The Technology Acceptance Model (TAM), which historically was applied to information systems in a business context, builds on the Theory of Reasoned Action by implementing factors for measuring attitude based on technology acceptance criteria.

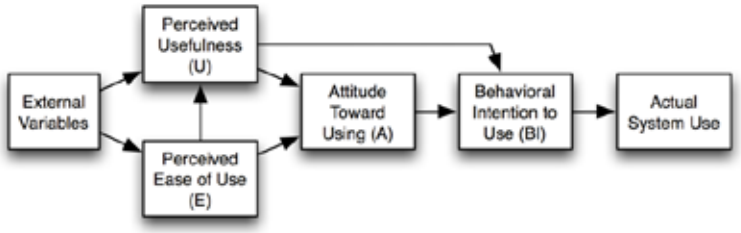

Figure 3: The Technology Acceptance Model (Wikipedia 2013)

The criteria introduced by TAM includes perceived usefulness and ease of use. In the landmark publication on the topic, Fred D. Davis defined perceived usefulness as "the degree to which a person believes that using a particular system would enhance his or her job performance" where useful is defined as "capable of being used advantageously" (Davis 1989, 320). He went on to define perceived ease of use as "the degree to which a person believes that using a particular system would be free of effort" where ease is defined as "freedom from difficulty or great effort" (Davis 1989, 320). The research found that both perceived usefulness and ease of use were significantly correlated with self-reported indicants of system use (Davis 1989).

Furthermore, Davis found that “usefulness was significantly more strongly linked to usage than was ease of use” (Davis 1989, 333). Elaborating on this point, he stated

“although difficulty of use can discourage adoption of an otherwise useful system, no amount of ease of use can compensate for a system that does not perform a useful function… thus, a major conclusion of this study is that perceived usefulness is a strong correlate of user acceptance and should not be ignored by those attempting to design or implement successful systems” (Davis 1989, 334).

Thus, TAM can help us better understand many of the human decisions making factors that contribute to adoption, thereby enhancing the power of DOI. To build on these theories further, we still need to gain a deeper understanding of innovation, communication channels, and the social system. To begin, we will start with the innovation, but with a specific type of innovation that DTCG health testing falls into.

3.5 Disruptive Innovation and Crossing the Chasm

Disruptive innovation is a specific type of innovation that creates new markets and upends existing markets, and in the process, displaces established market leaders and products. The phrase disruptive technology was coined by Clayton M. Christensen in his 1995 article *Disruptive Technologies: Catching the Wave*, and later expanded on in his 1997 book *The Innovators’ Dilemma*. Christensen theorized that disruptive technologies would initially lag behind established ones since they satisfy only the needs of a small group, such as the innovators or early adopters, but over time as the technology matures it starts to satisfy the broader needs of the mainstream market compromised of the early and late majority (Christensen 1997).

Disruptive innovations are divided into two groups: product discontinuities and process discontinuities, where the discontinuities are either competence-destroying or

competence-enhancing. Competence-destroying discontinuities require new skills, abilities, and knowledge in the process of delivering a new product class. Competence-enhancing discontinuities are achieved by drastic improvements to existing products and thus don't require new skills, abilities, and knowledge (Thomond and Lettice 2002). When disruptive innovations are competence-destroying, such as DTCG health testing, they involve dramatic leaps in customer knowledge and use. As a result of this, there is a critical hurdle that needs to be overcome to achieve critical mass adoption by the early majority and late majority (Veryzer, Jr. 1998).

This hurdle, referred to as a chasm by Geoffrey Moore in his book *Crossing the Chasm*, represents the challenge of getting from early adopters to the early majority. To highlight this challenge, Moore updated the typical adoption curve from Rogers' diffusion research which was then applied to the Technology Adoption Lifecycle (TALC). His updates included tweaks to the adopter category names to convey particular influencing factors about them and placed a visual gap, the chasm, in between the early adopters and the early majority.

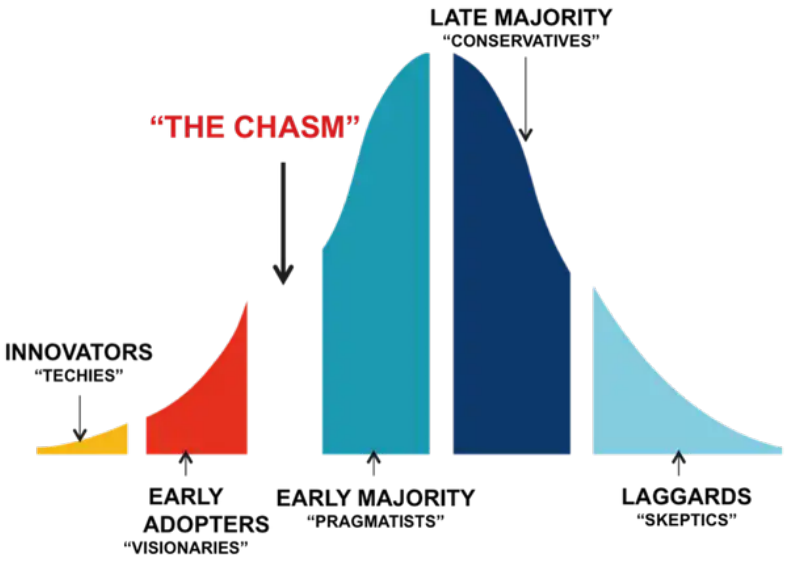

Figure 4: Crossing the Chasm Adoption Curve (Dwayne Nesmith 2017)

For Moore, to get from early acceptance to the start of the critical mass, companies need to make intentionally strategic choices about positioning the product, building a marketing strategy, choosing the most appropriate distribution channel, establishing pricing, creating a whole product concept, and choosing a target market. All of these are critical considerations; however, for this thesis, we will focus on the last two. When choosing a target market for a disruptive innovation, companies cannot be all things to all people when trying to cross the chasm. They must focus on a specific segment within the potential adopter early majority pragmatist category. This segment should have a particular need that the disruptive innovation can satisfy because it makes the group more receptive, and easier to market to, thus making it possible to overcome their inherent skepticism that goes along with being a pragmatist (Moore 2014).

To scale this model, Moore put forth the idea of the bowling alley in one of his later books, *Inside the Tornado: Strategies for Developing, Leveraging, and Surviving Hypergrowth Markets*. The bowling alley advises companies to line up all of the needs of specific pragmatist groups in such a way whereby you sequentially add more features, which satisfies the needs of more groups of pragmatists. As this happens, the disruptive innovation increasingly becomes more of a whole product concept that serves the entirety of the needs of consumers. When this happens, and more user segments within the pragmatist's adopter category adopt, a point is eventually reached which Moore calls the tornado. In this period, adoption of the innovation moves into the hypergrowth phase along the S Curve described in DOI, and the late majority begin to adopt the innovation in increasingly greater numbers with less need for social influence from those with higher social status, and eventually, the innovation becomes a social norm (Moore 2004).

In light of Christensen's theory of disruptive innovation and Moore's *Crossing the Chasm* model, we now have a better understanding of the challenges of obtaining critical mass adoption of disruptive technologies like DTCG health testing. But, we still need to explore how communication channels and the social system aspects of DOI effect adoption.

3.6 Communication Channels and Social Influence

In the early days of diffusion and acculturation research, it was stated that direct contact was needed for the spread of innovations. While that holds true, direct contact is by no means the only mode of transmission today, and, it may be argued that it is now

the minority mode in a world filled with electronic communication. Electronic communication takes the form of TV and the internet at large but also includes specific internet-based technologies such as mobile phones and social networks which in some cases such as Facebook, have grown larger than many countries. In this new world of electronic communication ideas and innovations can spread quicker and to more people than could have been imagined in the days of the early diffusion and acculturation research, or even Rogers' research for that matter. Likewise, electronic communication has become the dominant communication channel affecting adoption and diffusion.

But, when Rogers first published the *Diffusion of Innovations*, TV was still in the process of becoming the norm, cable TV and the internet had not yet been invented, the need for around the clock media content was not yet a business problem needing to be solved, and mass consumption within echo chambers on mobile phones wasn’t even a dream outside of science fiction. Likewise, the DOI incorporated the two-step flow of communication model which comes from Paul Lazarsfeld and Elihu Katz (Katz and Lazarsfeld 1955). In that model, it was stated that most people form opinions from social influencers who are themselves influenced by mass media. These social influencers were assumed to have greater access to media, and thus acted as a translator of media content for the masses. This two-step model was in contrast to a one-step model which theorizes that people are directly influenced by mass media, which was assumed to not be relevant given the inequalities in access to mass media at the time. Today though, communication researchers theorize that both of these models, as well as other more complex forms of communication playout across the various forms of electronic communication channels, especially social networks.

In fact, in one recent study of political communication on Twitter, four types of nodes: "Voice," "Media," "Amplifier," and "Participants" were identified (Hilbert, Vasquez and Halpern 2016, 7). Voices were the individual or organizational social network accounts. Media was self-identified media outlets. Amplifiers were social influencers, that did not belong to the previous two groups, but had public status which could stem from formal authority (politicians, non-specialized organizations or organization with a focus besides the conflict or media, general activists, union leaders, etc.), or public visibility (actors, artists, musicians, celebrities, bloggers, athletes, etc.) Participants consisted of all other people. In this study, it was found that "the average Voice is the most intense communicator (highest centrality), followed by Media outlets and only then Amplifiers" but "Amplifiers are more omnipresent and maintain the strongest communication link with Participants." This finding led the authors to conclude that both one and two-step processes were in use (Hilbert, Vasquez and Halpern 2016, 17).

So, if this is true, how does it relate to DTCG and social influence? The answer is that social influence can occur through contact with someone such as a family member, a friend, a person of perceived authority, businesses, or mass media; and this social influence plays out in person or electronically. To explore this, let us first look at some previous research on the adoption of genetic testing that made use of theories discussed in this chapter. We will use these studies to demonstrate how the decision-making process has occurred in the early adoption of genetic testing and to point out how social influence and norms have affected the decision to adopt genetic testing in real world settings.

One study which looked at early adoption of genetic testing made use of the DOI theory to understand the adoption of genetic testing among women who were participating in genetic counseling related to the BRCA1/2 gene variant. In this study it was found that “the uptake of BRCA1/2 testing among women undergoing genetic counseling was associated with innovative characteristics of the participant and the perceived compatibility of the test with existing values and needs” (Armstrong, et al. 2003, 92). Furthermore “most participants had heard of BRCA1/2 testing from a source other than their physician and had sought testing because of a personal or family member’s cancer diagnosis” (Armstrong, et al. 2003, 92).

Another study that looked at early adoption of genetic testing used Ajzen’s Theory of Planned Behavior (1991) to understand why an individual may take a genetic test for Alzheimer's Disease (AD) (Ajzen 1991). It was found that the subjective norm was the strongest predictor of adoption for individuals who were told that positive results on the test correlated to a 90% chance of developing AD. This was in contrast to another group who was told that positive results on the test correlated to a 50% chance of developing AD. For the latter group, a positive belief, such as having the ability to deal effectively with the results, was the strongest predictor. The authors summarized their research by stating “our findings highlight the influential role beliefs about genetic testing and normative beliefs in decision-making” (Frost, Myers and Newman 2001, 108).

With these studies in mind, now let us look at the social system component of DOI by bridging the previous findings into a discussion on some of the sociocultural

forces that contribute to shaping the sociotechnical normative beliefs of our society in the United States.

3.7 Science and Business as Social Norms

It can be argued that in the United States, trust in science is a normative belief, with the majority of the population supporting science as an institution of our culture. In fact, in the recently released National Science Board Science and Engineering Indicators for 2018, it was stated that “Americans have high confidence in the scientific community. Amid a long decline in public confidence in several U.S. institutions, many Americans continue to have a “great deal of confidence” in the scientific community (National Science Foundation 2018, 20). This perception has endured over 3 decades and is second only to confidence in the military (National Science Foundation 2018).

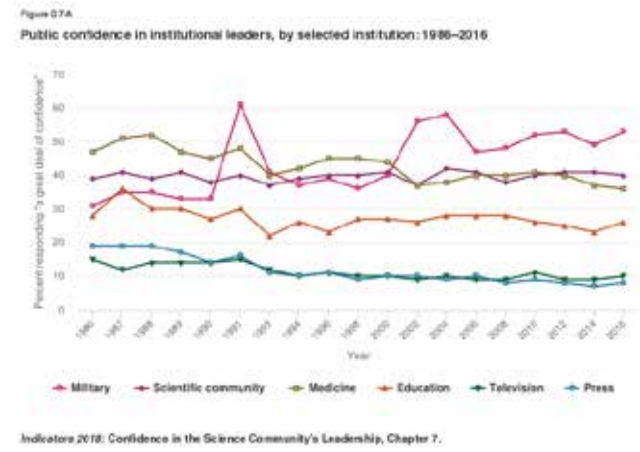

Figure 5: Public confidence in institutional leaders, by selected institution: 1986–2016 (National Science Foundation 2018)

Building on this, it was found that the public have consistently maintained a very positive view of science as a body of knowledge that benefits society. It was found that “Americans believe that science creates more opportunities for the next generation, that

its benefits outweigh risks, and that the federal government should provide funds for scientific research” (National Science Foundation 2018, 20).

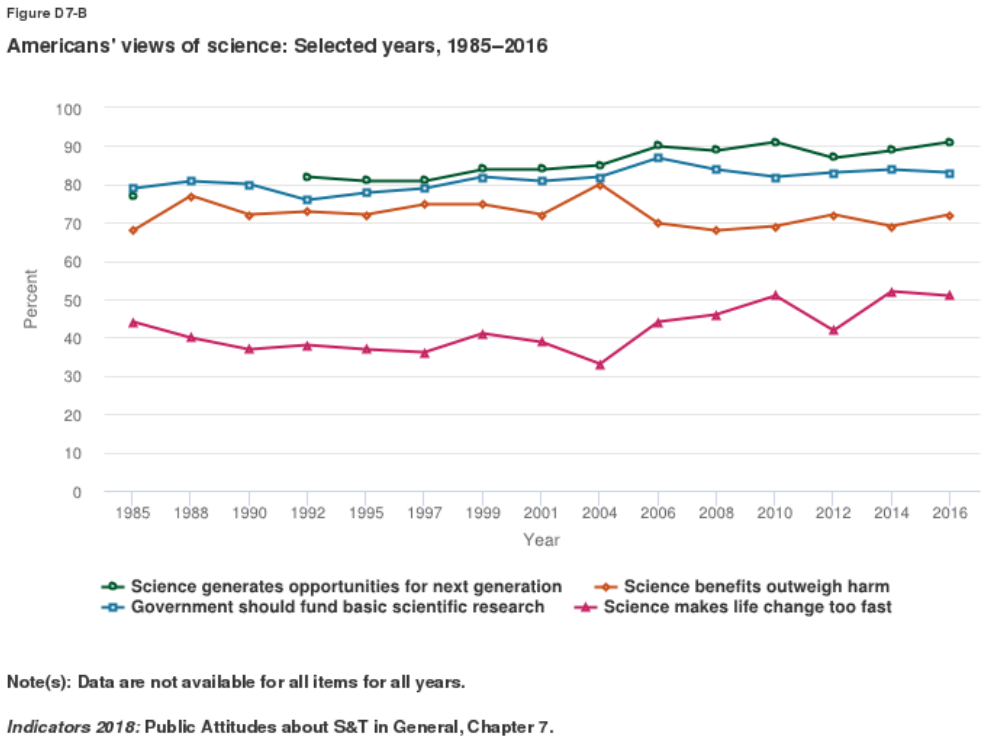

Figure 6: Americans' views of science: Selected years, 1985–2016 (National Science Foundation 2018)

Furthermore, when the participants were asked about how they feel about scientists, it was found that “Americans have a positive view of scientists. The clear majority of respondents agree or strongly agree that scientists work for the good of humanity, help to solve problems, and want to make life better for the average person. These views have remained mostly unchanged since 2001” (National Science Foundation 2018, 20). But if above average trust and belief are placed in science as a body of knowledge and as a social institution, as well in the social influencer scientists, then we must ask, how did this social norm come to be, and what historical social forces created it?

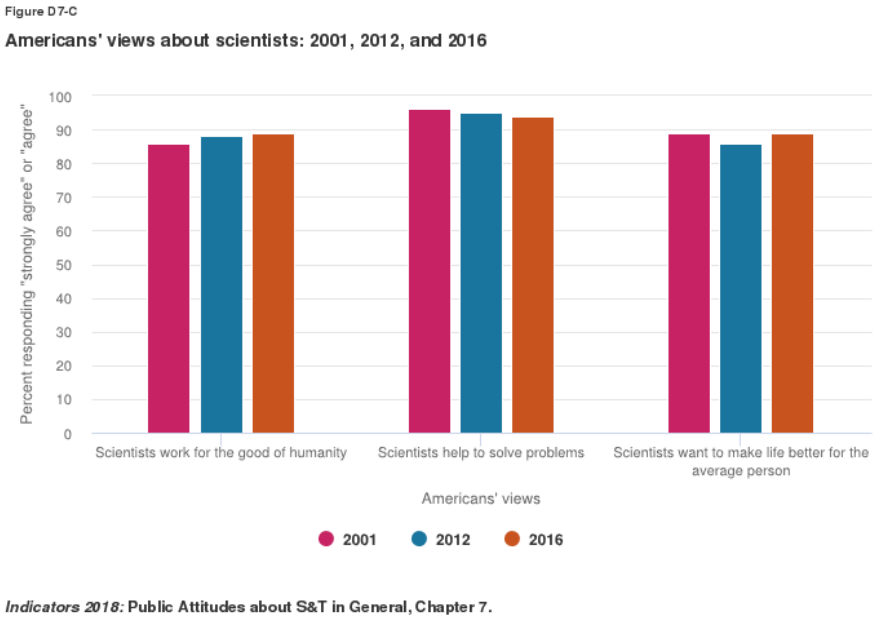

Figure 7: Americans' views about scientists: 2001, 2012, and 2016 (National Science Foundation 2018)

The United States is thoroughly rooted in the Protestant work ethic, which according to Max Weber gave rise to the process of rationalization which embodied the belief that "one can, in principle, master all things by calculation" (Weber 1946, 139) This in turn led the rise of the scientific revolution, capitalism, and industrialism which created the foundation for our modern technoscientific economy.

In this economy, technoscientific products that are sold by corporations exert a great deal of control on our lives from the way we travel, to how we communicate, to how we manage our health. Likewise, scientists and the studies they produce hold a great deal of social status. This is observable simply by looking at nearly any mass media source, be it in print or electronic. In these sources, you will typically find a science or health section, which is stocked full daily with summarized briefs of the latest research, and even if you don't go search for those headlines, don't worry, because they often float to the front page. But why is this?

Some theorists have argued that scientists, and corporations, often align and disseminate their research and public relations with the media via a phenomenon known as media orientation (Weingart 1998). This was true of the scientists involved in the Human Genome Project (HGP), as well as the DTCG corporations today. Examples of the effects of this process are seen in a headline discussed earlier, where Time Magazine named The Retail DNA Test as its 2008 *Invention of the Year*, or more recently when Fortune called attention to *23andMe Raises Another $250 Million—and Wants to Use Your Genetic Data to Make Drugs* (Fortune 2017).

The reason this is important is that while this process can be useful for the spread of ideas, this orientation, and the outcome of this process, is not inherently neutral. In fact, in a previous study, which conducted a metaphor and discourse analysis of media that related to the HGP, it was found that the metaphors and hyperboles used attempted to steer the discourse towards public euphoria (Nerlich 2002). This is a concern because media can influence social change like discussed in the Hilbert et.al. study.

Further amplifying the effectiveness of medialization is advertising. Today, the most common advertising strategy used by companies in health is called Direct-To-Consumer (DTC) advertising, which is a term that has been used to describe the advertising tactics of pharmaceutical companies since the 1980s. DTC advertising makes use popular media such television, radio, magazines, newspapers, billboards, direct mailings, and more recently the internet, to target consumers directly (Ventola 2011). The power of DTC advertising, especially in a world of contextual based advertising on platforms like Facebook, is that it allows corporations selling

technoscientific innovations to get out in front of consumers who match a very specific profile they wish to target and make promises to address their needs.

3.8 Promissory Discourse and Future-Oriented Knowledge

The promissory discourse used to attract consumers is based on “future-oriented imaginations of wellbeing, disease prevention and personal empowerment” (Arribas-Ayllon M 2011, 53). The concern is that by invoking language that promises the consumer that their future state can be better than their current state, the DTCG companies are playing on the consumers’ own personal vulnerabilities, which in turn leads them to trust the testing process. This subjective appeal to emotion helps to sidestep the need for deceptive marketing practices based on promises related to disease diagnosis, prevention, or treatment, and instead supports the DTCG companies in attracting consumers through broad claims that can be made without regard for the governmental regulatory concerns.

In a study of 46 DTCG websites, it was found that the appeals most often came in the form of a statement or testimonial that lays claim to positive feelings that a consumer will have after taking a test based on knowledge gained (Saukko 2013). Similarly, though occurring less frequently, the appeal may also seek to highlight the negative emotions, such as fear or regret, that may exist for a consumer who has not yet taken a test, and thus lacks the knowledge they could have in the future if they were to take the test. The most popular positive emotional appeals were found to be warmth and empowerment, occurring in 60.9% of the websites. The second most popular positive appeal, which was found in 34.8% of the websites, was assurance. These

appeals were followed by relief and happiness/joy, being found in 26.1% and 21.7% of the websites respectively. Fear was the most common negative emotional appeal used, occurring on 26.1% of the websites. This was followed by regret on 10.9% of the websites. It was also noted that the websites often make use of “healthy-looking, smiling people in a warm family setting, implying that genetic testing could bring about such desirable outcomes” (Liu and Pearson 2008, 141). Numerous other studies have also come to very similar conclusions, and have called attention to the fact that the language of these websites seems to resonate with consumers, given the discourse echoes the current beliefs in health that emphasize personal choice and responsibility for one’s own health (Saukko, 2013).

3.9 Biosociality

In 1996 Paul Rabinow coined the term “biosociality” to call attention to the implications of the Human Genome Project (HGP) (Rabinow 1996). In his writing, he described how social identity based on biological conditions could not only alter people’s personal identity, but also mediate their social relationships (Rabinow, 1996). While this term may appear self-evident based on the fact that humans are biosocial beings: biological animals and social animals, Rabinow was articulating a cultural trend in which the biological, and specifically the genetic, was being elevated in importance. Since then, and with the rise of DTCG, the concept of genetic-based biosociality has proven to be a point of interest for consumers in the US. A quick search on YouTube for Ancestry or 23andMe results produces many thousands of DTCG “results videos” in which the creators call attention to their new found understandings of their genetically

constructed ethnic identities. Similarly, the forums of Ancestry, 23andMe, and GEDCOM are active with conversations related to ethnicity and medical conditions.

Advocates state that biosociality is helping individuals to better understand their identity and achieve a state of autonomy or control over their own health, and cite how virtual communities are emerging around rare genetic conditions, thereby allowing like individuals to connect with one another in ways previously not possible (Novas, 2006). Critics however fear the worst. Many call attention to concerns regarding our not too-distant past with eugenics and the need to protect against direct discrimination along the lines of isms such as racism, sexism, classism, ableism, anti-Semitism, ageism and heterosexism, all of which are valid concerns (Allen 1999). Others have expressed the need to be aware of indirect causes that allow some of these isms to perpetuate, such as the structural violence which impacts access and outcomes to biomedical technologies and care, for they only reinforce the unequal relationships among individuals and between societal institutions such as government (Rahaman 2011).

Furthermore, and possibly the greatest concern of all, is that in an effort to be ever more rational and controlled, the bureaucratic system governing biomedicine may institute and require a new form of citizenship, that of the genetic citizen, and in the process reinforce even greater social control over individuals in favor of the bureaucratic jurisdiction of biomedicine, and increasingly to the benefit of the private corporations that profit from the sale of biomedical technologies (Heath, Rapp, and Taussig, 2007).

3.10 Biocapital

Medicalization is a paradigm of western biomedicine that "assumes that all

human dysfunction might eventually be traced to such specific causal mechanisms within the organism," and it "presupposes a clear mind/body distinction where ultimately the causal agent of illness would be located in the human body" (Turner 1987, 10). As a result of medicalization, health has increasingly become a commodity for purchase and consumption with the goal of addressing all known health issues (Maturo, 2012). In the past few decades, this trend has expanded to incorporate a new form of commodification, one that merges capitalism and biotechnology. This commodification seeks to capitalize upon research in molecular biology through the appropriation of living nature—literally capitalizing life (Yoxen, 1981). This form of capitalism which is called biocapitalism makes use of the living and biological elements thereof (Helmreich, 2008). It has applied to some existing industries like reproductive technology and will increasingly apply to fledging industries like stem cell research, but it also quite appropriately applies to genomics and all of the other omic sciences in the present (Helmreich, 2008).

Biocapital will become the new form of capital which expands on Bourdieu's forms of capital, and with it new opportunities and threats to equality as governments, corporations, and individuals negotiate for control of the data, and what can be done with it. If the individual, there is an impressive opportunity for empowerment. Their data could be exchanged to help push science forward in the spirit of rationalization, while earning money in the spirit of capitalism. If designed correctly, it could be a relatively fair trade that pays dividends on future value created for businesses or governments. Correspondingly business, like 23andMe and the other DTCG companies who have the skills and technologies to create the markets which support the two-sided business

models of biobanking can continue to earn substantial revenue, and if they wanted to, they could share the wealth generated via the biocapital they are collecting with the consumers who are providing it to them.

CHAPTER 4

PROJECT DESIGN

This chapter details the process of the research, including the research questions, research methods, project timeline, IRB review process, informed consent process, sampling design, recruitment process, semi-structured interview and observations outcomes, coding structure, and demographics.

4.1 Research Questions

Research questions were developed to guide the research and project design. The questions were crafted with the goal of addressing the immediate need of Sequencing.com and to begin to understand the broader landscape of DTCG. The research questions were:

- What beliefs, values, lifestyle, priorities, needs and wants contribute to an interest in consumer genomics?
- What are the motivations for consumers to make use of consumer genomics?
- What gaps in understanding genomics must be overcome before consumers can make use of genomics?
- How does the genomic data need to be transformed and presented to create educational opportunities and meaningful insights that consumers can apply to improve health outcomes?
- Are consumers changing any health behaviors as a result of the test results they receive, and why?
- How do consumers feel about sharing and owning their data?
- What ethical and privacy concerns do consumers have?

4.2 Research Methods

An ethnography of DTCG was conducted. Ethnography was selected for its ability to be both inductive and deductive, thereby supporting generative and evaluative research. This opportunity was desired since the research sought to broadly explore DTCG consumers, but also to produce some actionable insights that Sequencing.com could use to guide their product management strategy.

Ethnography is also valued for its ability to be contextual and reflexive, in that it situates the findings in the collective circumstances where they were uncovered, and is self-aware of the effect the researcher has on the research design and process (Boyle, 1994). Furthermore, it allows for the incorporation of a range of methods, which may include qualitative and quantitative.

This study employed qualitative methods to collect data. The reason for this is that the study was mainly interested in discovery given the disruptive nature of DTCG testing. Discovery research was deemed fitting for this project because “the goal of discovery research is to uncover and understand the cultural system that frames human action to provide a direction for creating new products and services” (Squires 2002, 107). To do this, researchers “collect and analyze a combination of verbal, observational, and contextual information to identify what people say and do in their natural environment” (Squires 2002, 107).

Likewise, this research made use of semi-structured interviews and observations. Semi-structured interviews, or in-depth interviews, are an open-ended interview that follows a script to cover all essential topics but also leaves room for variation to uncover unexpected insights. (Bernard, 2006). Participant observation was also used to gain a

sense of what Sequencing.com users think about DTCG health testing in relation to the website. This was done as a way of situating their knowledge in the context of use.

4.3 Project Timeline

The following timeline was used to guide the research process

4.4 Sampling Design and Recruitment

The focus of the study involves two groups of consumers who were defined as 1) individuals who had previously used genealogical genomics products but not health products like Sequencing.com, and 2) individuals who had used Sequencing.com. The groups were selected to compare and contrast the beliefs, attitudes, intentions, and other motivating factors that influenced the groups to take the respective tests. Each group was intended to include 10 participants, for a total of 20 research participants. However, only nine Sequencing.com health participants were recruited. All participants

were required to be over the age of 18. The study sought to find a diverse group of participants that varied in age, gender, race/ethnicity, and socioeconomic status to achieve a sample that approximates the public of the United States. The participants were recruited in two ways based on the need to get both genealogy participants and Sequencing.com participants.

Across both groups, participants were majority millennials (57.8%), female (57.9%), and never married (57.9%). All participants had taken some college courses, with the largest group having an undergraduate degree (36.8%), followed by participants who had taken some college courses but not earned a degree (31.6%). Overwhelmingly, the majority of participants did not study (78.9%) or work (89.5%) in science, and the majority were employed full time (52.6%). The majority were also middle class based on family size an annual income between 66 percent and 200 percent of the median U.S. household income, according to the Pew Research Center (Pew Research Center 2016). The majority of participants also identified their ethnicity as white, of European descent (57.9%), and live in urban (78.9%) environments. What follows, is a breakdown of demographics by group, to compare and contrast the two.

The genealogy group was recruited via userinterviews.com for a half hour phone interview. This process involved the researcher creating a project on userinterviews.com. The project creation required the researcher to detail the title, study type, description, compensation, communication modality, computer requirements (if required), phone requirements (if required), and browser requirements (if required). The researcher also had to select between consumers or professionals as the target audience. Once the research project was posted and accessible on the

userinterviews.com website, potential participants were able to review the project details and express interest in the research project, assuming they had a userinterviews.com account. If they expressed interest, they were required to fill out a screener survey which was created by the researcher and posted as part of the project creation process.

The screener survey sought to advise them on the informed consent process which they would have to engage in if selected and to gauge more information about their past experiences with genetic genealogy as well as demographics. The results of the screener survey were recorded in the userinterviews.com control panel which only the researcher had access to. After reviewing the results, the researcher invited ten potential participants, who then had one more opportunity to accept or deny the invite. If the participant accepted the invite, they then selected a time on the researcher schedule based on availability that was also detailed in the project creation process. Once a potential participant accepted the researcher was then able to communicate with them directly based on the messaging platform that is built into the userinterviews.com control panel. Participants who completed the research interview for the genealogy group received a $30 Amazon electronic gift card which was sent directly via userinterviews.com. This was processed as soon as the interview was completed.

The genealogy group had 134 potential participants complete the screener survey. Ten participants were initially contacted and invited to participate in the research. Of those 10, three participants canceled before the start of the interview, and one did not show, and thus the interview was canceled after a period of time by the researcher. Four subsequent participants were contacted, all of whom participated.

The Sequencing.com health group was recruited for a one to one-and-a-half-hour interview and observation session by pulling a list of users from the Sequencing.com database that met certain criteria. The criteria defined sought users who self-identified as consumer users during the sign-up process, who had uploaded at least one DNA data file, and used at least one application to analyze at least one DNA data file in the last year. The data also contained information on what service initially produced the DNA data file, such as AncestryDNA, 23andMe, MyHeritage, Genes for Good, and others. This list of users was used to identify potential participants. Those potential participants were then emailed via Sequencing.com's branded MailChimp account and asked to participate in user research. The email included a link to a screener survey that the research created in SurveyMonkey. If the potential participants wished to express interesting in being part of the study, they were required to fill out the screener survey.

The screener survey sought to advise them on the informed consent process which they would have to engage in if selected and to gauge more information about their past experiences with Sequencing.com as well as demographics. The researcher then reviewed the screener survey results within the SurveyMonkey control panel and then emailed potential participants directly by email using a sequencing.com email address to set up the research sessions. Participants who completed the research interview and observation for the Sequencing.com health group received four $25 coupons to use on Sequencing.com. These coupons could be used to purchase apps that are used to analyze the user's DNA data files. These coupon codes were processed within two weeks.

A small subset of Sequencing.com customers were selected as potential participants. The subset was made up of 559 potential participants. The 559 potential participants were grouped by the number of times (1-5, 6-10, and 11+) they had used Sequening.com to analyze a DNA file. Of the 559, 530 were invited to participate in the research. They were all emailed three times over a three-week period via Sequencing.com's e-newsletter service, MailChimp. The MailChimp email contained the link to the screener survey. 35 potential participants filled out the screener survey. However, 8 were disqualified based on their answers. All of the remaining 27 potential participants were emailed by the researcher directly using a Sequencing.com email address. Of the 27 participants, two declined, and twelve never replied or confirmed a time to participate. The remaining 13 were scheduled for interviews and observation. However, four of them did not show.

4.5 Demographics

Demographic data was collected via written screener survey instrument for both groups. The screener survey collected demographic data for the participants' age, gender, marital status, education level, if they studied science at a higher education level, employment status, if they work in science, income, their ethnicity (categories taken from the U.S. Census), and if they lived in a urban or rural environment.

4.5.1 Age

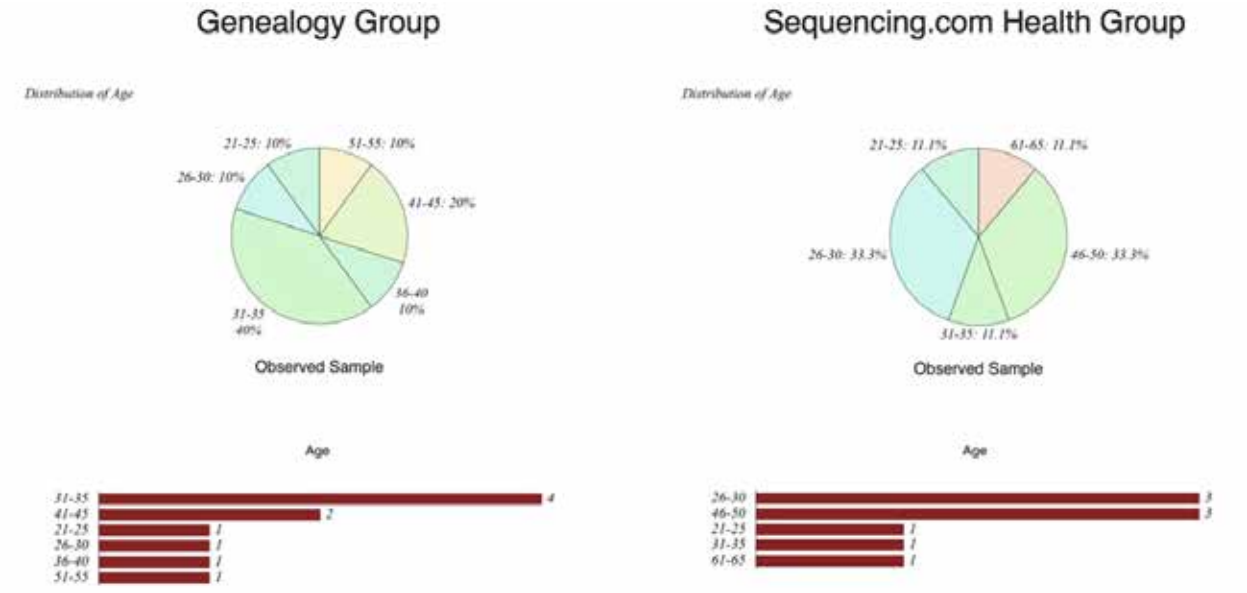

Figure 8: Age by Group

Age varied considerably within each group, however, if the mean is calculated for each age range selected by the participants, and the average is then taken for each group, the genealogy group has an average age of 37 whereas the health group has an average of 38.5.

Therefore, though there is a high degree of diversity within each group, across the groups, there is a similarity in the average age. However, given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.2 Gender

Figure 9: Gender by Group

Gender among the genealogy group was split evenly with 50% being male and female; however, in the Sequencing.com group, there were six (66.7%) females and three (33.3%) males. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.3 Marital Status

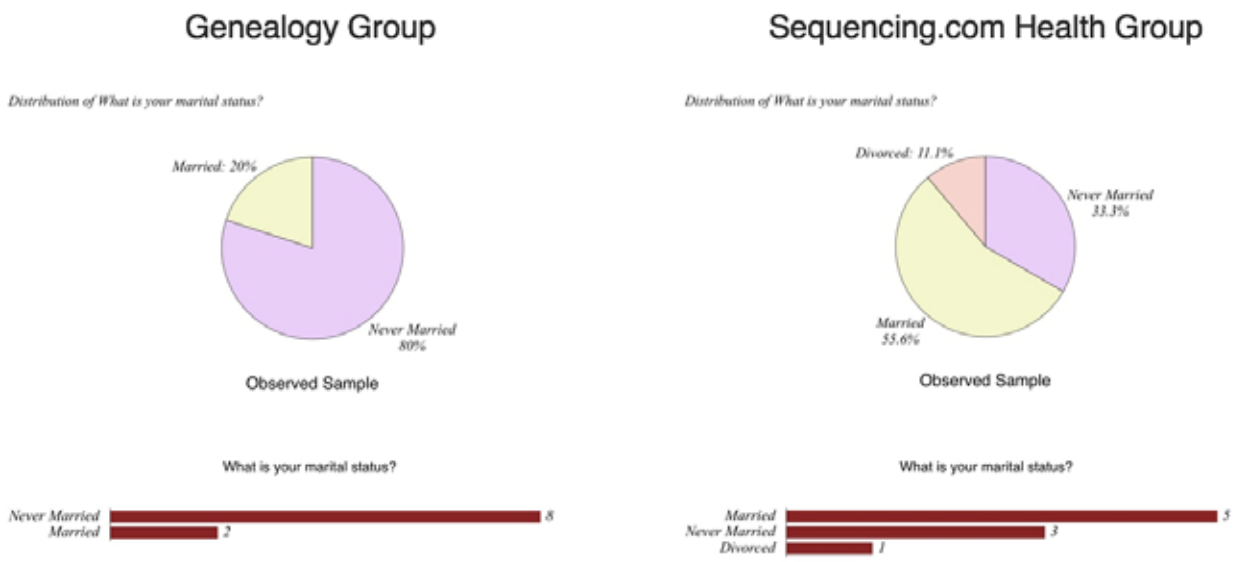

Figure 10: Marital Status by Group

Marital status was skewed significantly with eight (80%) of genealogy participants having never been married compared to three (33.3%) of the Sequencing.com participants having never been married. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.4 Highest Level of Education

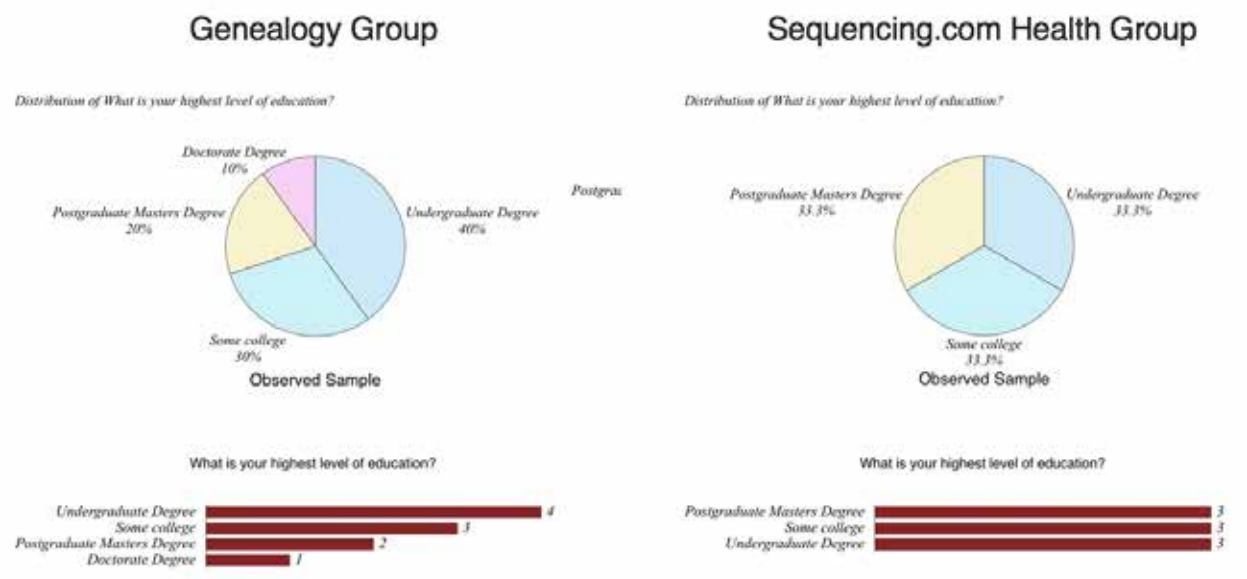

Figure 11: Highest Level of Education by Group

Education level varied considerably within the genealogy group, however, less so in the Sequecing.com Health group. Furthermore, though there are varying degrees of diversity within each group, across the groups, there is a similarity in the level of education. In both groups, full the majority of participants did complete higher education degrees, which does seem to align with early adopters often having higher degrees of education. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.5 Studied Science

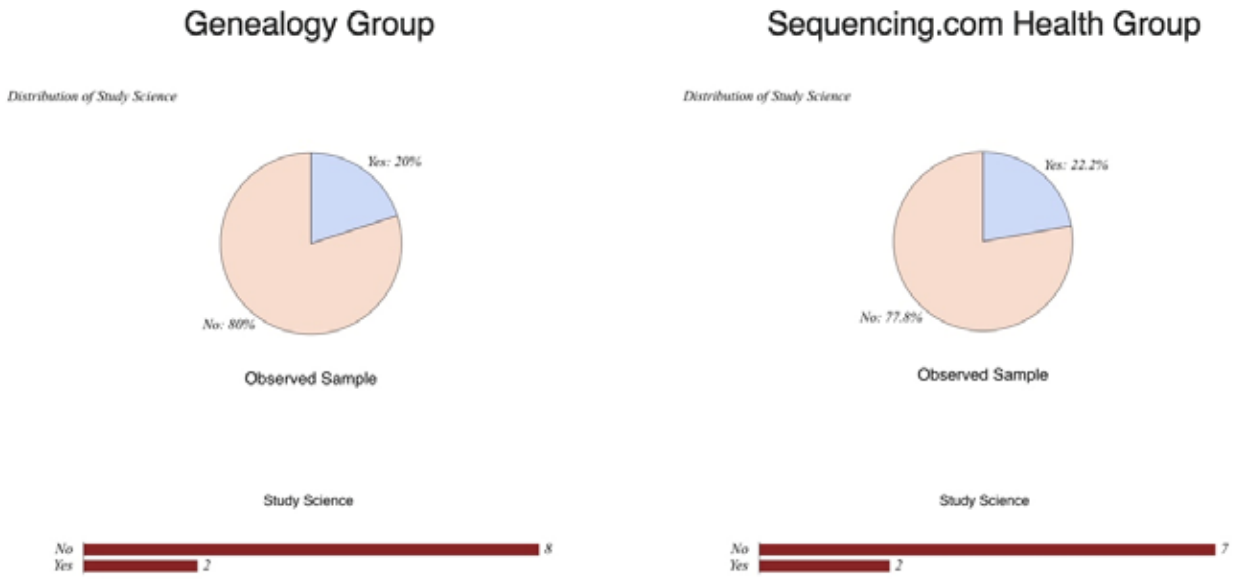

Figure 12: Studied Science by Group

Of the demographic variables, studied science was one variable which varied the least between groups, with both groups demonstrating a similar percentage of individuals who did and did not study science at a higher education level. This was explored because it was thought that it might influence how individuals came to be aware of DTCG testing, or how they perceived it. Understanding if studying science influences consumers may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.6 Employment Status

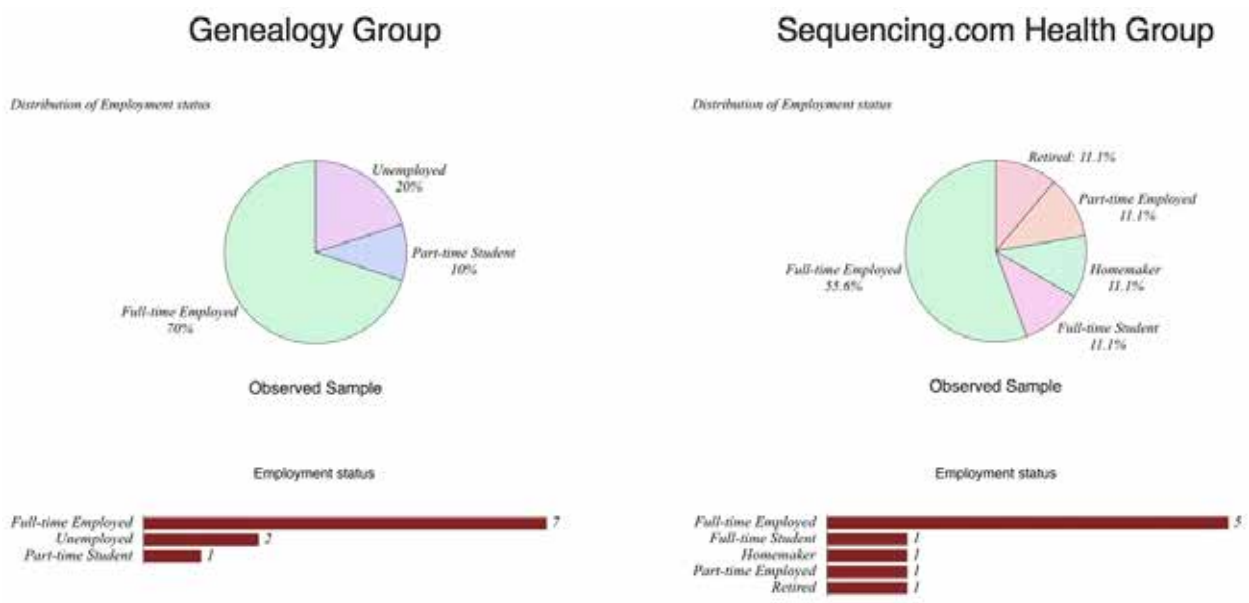

Figure 13: Employment Status by Group

Employment status varied considerably within the Sequencing.com health group, however, less so in the genealogy group. In both groups, full-time employment did represent the majority, which does seem to align with early adopters often having higher degrees of disposable income. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.7 Work in Science

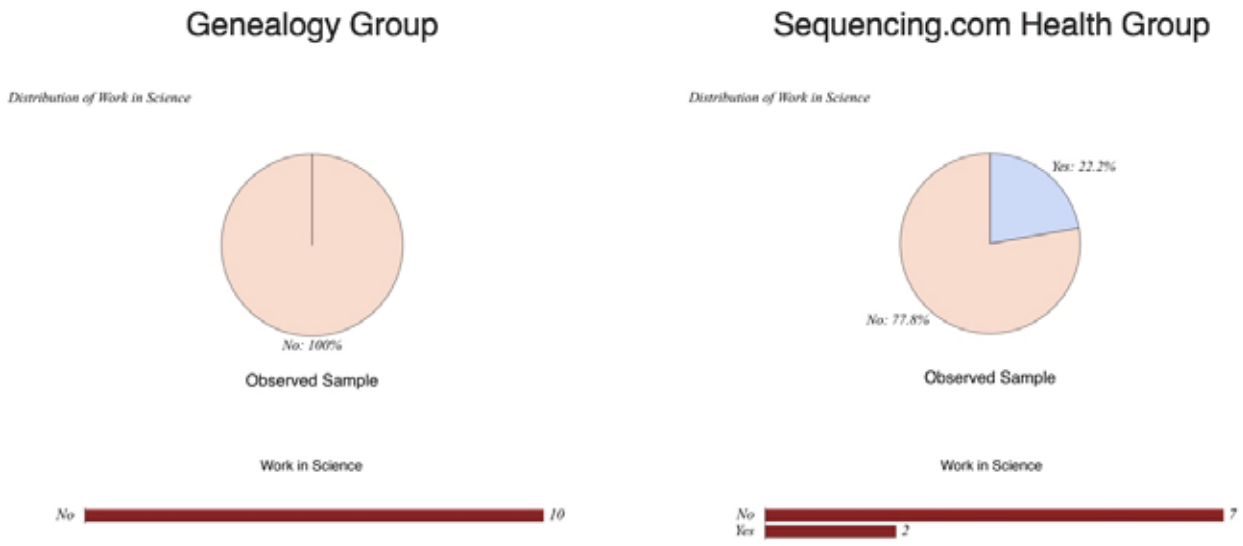

Figure 14: Works in Science by Group

Of the demographic variables, works in science was one variable which varied the least between groups, with both groups demonstrating a low percentage of individuals who do not work in science. This was explored because it was thought that it might influence how individuals came to be aware of DTCG testing, or how they perceived it. Understanding if working in science influences consumers may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.8 Income

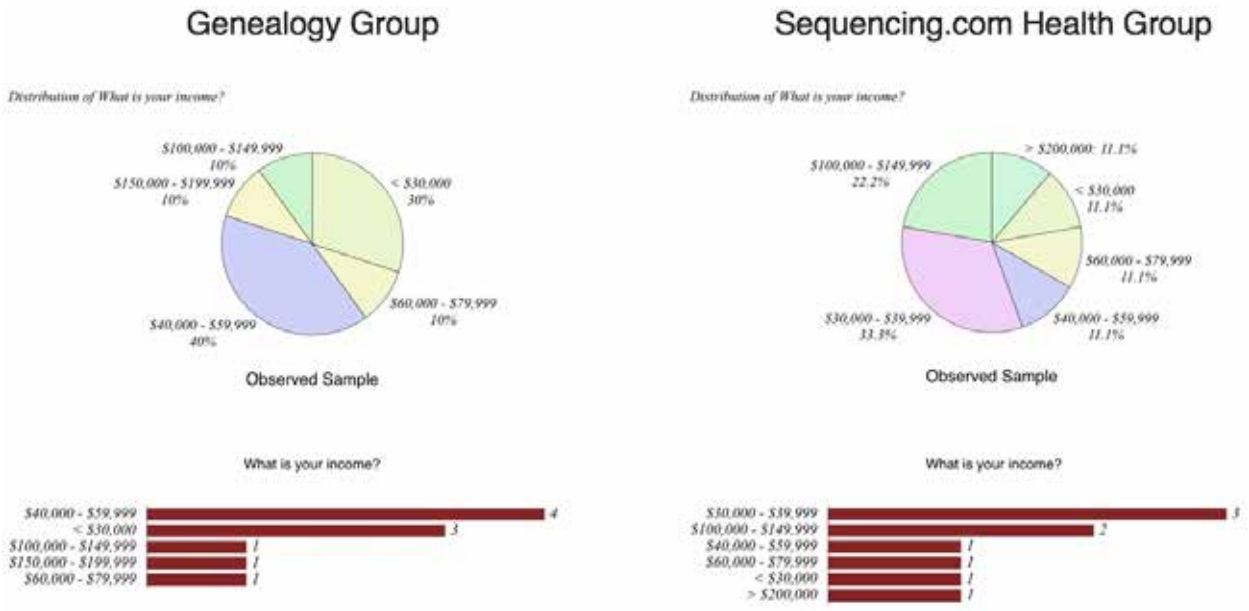

Figure 15: Income by Group

Income varied within both groups. However, the Sequencing.com group showed slightly greater variation, including being slightly skewed to higher income, which does seem to align with early adopters often having higher degrees of disposable income. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.9 Ethnicity

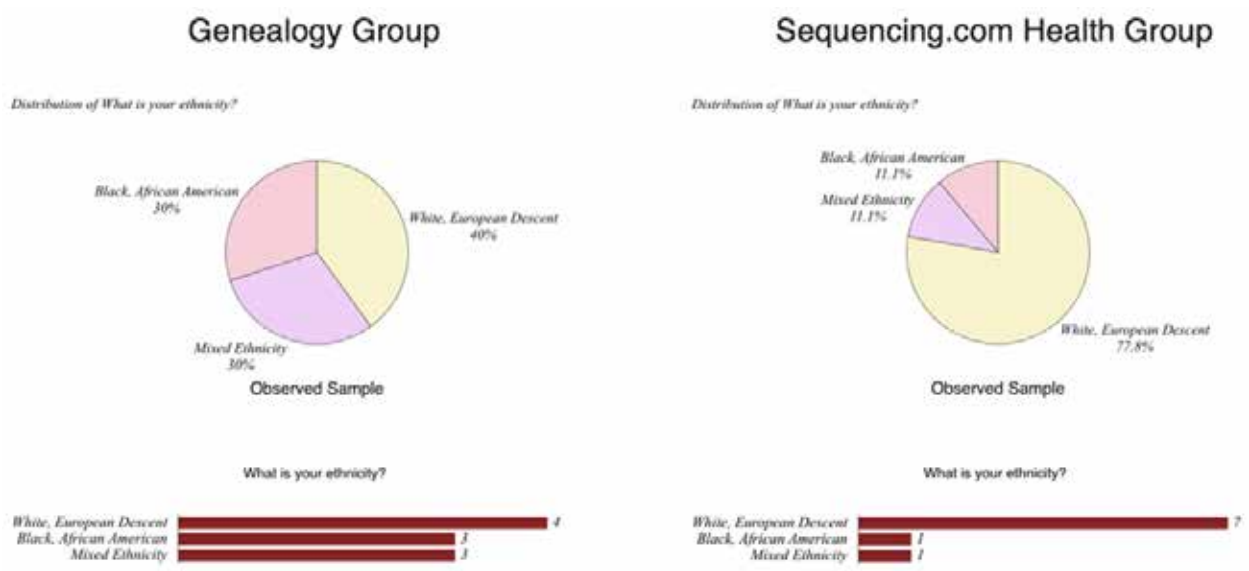

Figure 16: Ethnicity by Group

Ethnicity varied greatly with the genealogy group having three (30%) mixed ethnicity participants, three (30%) black, African American participants, and four (40%) white, European descent participants. The Sequencing.com group, on the other hand, was made up of one (11.1%) mixed ethnicity participant, one (11.1%) black, African American participant, and seven (77.8%) white, European descent participants. This was explored because it was thought that it might influence why genealogy consumers take the tests given that there is a large component of genealogy research that relates to group identity. But given the sample size, more research is needed to determine if this is representative of the consumer market.

4.5.10 Urban/Rural

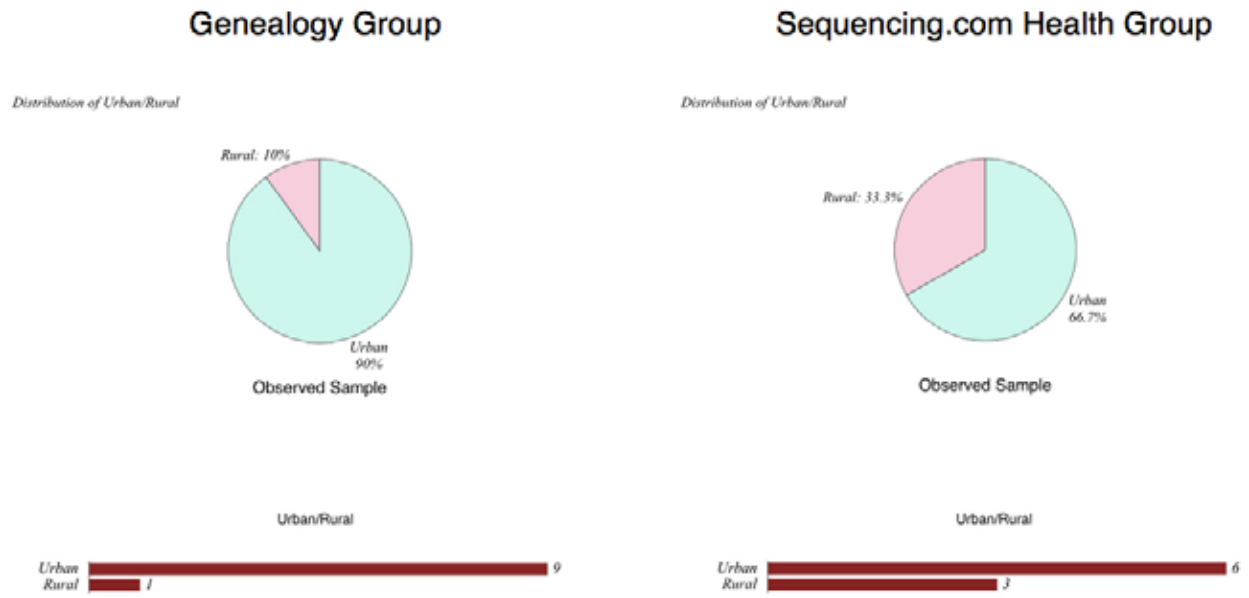

Figure 17: Urban vs. Rural by Group

The majority of participants lived in an urban environment, however the genealogy was slightly more urban. This difference may be important when defining the target market, but given the sample size, more research is needed to determine if this is representative of the consumer market.

4.6 Semi-Structured Interviews and Observations

A total of nineteen participants took part in this study. Ten of them had previously used genetic testing for genealogy services at least once, and nine of them had previously used Sequencing.com to analyze their DNA for health purposes at least once.

The genealogy group participated in virtual semi-structured in-depth interviews which were conducted via the screen share and conferencing service GoToMeeting. The audio was recorded for the genealogy participants, but no video. The

Sequencing.com group also participated in virtual semi-structured in-depth interviews, but the research session also included an observational component to gain a greater sense how participants make use of Sequencing.com in context. These sessions were conducted and recorded via the screen share and conferencing service GoToMeeting. The audio and video were recorded. The video which was recorded involved a screen capture of the user's monitor, and not of the user itself.

The interviews and observations followed a guide that sought to foster a natural conversation to uncover unknown insights. Throughout this research, the participants shared their past experiences, beliefs, values, perceptions, and concerns regarding DTCG, both as it relates to specific tests they had taken, as well as its larger role in society. At no time throughout the process did any participant skip a question, though they were made aware that if they felt uncomfortable with any question, they certainly could do so. Similarly, no interview or observation was cut short for any reason.

4.7 Qualitative Analysis

Qualitative analysis is the process by which social scientists make sense of the qualitative data they collect. It is inherently interpretive as it involves "reducing peoples' words to the researchers' words about the meaning of their words or actions or artifacts" (Bernard 2006, 452). However, it is my no means an unstructured or unguided process despite the data itself initially being unstructured. In fact, it is a very deliberate process with the goal of creating a structure that helps to explain the data. To accomplish this, researchers iteratively work through a cognitive process intended to find emerging themes in the data. This process requires "researchers to notice, define, describe,

count, compare and contrast, and match up things in the data that go together" (LeCompte and Schensul 2012, 92). Through this process, the researcher begins to retell the story based on how they see the relationship between the emerging themes and how those themes are situated in and related to the larger sociocultural context so that the deeper meaning within the data can be extracted and made shared.

In this research, thematic analysis was the qualitative method used to make sense of the qualitative data. Thematic analysis is a process for encoding qualitative data with codes. The codes are often descriptive, and then built up into a list of more interpretative themes. "A theme is a pattern found in the information that at the minimum describes and organizes possible observations or at the maximum interprets aspects of the phenomenon" (Boyatzis 1998, vii).

Thematic analysis was selected as a method because it is not a methodology tied to a specific theoretical or epistemological position like thematic discourse analysis, thematic decomposition analysis, IPA, and grounded theory. This is not to say that it is atheoretical, it is simply flexible in its choice of a theoretical or epistemological paradigm. Within the broader body of thematic analysis knowledge, there are various perspectives of how it should be carried out.

Some researchers believe in a top-down theoretical or deductive approach that is driven by the researcher's theoretical interests, or even the project goals and research questions, especially in applied research. This model of thematic analysis tends to provide a detailed description of the data that supports the researcher's theoretical interests or project goals, but it is often less of a rich or thick description of the data. Other researchers take a bottom-up approach that is more interpretive. In this model,

the themes produced may have less of a relationship to the data itself and may provide less support in answering the research questions directly, however, the insights produced often produce a richer or thicker description with larger sociocultural explanatory power (Braun and Clarke 2006).

4.8 Coding Process

To code the interviews and observation, the audio was first transcribed using artificial intelligence natural language processing services to get a base version of the text. The text was then cleaned by the researcher for errors and broken up by speakers. The text was then exported as a text document and added to a spreadsheet for coding. An initial top-down descriptive approach was carried out on a subset of the interviews to develop a working descriptive code template in the spirt of template analysis, which is one version of thematic analysis. This template was then used to code the remaining transcripts with the descriptive codes. Following this first coding step, a bottom-up interpretive approach was used in the course of this research to begin building the codes up into more interpretive themes and subthemes.

The goal of using a mixed methods approach for coding was to allow for both deductive and inductive approaches. The deductive approach was intentionally used to explore the specific research questions as it aligns to the theory discussed in the literature review. The inductive approach was used to uncover questions and insights that could not have been anticipated at the outset of the research. This holistic approach was valued because the research sought to understand and address immediate concerns as well as future concerns. Immediately, the research seeks to

produce actionable design anthropology informed insights that can help Sequencing.com better define their target market and whole product concept based on Moore's *Crossing the Chasm* for getting disruptive innovations adopted. But, the research also seeks to understand the larger sociocultural context of DTCG as a disruptive technology so that a long term strategic intent can be crafted that will support Sequencing.com in achieving a sustained competitive advantage as the innovation diffuses and the market matures.

4.9 Limitations of the Study

The potential limitations of the study include, but may not be limited to the following:

- The Sequencing.com group, while representative of the company's customer base in that it was about 70% women, is not truly representative of the United States and thus may not be fully generalizable to the consumer market.
- The interviews were based on self-reporting which may introduce errors in the data collected as a result of a mismatch between what the participants said, and what they truly do.
- The observations of the Sequencing.com health group participants were carried out virtually, thus limiting the ability to situate the participants' use in the complete context that is also environment aware.
- Triangulation or quantitative measures were not employed in this discovery study, and thus the findings may not be accurate or generalizable to the consumer market.

CHAPTER 5

FINDINGS AND ANALYSIS

This chapter details and analyzes the findings of the interviews and observations. The chapter is grouped into five major concepts related to the process of diffusion and adoption, the experience consumers have taking tests, and perceptions regarding potential future harm or ethical issues.

5.1 How Awareness of DTCG is Diffused

Bertrand Russell once said “he knows what he has seen and heard, what he has read and what he has been told, and also what, from these data, he has been able to infer” (Russell 2009, 9). Building on this one might say the ability to adopt an innovation is dependent on the ability to learn that an innovation exists. This applies to DTCG as it did once to flint axes, but it also applies to ideas or practices of a culture. Therefore, for us to begin to understand why a consumer would adopt a DTCG, we must first lean about the sociocultural processes that contribute to ideas spreading, and why they are adopted. In speaking with the participants, it was found that there were two dominant modalities of communication that supported knowledge acquisition, and that kinship and social norms played an important role in the awareness of DTCG.

5.1.1 Gaining an Awareness of DTCG

Dating back to the *Kulturkreis* school of diffusionism, anthropologists have argued that ideas, or cultural traits diffuse through a process of borrowing that radiates out from one or more cores. In the case of the diffusion of innovations, the DOI theory

demonstrated that this is often a result of communication that passes from early adopters or other figures of authority, to the subsequent adopters. When this happens, the potential adopters learn of the innovation, and can begin the evaluation process which ultimately leads to the decision to adopt or not.

Likewise, it is critically important to understand the communication channels that play a role in the process of knowledge acquisition. In the DOI, Rogers theorized this process was primarily carried out by mass communication (Rogers 2003). He based these ideas on information-flow theory, specifically Paul Lazarsfeld's two-step flow theory (Katz and Lazarsfeld 1955). In that model, the social influence of a few peers or figures of authority was the driving factor in making people aware of the new innovations. The peers or figures, are considered opinion leaders, who after learning of new ideas from mass media, spread them to others. Likewise, they have a strong effect on adoption during the evaluation stage of the five-step decision making process.

However, more recent research such as the Hilbert, Vasquez, and Halpern communication study cited in the literature review has demonstrated that the two-step flow theory model may no longer be the only model for the dispersion of ideas. In their research, both one-step and two-step models proved to be effective in transmitting ideas, and thus direct mass communication as well as ideas spread by opinion leaders played an important role in the process (Hilbert, Vasquez and Halpern 2016). Similarly, recent studies of DTCG testing have demonstrated the same. In one study that surveyed 3,185 participants, the majority of participants stated they learned of the tests through radio, television, and the Internet directly (Agurs-Collins, et al. 2015). In this study, both methods were found to be present, and in some cases appeared to work in

tandem with one reinforcing the other. Therefore, it does appear to be the case that multiple methods of communication play a role in the spreading of knowledge regarding DTCG testing.

In the present study, advertising was the most common modality for becoming knowledgeable about DTCG testing. Advertising typically came in the form of internet or TV advertisement.

> A lot of advertisements via TV and Internet. (Sarah – Genealogy Group)
>
> I know that like I didn't really know anybody who had taken it that I remember, but I know there was like a ton of ads. (Don – Genealogy Group)
>
> I was building my family tree on Ancestry.com and I kept seeing, advertisements about it. (Vanessa - Genealogy Group)
>
> Really through online, or not online, but through television ads. It was actually purchased for me from my, from my parents as a Christmas gift. So that's how we kind and I believe that's how they found out about it through like television ads. (Tom - Genealogy Group)
>
> Yeah, it was like an ad online. I was taking some courses online and I think it just popped up as an ad online and I got curious. So I went to look because I had been trying to look about our family history and I had heard some things that I didn't think were right about our family because my Aunt was doing some ancestral research and I didn't think she was doing the right historical research. So I got involved in that. (Erin – Sequencing.com Health Group)
>
> Probably the TV commercials once it became, you know, kind of mainstream and easy, easy to access it. (Scott – Sequencing.com Health Group)
>
> I think just mainly commercials when things like Ancestry and 23andMe came out. That was probably my first experience with even wanting to know more about it. (Sandy – Sequencing.com Health Group)

Social Influence was the second most common modality for becoming knowledgeable about DTCG. Social influence most often came from family or friends; however, in some other cases, it came from figures of authority such as teachers or doctors.

> My Dad did 23andme himself and then announced the fact that I did this at Thanksgiving a few years ago and the rest of us kind of got annoyed at him and said. Hey, what gives? And we ended up getting him into doing DNA testing for the rest of the family. (Amy – Genealogy Group)
>
> I first learned about it through my college. It was my geology class actually because we were talking about artifacts and looking at different fossils and things and then they mentioned that you can actually look up your own heritage and lineage your ancestry on different websites like Ancestry, so that's the first time I heard about it, and then they also had different commercials advertise on TV, so that's when It triggered in my mind, I just wanted to find out for my own curiosity what my lineage was. (James – Genealogy Group)
>
> A lot of people that I follow, well not a lot of people, but people were posting videos of their results and so it was kind of making me interested. (Eathan – Genealogy Group)
>
> Sequencing I actually saw an ad on Facebook someone had, and someone had posted on their ad that this had to be a bunch of hogwash and another person who had actually signed up through them said no, actually this is really good stuff and posted, all their results that they had run through and said, no, actually I had run my Ancestory.com stuff through it and it's actually really good stuff. And so I decided to go ahead and, and just run my stuff through it and the results I got seemed to be legitimate. (Erin – Sequencing.com Health Group)
>
> I was on a website or on Facebook actually and somebody had mentioned Genes for Good that they did free testing and so I signed up for it and I got it. (Robyn – Sequencing.com Health Group)
>
> I had some tests done in 2015, it was actually for cholesterol, but as part of that he [Dr.] did some genetic testing and so that was my first inkling that we could actually get our genes tested. (Brenda - Sequencing.com Health Group)

Interestingly, there was an inversion between the groups with the majority of the genealogy group first learning of DTCG testing through advertising, compared to the majority of the Sequencing.com health group first learning of DTCG testing through social influence. The difference may simply be a result of the different states of maturity between genealogy and health tests. This assumption of maturity is grounded in the estimated sales figures of leading DTCG companies such as Ancestry who is thought to control about 62% of the total DTCG market. (Forbes 2017). Likewise, it is being

theorized that the genealogical market is further along on the adoption curve than the health testing, and as such, is spending more money on advertising to attract consumers. However, more research is needed to understand if there are any other sociocultural forces mediating the type of communication that is affecting knowledge acquisition.

5.1.2 The Influence of Kinship on DTCG Adoption

Building on social influence as a broad modality of communication that promotes awareness of DTCG testing, the specific influence of kinship was explored. Kinship represents the network of social relationships a person is enmeshed in through descent and/or marriage. Since genetics are passed down through offspring, the concept of kinship is intimately connected to the DTCG genomics. But besides that, the sociality of kinship also appears to play a more influential role in shaping opinions that contribute to the decision to adopt an innovation or not.

In research similar to that of Rogers' early farm innovation research, it has been demonstrated that "structural features of the personal communication network - particularly connectedness and integration - in relation to kin membership in the ownership of the farm do contribute some understanding to the process of innovation adoption" (Warriner and Maul 1992, 289). In more recent internet-based research, kinship has been shown to increase the willingness of a consumer to provide personal information online (Limayem, Khalifa and Frini 2000).

Similarly, in previous DTCG studies, it has been noted that "the taking of DTC tests is typically not the solipsistic activity of an individual person, but something that is

done with, or with reference to, family members, significant others, friends, or even society as a whole. In this sense, genomic information is personal and social at the same time: it is personal, but for more than one person" (Turrini and Prainsack 2016, 5). In the course of this research, similar results were found. Participants often cited kinship relationships as a factor that led to knowledge acquisition and adoption. Many participants spoke of how their parents or siblings took the tests, and as a result, they wanted to as well. In fact, they often took the tests together, and parents spoke of ordering the tests on behalf of other family members such as their children. To this end, kinship was often a motivating behavioral intention for taking the tests because they wanted to learn about their genetics for genealogical or health reasons.

> Well my family was interested in it, so I, you know, I learned about, you know, what they knew and so it was always sort of talked about. So it was always an interest within my family as well. "So it was something I kind of grew up with it, you know, uncle so and so or, and so and so, or my cousin's such and such did such and such and live so on. So this place and that place, so it was interesting, I learned about were all interesting people and I found it kind of fascinating. (Ruth – Genealogy Group)

> Before the FDA thing, yes because at least when you come from a good family situation, you trust your parental figures, so based on that and the fact that I was in law school at the time and that they couldn't do a product that is bad, because of a products liability that is dangerous, that I trusted that they were going to, provide me with the results that were probably accurate and thereby helpful. (Amy – Genealogy Group)

> Doing my own research. Also my grandfather used that website as opposed to Ancestry. He had a good experience with it… Wanting to know more about my background. I'm not really one hundred percent sure about it. My family, they only really had a rough idea of our our roots. Yeah. So, when my grandpa did it, that's really what interested me could go on and do it myself. (Vanessa – Genealogy Group)

> It was actually purchased for me from my, from my parents as a Christmas gift. (Tom – Genealogy Group)

> Yeah, it was probably initially talking to someone. I don't think I saw an advertisement about it. Then I probably read some articles on it after that. Newspaper articles. But initially it was probably talking to friend or family member. (Alex - Sequencing.com Health Group)

> My sister, she's interested and because of me she joined the 23andMe and she's doing the research but she's not putting everything on the Internet. That's her choice. But she's interested in as well. So I'm always showing her what little I know and she finds a couple of things I didn't know. Anything I find out well it applies to her 50 percent. So she's always interested in that. (Scott - Sequencing.com Health Group)

> Well for my boys, they were both incredibly lactose intolerant when they were babies. We had real issues when we were trying to feed them when they were children. Horrible, horrible, horrible issues. And I mean we figured it out pretty fast, but then when we did the genetic testing on lactose intolerance, which was one of the free ones, it showed that they had, I complete genetic intolerance to lactose. Which makes total sense. Perfect sense because they still can't have any lactose and it just, it was kind of nice to have that test come through. Because the rest of my side of the family, we have no problems with that, but my two boys have a total problem with it and they've had problems their entire life. So it's kind of nice to see that verification just because they almost died because of it. (Erin – Sequencing.com Health Group)

> Actually I am in a same sex marriage and we are wanting to have children and I'm just interested in both of our genetic make when choosing a donor and trying to maybe eliminate some of those illnesses or diseases that are our genes may carry by offsetting them with a donor who don't know, who don't have those types of issues. So that was the original, I guess medical necessity for us before we have kids or before we started the context of doing that. (Sandy – Sequencing.com Health Group)

> I knew that my maternal grandmother had some half siblings that she had lost contact with and that was my main motivation. I wanted to see if I could find those people or their descendants and I actually did. So that was pretty exciting. That was my biggest one. And then just sort of the health things I thought would be interesting. (Claire – Sequencing.com Group)

This study found that both advertising and social influence were effective as a communication method to diffuse DTCG testing; however, of those, social influence by way of kin appeared to be the most powerful force. For not only could it produce awareness of DTCG testing, but it also appeared to enhance the sociality of the

process, and as the next section demonstrates, trust as well. Therefore, I argue that both advertising and social influence can and should be employed when marketing DTCG testing; to the degree that kin relations can be leveraged to influence adoption, they will increase effectiveness. Thus when defining a target market, it would be ideal to focus on the kin of previous adopters.

5.2 An Ecology of Trust: Science, Social Influencers, and Promissory Knowledge

Building on Rogers' DOI theory, other researches have sought to incorporate additional dimensions to the model to better understand the decision to adopt. One addition to the body of knowledge has focused on trust. Trust is broadly speaking a belief in the reliability or trust in something (Dictionary.com n.d.). Trust is especially important for e-commerce-based business models because typically consumers lack the human interaction they are accustomed to in traditional brick and mortar experiences. Furthermore, research has shown that online trust partially mediates consumers' behavioral intent, which is a key factor for adoption in the DOI (Bart, et al. 2005).

Given this, researchers have attempted to define what embodies online trust. While there are many definitions, Bélanger et al. (2002) defined trustworthiness as 'the perception of confidence in the electronic marketer's reliability and integrity" (Belanger, Hiller and Smith 2002, 252). This definition was used in the course of this research for two reasons. First, because DTCG testing is sold through e-commerce websites, and as a result, potential consumers need to have trust in the scientific claims that are being made on websites and/or advertisements. Second, because genomics is a highly

specialized and deeply complex science that most people are not formally trained in, and in the past, the reliability, or clinical validity of the tests has been called into question (Hogarth and Melzer, 2008). Given this, the research sought to explore consumers' trust in the DTCG products. They were probed about their trust in the claims of the DTC companies, as well as their trust in the results and science at large.

5.2.1 Trust in the Scientific Claims

In the United States people often do receive some form of health education during the course of their primary or secondary schooling; however, far fewer receive instruction regarding genetic education. Therefore, a small percentage of the population has any significant degree of genetic literacy, or the capacity to obtain, process, understand, and use genomic information for health-related decision making (Hurle , et al., 2013).

Despite that, a 2018 research study by the National Science Board demonstrated that Americans overwhelmingly support science and scientists (National Science Foundation 2018). In this study, only four out of the nineteen participants had studied science (biology, chemistry, or similar) at a higher education level, yet all of the participants had opted to take one or more DTCG tests; and in the case of the Sequencing.com participants, they had often analyzed their data using multiple web-based services. When asked about the claims the DTCG companies were making, the majority of the participants had a favorable view of the scientific claims outright, or after a brief bit of online research. Interestingly, in the responses, some participants stated

that they believed in the process because it was science based, while at the same time acknowledging that they didn't understand it.

One such participant, Don, articulated this best. Don is a millennial who has only acquired some college education and is working part time. He is not married and earning less than $30,000 per year. He has not studied science and does not work in science. He became aware of DTCG testing through an advertisement and was not influenced by kin. Though he admits he does not understand the science, he feels the companies are sure about the science, so he trusts in that.

> Yeah, I mean I was like, you know, I think it's all about genetics, so it's not something I personally understand, but these are companies that do genetic testing, like they seem pretty sure. You know, like scientific facts. (Don – Genealogy Group)

Other participants were less open about their potential lack of literacy, but were no less positive about the scientific claims.

> I understood that the science behind it made sense. Like logically you could tell from DNA what your heritage is. So I trusted the science as well as the testimonials. (Toby – Genealogy Group)

> Well, I didn't think it could be something as simple as done online. I thought it has to be like a whole lab procedure, where they draw blood, swab your mouth and look at your DNA, run some tests that'll take weeks only and it was like a whole procedure, but I just filled out the form online and it just broke everything down. For me it was, I thought it was going to be a whole drawn out process, but it actually wasn't. (James – Genealogy Group)

> Initially, I thought that it is cool that you could just simply spit into a tube and get us to the genealogy or health information at your fingertips. That's very progressive and hopefully helpful and later medical decisions you would make. (Amy – Genealogy Group)

> I'm probably slightly skeptical just because I don't necessarily know the number of respondents or the number of data points that they're comparing to. I'm sure it would say, but I'd have to actually look. But for the most part I feel like especially if something does have a good base of research that in general I can probably trust it. (Claire – Sequencing.com Health Group)

> I think I was little bit skeptical, but when I clicked the ad and I read into it more, it seemed pretty straight forward. I mean, you just send your saliva and that's it, you know, and wait for your results. I didn't have any limitations about wanting to do it. (Vanessa - Genealogy Group)
>
> I believe science is really, it proves a lot of stuff. I actually started out as a physics major in college... I have a very strong belief in it and you know cause my life started out that way. My father's an engineer, my sister's an engineer, so I do believe in logic. I believe in science. I believe in math and I'm encouraging my boys to go that way. (Erin – Sequencing.com Health Group)
>
> Just spit in the bottle and find out about your heritage and maybe some health things. So I thought it pretty neat." (Scott – Sequencing.com Health Group)

5.2.2 Trust in Online Social Influencers

Many participants appeared to put trust in the claims as a result of online social influences. Online opinion leadership can come in many forms. Historically, user-generated content (UGC) such as online reviews or forum posts were the primary modes of influence on the internet. However, in more recent years, brand ambassadors and social media influencers are also starting to play an important role. Interestingly, in almost all cases, these online social influencers do not share an immediate connection or relationship to the consumer, and yet, consumers often form their opinions as a result of what they read.

In this study, online reviews played an important role. Online reviews are part online reputation systems that allow consumers to share their thoughts and provide feedback on a product or service (Resnick, et al. 2000). Previous research has shown that consumers make significant use of online reviews when making a decision to purchase or not. In fact, in a 2010 survey of U.S. internet users 92% stated that they read online product reviews and 89% of them stated that product reviews influenced their product choice (Freedman 2008). In this study, participants made similar

statements. Interestingly though, almost all of the participants that did were part of the genealogy group.

Eathan, an African American full-time employed, married Gen Xer, summarized the trend of looking for reviews best. As he stated, he reads reviews before buying anything online. For Eathan, the volume of stories on Amazon was important, as was the ethnic diversity of respondents.

> What I do is when I buy anything, I always read reviews. So, I went to Amazon and I was surprised they sold it on Amazon and then there was a lot of reviews. Like, I think Ancestry had like thousands of reviews and it was mostly positive. People were writing long reviews saying it's very well done, you know, it's pretty good. They're giving pros and cons, but most of it was positive reviews. And all types of people, you know, European people, African people, all types. So I kind of had a good feeling because it was getting good word of mouth from the reviews. (Eathan – Genealogy Group)

Many of the other participants did not read as many reviews, or specify the same criteria of volume or diversity as Eathan; however, they too deemed the opinion of others to be important.

> For the most part because we read some online reviews as well and saw that it was like legit, it wasn't like a scam or anything like that. So I mean, you know, just looking at some different online reviews or you know, reading an article about it, you know, kind of looking at it a little bit more and you know, it seemed like a legitimate, a illegitimate deal. (Tom – Genealogy Group).

> I wanted to make sure they would keep my genetic data private and safe and secure. Once I, you know, I read a couple reviews on it once I made sure that, that, that was the case, then I didn't have any qualms about using the site. (Alex – Genealogy Group)

> So when there was some kind of a sale or a special and I kind of looked at all the DNA tests and this particular one had pretty good reviews. So I was like, OK, well let me just do that. (Tracy – Genealogy Group)

> I read a couple reviews on it once I made sure that was the case, then I didn't have any qualms about using the site… I looked at a different articles, different forums for people who had used it previously or were currently using. It's kind of different reviews out there. (Alex – Sequencing.com Health Group)

Other participants did not reference online reviews, but other forms of online opinion leadership such as testimonials, social media comments, and webinars that acted as a social influence on their decision to adopt.

> The advertisements use personal stories of people who have actually gone through the process and found out interesting things about their heritage that they didn't know. And I understood that the science behind it made sense. Like logically you could tell from DNA what you're heritage is. So I trusted the science as well as the testimonials. (Toby – Genealogy Group)

> I would say probably on YouTube probably the first time I heard about it. and like two years ago, I feel like maybe two and a half years ago... Yeah. A lot of people that I follow, well not a lot of people, but people were posting videos of their results and so it was kind of making me interested in and aware of the products that you actually could buy the kit and get your DNA tested. (Eathan – Genealogy Group)

> Sequencing I actually saw an ad on Facebook someone had, and someone had posted on their ad that this had to be a bunch of hogwash and another person who had actually signed up through them said no, actually this is really good stuff and posted, all their results that they had run through and said, no, actually I had run my Ancestory.com stuff through it and it's actually really good stuff. And so I decided to go ahead and, and just run my stuff through it and the results I got seemed to be legitimate. (Erin – Sequencing.com Health Group)

> It was actually the, that Webinar I mentioned, I hadn't realized still that you could, that there were sites that you can upload your raw DNA data to and get health information back from it. I was thinking, that I would just have to talk to a doctor about it who explain different things were... One of the things she talked about was just sort of lifestyle things like, you know, what would be the best kind of exercise and, you know, should you be drinking caffeine or not and that kind of thing. So that peaked my interest, but I do have some genes that popped up that concerned me and I thought, wow, I really need to research this some more and this could be a good first step. (Brenda – Sequencing.com Health Group)

> I was on a website or on Facebook actually and somebody had mentioned Genes for Good that they did free testing and so I signed up for it and I got it. (Robyn – Sequencing.com Health Group)

5.2.3 Trust in Claims of Promissory Future-Oriented Knowledge

Other participants appeared to be less trusting in regards to the science claims of the DTCG companies but were still willing to try the DTCG tests based on the belief that

they might learn something interesting about themselves. Though hesitant, they expressed hope or the desire to learn cool stuff.

In previous literature, the exchange of genomic data for potential future value is considered representative of the promissory capitalist model of the new bioeconomy. In the case of DTCG, that model is grounded in the concept of future-oriented knowledge, which is based on the assumption that over time consumers will be able to learn increasingly more about themselves as more people share their genomic data, since the predictive power should rise with more data. The belief that over time there will be more predictive power is grounded in the ability to conduct statistical analysis of genomics at the population level. It is a perspective that can trace its roots to the concept of medicalization. A corollary to medicalization in our modern technoscientific molecular era is geneticization.

Geneticization is a term used to describe the “expansion of health and illness via genetic technologies; differentiation of individuals on the basis of genetic variation; construction of biological phenomena through inappropriate labelling of health and disease as ‘genetic’ rather than social, structural or environmental; political economy of disease prediction and prevention; and socio-cultural expectations that reinforce the use of genetic technologies, especially in the context of women’s reproductive choices” (Arribas-Ayllon 2016, 133). In our increasingly geneticized world, patients have become consumers who believe through commercial transactions they can understand themselves fully by way of genomic analysis. In this study, numerous participants embodied the hope and spirit of the promissory economy, even in many cases without the ability to verify the reliability of the science that their trust ought to be based on.

The lore of future promises was most interestingly described by Tracy. She is an African American who feels her identity, as well as the history of her people were ripped from them as a result of slavery. She passionately wants to learn more about her identity, and wants to believe the claims of the DTCG companies. For her, it would be a dream come true to learn more about herself as a result of her genetics, and trusts out of hope in the potential future knowledge she may learn.

> You know, I was like, I don't know, I don't, I don't know for sure and knew like it could've been a possibility and I was clinging to the hope that it was true. So it's kinda like, it's kinda like a child's fantasy when they say, you know, you're gonna meet this princess and even though you may not ever meet the fairy princess, you always, you always dream about the possibility of meeting that very princess or growing wings and flying off or meeting ferry and stuff like that. So it's always that hope and that dream kind of like childlike behavior. And so I wanted it to be true, but I don't really know. (Tracy – Genealogy Group)

Most other participants were far less passionate in articulating why they trusted the future promises, but nonetheless felt it was worth doing to potentially acquire that knowledge.

> Well, when I first read it, I didn't have much. I was like, I was kind of. How can I say. I was like, I didn't believe it. I don't believe it, I'm like no. Like no this can't be for real. Like no. These tests, no how accurate are these. Like, I didn't believe in it. You know what I'm saying, they can't be real. Only way to find out if it's real, so some of your heritage and then do it. (Sarah – Genealogy Group)

> You can't trust everything, you know, until you just make yourself a test dummy. I figured it would be a good shot to be something to learn from. Especially something about myself that I didn't know. So I just gave it a shot man. Why not? I got nothing to lose. (James – Genealogy Group)

> I mean a lot of it is hypothetical and theoretical, so, I'm just interested in seeing how far we can advance. (Scott – Sequencing.com Health Group)

> I think you know, at the time it was, it was newer and at the time I was a little skeptical that it would be able to give you results that accurately reflected your risk, since it was so new and there was I guess limited amount of information at the time among other people and then genetic testing overall. But now as, as it's been a few years now and there has been more people who have done these

> tests and there's a lot more data they can correlate different risk factors, I'm becoming more confident in the analysis. (Alex – Sequencing.com Health Group)
>
> Not immediately. I certainly did a lot of research just into it in general to see how they would sort of be able to use my information because that was my main concern. But I was kind of was overruled by all of the cool stuff I could find out. (Claire – Sequencing.com Health Group)
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> I think it makes things a little easier, yeah. I mean there may be things that maybe the genomic testing when we might have to do more genetic testing. When the genetic testing easier and more accurate, we may have to do them again sometimes. Especially when my kids get older, you know, when you might have to do it again because I realize science gets better, techniques get better. So we're not going to just go with what we've already done, but yeah, I think, I think this is definitely this is a, this is the way of the future. If you asked me, I think we should just be doing this kind of stuff. (Erin – Sequencing.com Health Group)

The two methods examined for building trust proved to be effective in influencing consumers to adopt DTCG testing, and given that, some questions arise. Is it fair to intentionally appeal to consumers through promises of future oriented knowledge which may or may not come true? Should consumers be listening to social influencers who themselves likely came to believe the claims through the same process earlier in the adoption curve? Who should be the opinion leaders if scientists and businesses have previously demonstrated cooperation through the process of medialization?

While this thesis may not be able to answer those questions universally, it does suggest that when marketing DTCG products, it would be more ethical from a utilitarian perspective to base any claims in the present realities. To that end, companies offering DTCG products should describe shortcomings in methods, datasets, or scientific basis ought to help consumers make the most informed decisions, given that most lack formal science knowledge about such products.

5.3 Identity Making: The Body, Others, and Place and Time

In a 2016 study, Turrini and Prainsack stated that “genetic or genomic data can serve as a starting point to tell a story about ourselves, claim a place in the ongoing evolution of bio- medicine, or contribute to medical research” (Turrini and Prainsack 2016, 6). When speaking with participants in this study, that claim proved to be true.

For the participants in this study, the motivation to take a DTCG test often was related to understanding oneself and/or their kin. This interest frequently involved concepts of the body, place, and time - the past or the future. In some cases, participants were interested in both themselves and their kin, as well as the past and the future. Furthermore, a difference between the two groups emerged with the genealogy group often very specifically articulating their desire to learn more about family history, and the Sequencing.com health group most often stating their interest was personal health.

However, it should be noted that all of the Sequencing.com health group participants also took one or more ancestry tests in the past. Taking these tests is the method by which they got their genetic data for analysis on Sequencing.com. Given this, some of the Sequencing.com participants also mentioned family history as an interest. Similarly, some of the genealogy group used 23andMe as their testing service which resulted in them receiving health data, and thus some participants from this group also mentioned health as an interest.

Therefore, while the two groups primarily leaned in one direction or the other, there was a degree of overlap in regards to interest, and though the data could be

analyzed from a family history versus health perspective, other more salient concepts emerged in analysis.

5.3.1 Narratives of Self in Relation to the Material Body

In medical anthropology, the body is a quintessential unit of analysis that is rife with overtones of the physical, psychological, and symbolic. It is at once material and ephemeral, with distinct meanings at the cultural, societal, and individual level. To this end, concepts of the body are social constructs that grow out of the cultural beliefs of a group of people, as Marcel Mauss discussed.

According to Mauss, behaviors such as acceptable facial expressions and other physical acts are largely shaped by the group we live with (Mauss 1973). As such, the material body, and the social meanings that are embodied within our understanding of it, have varied historically throughout the cultures of the world. And while the diversity of thought concerning the body has been demonstrated to be vast, it was not until the past 60 or so years that the concept of the body took on a distinctly western biomedical conception. This trend, which grew out of the conception of medicalization and geneticization previously discussed, is resulting in wholly new conceptions of identity that are at their essence, biological.

These new conceptions of self are based on Paul Rabinow's concept of biosociality, or an identity based on genetic or biological conditions. These conditions have the ability to alter one's own sense of personal identity, as well as the social relationships they are part of (Rabinow, 1996). In this study, it was found that the majority of participants echoed these ideas, with participants emotionally speaking

about DTCG in relation to who they were, as a result of their genetic lineage and makeup. This was found in both the genealogy and health group, albeit in slightly different ways, with the genealogy group feeling their genetic identity defined who they were in relation to concepts of ethnicity, while the health group framed their identity in more of a biomedical way.One participant, Ian, was particularly interested how his genetics shapes his unique health and social identity. As a full-time employed married millennial working in science, with an undergraduate education in science, he articulated this point the clearest.

> I was definitely excited to like learn about what specifically my body or what the DNA would say about the things that are unique to me and the family ties or the health aspects of it too. It can be within that. (Ian – Sequencing.com Health Group)

Other participants, while possibly not as succinct as Ian, also made refences to the materiality of their identity of self.

> Just to know my background because you know, anybody can say that you know I'm Caucasian or that I'm African American, but they don't know to what extent that they are Caucasian and African American. So I just want to know a little bit more about my own ancestry and what genes comprise this beautiful specimen. (James – Genealogy Group)

> Yeah, I mean because again, I came from the sperm bank in New York, you know, a specific time in a specific place and the people that were living there were, you know, of certain nationalities and because I look so different from my mother, I assumed it was like southern European and the people that were in that area were Italian and Jewish, so I was like, well I'm probably Italian or Jewish or something like that from that area vaguely of the world. (Don – Genealogy Group)

> I'm curious because I've got some things going on that the doctors can't figure out… I thought that could be a way to open up a whole other realm of possibilities for them to be able to try to figure out what's going on… Yeah, more the medical aspect of it and you know, learning more about what I can do to keep inflammation down and get my body to the point where I can do those other things, where I can do more than just walking, where I can do exercises without having such exercise intolerance that I dropped… I'm not as hard on myself, for

> things and I'll say, you know, this just, this isn't because I'm overweight or it's not because of something else Its this condition that's causing a lot of things to happen. And I hate to say it, but you walk into doctor's office and the first thing they do is look at your size and they go, well, you're overweight. You need lose weight and that's why you are having all these issues. They don't go into the underlining, you know, neurological issues or anything like that to see what's going on. (Robyn – Sequencing.com Health Group)
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> I was interested in what genes were responsible for, you know, the susceptibility for different diseases… I'm just being aware of certain things that I am, you know, I guess more likely to experience just based off of my genetics. (Sandy – Sequencing.com Health Group)

5.3.2 Narratives of Self as Part of a Group

Building further on the concept of biosociality, it was observed that participants often spoke of wanting to learn more about themselves as a function of learning more about others. However, the notion of the other was not used in the reductive sense of "othering." In fact, the participants were referring to members of their "us" group, typically kin or distant members of their assumed ethnic clan. Many of the participants, particularly in the genealogy group, felt that by understanding their family history and ethnicity, they were better able to understand who they were.

For many of the participants, this sense of wanting to know about their "us" group was further amplified by feelings of uncertainty given life circumstances. One participant, Don, aptly demonstrated this. Don grew up in a house with a mother and father, however his father was not his biological father, given that his mom went to a sperm bank. As a result of this, he longed to understand his identity through the lens of his father, but he also longed to find others who shared this narrative of being a sperm bank child. Through DTCG testing he was able to find out about his father's ethnic identity, as well as network with others who fit the sperm bank child persona.

> Well for me personally, my mom went to a sperm bank to be impregnated with me so I didn't know what my ethnicity was on my paternal side. So that was like the, for sure the main factor… now I more understand, there's other people like me out there who like had paternal sides they didn't know about who came from, you know, the same situation. I don't know anybody else with my story quite my story and now I have, you know, at least two half siblings that I know of who share a very similar story and share the same father. (Don – Genealogy Group)

Similar to Don, many of the other participants shared stories of uncertainty as a result of not knowing the history of their parents given challenging life circumstances, or in some cases simply because of a lack of generational knowledge about the family ancestry.

> Mine was to find out you know more history on my background because my parents are addicts. So, I really wasn't raised by them so I don't know much about my background. I just knew I was Black, Mexican or Filipino. And I said well, there's gotta be more to it. You know just out of curiosity I did it… It was just to find out my ethnicity. I wanted to see what type of bloodline I come from given my DNA. (Sarah – Genealogy Group)

> I was interested because I wanted to learn more about my family's background in terms of where we may have come from as well as the health aspects, that I may or may not have been more at risk of. … Because my father is Jewish and my mom is Episcopalian I wanted to see where my ancestors came from both from the Jewish side point of view, even though I'm not Jewish because my mother's not Jewish, I consider myself Jewish regardless of that. And I wanted to see where the rest of the family came from… Yeah. I have a medical condition that affects us. Well it affects anyone, but it affects Ashkenazi Jews, my particular gene or whatever, that I could understand of it, affects more Jews than other people. (Amy – Genealogy)

> I thought it was really interesting. I've always been curious about my ancestry and my roots, so it's definitely something that appeals to me usually I don't respond to ads, but that actually did that time… Wanting to know more about my background. I'm not really one hundred percent sure about it. My family, they only really had a rough idea of our our roots. Yeah. So, when my grandpa did it, that's really what interested me could go on and do it myself… Yeah, my mom's side of the family, they've always suspected that their French Canadian. So, I wanted to verify that myself and it did come back to be true, to some extent. (Vanessa – Genealogy Group)

> I mean I thought it was a neat process because we always assume where we were from or you know, where our heritage was or whatever else. And then this

could either confirm it or kind of peak some interest. Cause I know that my grandmother, my maternal grandmother was adopted. And so, you know, there's always some uncertainty there. You know you never know where you might come from. It was just kind of a neat idea to kind of really, you know, kind of hone in on where, where we came from. (Tom – Genealogy Group)

I thought, I thought it could be a really interesting from a health perspective. I thought I would want to know if there was anything high risk I should be concerned about. Anything along those lines cause my, my father is adopted. So there's kind of an and unknown in that area… Like I said, my father was adopted. It's like an unknown area. He has a couple issues, but beyond that we don't really know what kind of medical history his side of the family has. So I thought it would be, it'd be great to kind of get to know that especially I now have a daughter and it would be good for her to know as well. (Alex – Sequencing.com Health Group)

We did the genome testing through ancestry.com because we actually live just next to a large Indian reservation and my kid's dad had told us that he had native American blood in him and here it's very big thing to know whether you have native American blood in you. So we needed to know whether we had native American blood in my kids. And then when I found, that Sequencing app online, I thought it would be a good thing to know more information because my kids were preemies and we had a lot of health issues with them when they were children and we had done testing on one of the kids. So I figured I would run everything through the available Sequencing apps that we were able to afford. (Erin – Sequencing.com Health Group)

5.3.3 Narratives of Self in Relation to Particular Places and Times

In participants' narratives, their material body and their "us" group were often situated in relation to particular places and times to further define their identity. For many of the participants, there was a deeply historical aspect to how they perceived themselves to be, as a direct result of the trials and tribulations of their ancestors. For some, particularly African Americans, the concept of lost time or history under the bondage of slavery was the most prevalent idea. However, family members coming from a distant geography for other reasons were also mentioned.

One participant, Tracy, most poignantly and passionately described her lost history as an African American. For her, the concern was not only immediate, but also

historical, as the structural violence carried out as a result of slavery has resulted in both the loss of her connection to her early American roots, but also the loss of connection for her ancestors to their African roots.

> I wanted to understand more of my ethnicity because African Americans, our history was lost. It's been decimated. And some part of me wants to know where I came from and where my ancestors been. Just because as an African American during the slave period, our history was ripped from us. We don't have that, that sense of legacy and so understanding where we've been gives, I guess gives a little bit of piece of my journey. My ancestors previous journey throughout the years. And so having that understanding that sense of self-worth and that we're more than just slaves. (Tracy – Genealogy Group)

Similar to Tracy, the majority of other participants in this group spoke of this particular problem with African American history; however, a similar problem of historically oppressed people was also found with Ruth discussing her family's Jewish heritage in Europe.

> Because of my particular heritage, a lot of records were lost or destroyed. So I was just hoping somehow, or somehow some way it could be found. (Ruth – Genealogy Group)

> Well personally in my case is I'm mixed. My father is African American and my mother is Korean. So that being said, I think it's a little harder to know your ancestry, especially being black in the United States. So I was kind of curious to see what will come back because we don't always know like, you know, a full family tree and you know, what countries we came from in Africa, etc. So it kind of was curious from me being what I am… Yeah, because really that was one of the main reasons too that I was interested in doing it was because my father, he passed away a years ago, but when he was alive he was not very, he didn't do a very great job of like really telling us about our roots and stuff. He really didn't tell us everything about our family. So we kind of were in the dark a lot of things. And because of our last name, I know a lot of Jamaicans have that last name, because I've met Jamaicans and they heard my surname, they said, oh, that's a very popular name in our country. So I was curious if they had more Caribbean roots. (Eathan – Genealogy Group)

> I should do it and see what all I'm made up of I guess. I think for me, because I am African American, I don't have it, I don't have as much information as far as heritage goes where I can like trace my lineage back generations. I can only go back a certain number of generations before there is like no information. So it

> was just interesting to me to want to get that information based off of my genetics. (Sandy – Sequencing.com Health Group)

Identity was demonstrated to be a crucial factor for choosing to adopt DTCG testing, be it for genealogy or health purposes. Given this, it is theorized that narratives of identity, along with the related concept of kinship, appears to be a fertile ground for appeals to consumers for use in advertising and language on the website. However, given the previous section concerning trust, it is also advised to not overstep or over promise what someone will uncover. Has was demonstrated by most participants, especially those in the Sequencing.com group, consumers today appear to go from testing service to testing service in hopes of learning more, plausibly as a result of shortcomings in the results or, at the very least, the presentation of the results.

5.4 A Biosocial Rite of Passage

Rituals were broadly defined by Victor Turner as prescribed formal behaviors for occasions not given over to technological routine, having reference to beliefs in mystical beings or powers (V. Turner 1967). They are known to exist in all cultures, and likewise, the study of ritual has been a hallmark of anthropology since its founding (Bell 1997). One type of ritual, rites of passage such as marriage or death, represent the transition from one state to another.

Rites of passage, and rituals at large, have been studied through the lenses of cultural materialism, functionalism, historicism, postmodernism, symbolic, and other anthropological theories for decades. Early leading figures like Durkheim and Mauss expounded on the role rituals play in society, and anthropologists since then have pored

over their meaning, frequently debating what constitutes a ritual. But despite the debates, one fact few have denied, is the importance of rituals to culture.

In the interviews, an unexpected finding emerged: all nineteen study participants described sharing the results of their tests with important people in their life. Their descriptions of this sharing moment gave it a ritual flavor, often with considerable emotional content. These sharing moments can be regarded as the completion of a rite of passage in Van Gennep's sense (V. Turner 1967). Participants have taken on a new identity and are communicating it to their social world.

Participants shared test results with family, peers, and in some cases people of influence. Many of the genealogy participants sounded especially excited when describing the process of sharing. While the Sequencing.com health participants mostly shared their results privately with their families, participants from the genealogy group often did this quite publicly, even going so far to share their results through social media to their extended networks. From a DOI perspective, the sharing ritual may be understood as the moment where DCTG users influenced the next wave of adopters.

Of the participants, Sarah was possibly the most vocal and excited when discussing sharing. For Sarah, an individual who demonstrated a relatively low level of genomic literacy throughout the interview, was incredibly interested in sharing her personal results with many of her social circles, including on online via Facebook.

> So yeah I've shared my information with everybody, my bosses my co-workers my kids my family. I have a Facebook page. I even took a screenshot of my results and post on mine. I shared a lot.. Just to put it out there like wow this is different. I took this test you guys and it worked. Wow, this might be a good thing that they've created. It is here to help us you know connect our long lost family members you know and maybe. Later on in years it will be a little bit cheaper where we can all afford it and start connecting our families. (Sarah – Genealogy)

But Sarah was by no means the only participant to share their personal data with vigor. The trend occurred equally throughout both groups, though as stated above, the health group was a bit more private in who they choose to share the data with.

> Just whole world knows now it's on Facebook…. It wasn't me necessarily trying to share the data. I just wanted to put it out there that there is something out here in case you were wondering if it can help you break down your, your, uh, ancestry background. So it was more like a free advertising type thing. (James – Genealogy Group)
>
> Yeah, I mean I posted it on Facebook. I showed my friends, I took screenshots and texted it to people. (Don – Genealogy Group)
>
> I Instagramed, the result and that's where I had to go back to it. (Tracy – Genealogy Group)
>
> I just verbally told people about it to…. they were friends but with a similar heritage. (Ruth – Genealogy Group)
>
> We share, we share them as a family and we share them with our extended family and you know, and even a couple of friends here and there too. (Tom – Genealogy Group)
>
> Yeah, the doctor, my twin sister and mother. (Amy – Genealogy Group)
>
> I told my family members about the results. (Vanessa – Genealogy Group)
>
> When I got my 23andMe results, I emailed a pdf of them to all of my immediate family members and then my aunts and cousins as well, even though they won't get the same results, I thought they'd be interested, especially in the maternal haplogroups since they're all on my mom's side then because we would share the same one. So some of them were more excited than others, but I am not sure how much I know my parents are interested in and getting their testing done. And I've done my 92 year old grandmother cause I was like, I just knew I would be so upset if something happened and I didn't get a chance to. So, and then my dad has just bought some for his parents, so, hopefully they'll get those in pretty soon. And that's the other thing I'm looking forward to see what genes came from, what parents and then which grandparents since… I thought they would find it interesting and I certainly found it interesting. So, I just wanted to share… I was certainly excited to share it with my family. maybe I was a little bit apprehensive with the doctor just because I wasn't entirely sure what their reaction would be. But I did get a pretty good reception, I would say they were, they were skeptical but not dismissive. So I thought that was, I don't know, that was a pretty good reaction to me. (Claire – Sequencing.com Group)

> I sent the report to my father because he was interested in some stuff and his wife was curious about it and so I sent it in terms of I sent my data as an example with explanations on how to interpret certain things. (Sophia – Sequencing.com Health Group)

> With my friend who was, she was curious what tools were out there. So I was sharing to show her an example of what she could get for herself. (Sophia – Sequencing.com Health Group)

> My family, and I did show my exercise one to my physical therapist. (Erin – Sequencing.com Health Group)

> Oh yeah, I have. I shared you know everything... I made it open source… If you go to Open Humans, I'm there and I shared all the DNA and I got all kinds of medical stuff. A lot of personal information in there. (Scott – Sequencing.com Health Group)

Since DTCG testing is still a privileged action, given that only an estimated 12 million US consumers have made use of the tests (MIT Technology Review 2018), the process fits Bell's conceptualization of ritualization (1992). Bell argues that ritualization is "a way of acting that is designed and orchestrated to distinguish and privilege what is being done in comparison to other, usually more quotidian, activities" (Bell 1992, 74).

5.5 The Current User Experience Landscape

User experience "encompasses all aspects of the end-user's interaction with the company, its services, and its products" (Nielsen Norman Group n.d., para 1). To achieve this, a design needs to meet the user's exact needs without any difficulty. But, it also goes beyond this basic premise. A good user experience also ought to delight the user. To deliver a good user experience, designs need to execute on critical aspects of the experience or interaction consumers will have with a product (Nielsen Norman Group n.d.).

One such critical aspect is utility. Utility is based on whether or not the product or service provides the features you need. Building on that is the concept of usability. Usability is indicative of how easy or pleasant something is to use (Nielsen Norman Group n.d.). It is important to any product or service but is intimately important to something like DTCG testing given how disruptive it as. For as Christensen theorized, disruptive innovations which are defined by competence-destroying discontinuities, require new skills, abilities, and knowledge; and therefore, require more effort on the part of the consumer (Christensen 1997).

Utility and usability come together and dictate how useful a product or service is. Usefulness is important because it contributes to why consumers adopt, if they continue to keep using the product and if they recommend it to others (Nielsen Norman Group n.d.). Thus, it intimately relates to the decision, implementation, and confirmation steps of Rogers' DOI theory. The research sought to gauge the participants' perceptions according to these concepts.

5.5.1 Utility and Lack of Information

The concept of utility is grounded in solving the need of a user. To that end, it is related to features a product or service, as those features are the functional aspects that can address the user's needs. In this study, the need the participants were looking to solve primarily echoed the sentiments captured above in the identity section. Per those findings, the primary goal of the participants was to learn more about themselves from a genealogical and/or health perspective. This applied to applied to all nineteen participants. The only other forms of utility voiced by the participants were to find

relatives. However, only three participants mentioned this in the course of the research, and one other participant mentioned contributing to science.

> I was intrigued and interested in and I thought it would be really cool to find out more specific detail about my genetic history and my heritage. I kind of had a general idea of where I'm from, but I thought it'd be cool to find out more specifics and maybe find out something that I didn't know. (Toby – Genealogy Group)

> Well for me personally, my mom went to a sperm bank to be impregnated with me so I didn't know what my ethnicity was on my paternal side. So that was like the, for sure the main factor. (Don – Genealogy Group)

> I wanted to understand more of my ethnicity because African Americans, our history was lost. (Tracy – Genealogy Group)

> I was interested because I wanted to learn more about my family's background in terms of where we may have come from as well as the health aspects, that I may or may not have been more at risk of. (Amy – Genealogy Health Group)

> I'm curious because I've got some things going on that the doctors can't figure out… I thought that could be a way to open up a whole other realm of possibilities for them to be able to try to figure out what's going on… Yeah, more the medical aspect of it and you know, learning more about what I can do to keep inflammation down and get my body to the point where I can do those other things, where I can do more than just walking, where I can do exercises without having such exercise intolerance that I dropped… I'm not as hard on myself, for things and I'll say, you know, this just, this isn't because I'm overweight or it's not because of something else Its this condition that's causing a lot of things to happen. (Robyn – Sequencing.com Health Group)

> I thought, I thought it could be a really interesting from a health perspective. I thought I would want to know if there was anything high risk I should be concerned about. (Alex – Sequencing.com Health Group)

> I was interested in what genes were responsible for, you know, the susceptibility for different diseases… I'm just being aware of certain things that I am, you know, I guess more likely to experience just based off of my genetics. (Sandy – Sequencing.com Health Group)

Some participants were left wanting more information after getting their results, which mirrors the finding that many of the participants used multiple DTCG testing

and/or analysis services. The concerns were that there was a lack of data, or the data was not explained sufficiently, and thus it did not address their need.

> I think it just seems like, you know, the basic stuff was like, oh, I'll like know what percentage of like what ethnicity I am and there's other information that I don't really understand or care to. (Don – Genealogy Group)

> If it can build like, it does go into detail, but like a more descriptive like pinpointing where everything comes from. Because with two percent Irish it didn't really give me anything very descriptive. It just said, you have two percent. I was ok, that's cool. (James – Genealogy Group)

> If they gave you more information than that would be different… It'd be nice to have some type of direction. It's like, you know, now that you got your results, these are some of the options that would have been nice than here's your DNA results. (Tracy – Genealogy Group)

> So just maybe more of an explanation of each of the results. I guess just more detail about not, not just the research but more detail about the actual result itself and what that means. (Ian – Sequencing.com Health Group)

5.5.2 Usability, Lack of Information, and Consumers' Knowledge

Usability is important because, without usability, no amount of utility can achieve the goal of producing a useful experience. Thus, one could argue without usability, utility cannot be achieved, and therefore the product or service can never be useful. In the course of the research, it was found that the participants were divided on the usability of the results they received. A small subset of the participants stated the results were usable. However, two out of the three still stated they would have liked more information, as discussed next.

> Yes, I did. They were both really the format that they came in was really easy to understand. I was just like a chart and then the left of everything right beside it. (Vanessa – Genealogy Group)

> Yeah. Yeah, it was, it was clear. I mean, it's stated clearly. Yeah, it was clear. (Ruth – Genealogy Group)

> I remember thinking that they were simple which was good in terms of understanding, you know, it's kind of more like a yes or no, or here's the simple way to understand this specific kind of results. (Alex – Sequencing.com Health Group)

> Yeah, it gives me confidence, but you also have to interpret it with caution in general. So I would definitely want to take any results or anything that I find out to a geneticist and confirm… because I would just need an expert or professional opinion, to kind of solidify some of the things. (Sandy – Sequencing.com Health Group)

Despite the three participants who said the results were usable, seventeen of the participants stated they needed or wanted more information or additional help. Some participants also outright stated that they had a difficult time using the results, which was often based on their knowledge about the complex science behind DTCG testing.

Of the participants, Sarah articulated this with the most frustration. Sarah is a Gen Xer with some college education who did not study science and does not work in science. She was interested in learning more about history, but struggled to understand all of the results she was presented with.

> Even once I got my results, the information is still a little. A little thing on their website. And I don't know how to read that gene lane. They gave me a gene lane. So they are not very helpful with that, because you know they're kind of a smaller company. It's a little hard for me to understand some of the stuff because I'm not that savvy on you know the DNA. I could just read the top of the page and understand what that says. But then they give you like it rumoring and these colors and numbers. I don't understand that at all. So, some of it is good useful information and some of it is absolutely like why did they even give us that if they are not going to tell us how to read it. (Sarah – Genealogy Group)

Other participants were less frustrated when speaking of the results, but still called clear attention to the fact that they did not understand many aspects of the results.

> What does an x match? Meaning what is the longest block. I don't understand any of that. So they need to put things in layman's terms would be a little bit more helpful if they go a little bit of way just to show what this means and how this

matches up on maybe more inclined to reach out. But I don't know what it means.. it's a lot of disconnects for me. (Tracy – Genealogy Group)

Yeah, I think they [genealogy results] make sense. I mean the ones that don't make sense are the 23andMe medical reports… there's just more information… I've had friends who've taken that code to like nutritionists and other types of healthcare professionals who can actually break it down even more. (Don – Genealogy Group)

Yeah, videos would because I went to YouTube and look them up myself. So maybe it's the website integrated more results that people put on me or something like. That would be cool. On the actual website. I mean they do a little bit. I think but not as much as they could. And I think that would really interesting because like I said, I immediately wanted to YouTube typed in reaction videos to, you know, and videos where people are walking through the whole process, taking the test and everything. (Vanessa – Genealogy Group)

Well if there's somebody that you could contact if you wanted any further information or questions or are something of that nature. (Ruth – Genealogy Group)

Just a basic explanation when you know, when you're not living in the scientific world, you kind of need that background… To sit down with a really qualified person who could go through and sit there with you, explain things, and answer questions and so on, you know, so instead of using an app or a website or what not, you'd be dealing with qualified expert. (Brenda – Sequencing.com Health Group)

I do need help deciphering the information and knowing if it is one that has enough information in it." … If they had something that was specific to, you know, finding out more, that would be amazing.... In like more about how to read your genetic results, you know, what of these things mean if there was some way to actually contact somebody to speak with them. We're not educated in that aspect of it. (Robyn – Sequencing.com Health Group)

5.5.3 Usefulness, Validation, and Applicability

Similar to the utility and usability findings, the participants were divided on usefulness. However, between the two groups, the genealogy group did find the tests to be more useful than the Sequencing.com Health Group. Participants in the genealogy group often made this determination based on concepts of identity and connectedness,

whereas the health group held this opinion based on genes validating a health condition or calling attention to a potential opportunity.

When speaking of usefulness, Ruth articulated an interesting point related to the earlier concept of identity. For Ruth, who lacks an understanding of her Jewish history given the atrocities of the Holocaust, DTCG testing helped her to find a connection to her lost past.

> That's what these DNA tests and things can help with that from an emotional standpoint. They can help you feel connected and also give you connections that may have been lost if you want that. (Ruth – Genealogy Group)

Some participants like Don echoed similar sentiments to Ruth, while others found the knowledge to be interesting and offer a baseline understanding in their quest to know more about themselves.

> I think I've got some good results out of that and it's pretty accurate after testing my kids. Made me feel better once I got my results. At first I was a little skeptical, I really was… I just hope that these results that I get from my next go round are as good as, ConnectMyDNA results, which I think they will be. So I'm just excited that my family and I are going to pursue a different avenue with a different company to where we can build the tree and have the opportunity to be able to connect each other. (Sarah – Genealogy Group)

> So I realized that my dad was Jewish and like for some reason I had it in my head that I was probably like Greek or Italian, but, and I think like part of me really wanted to know like where I was from in the world on my dad's side, like, like, region, and like if you're, if you're an Ashkenazi Jewish, it's like you're from anywhere in this giant area of eastern Europe and it's like not really like a nationality at all. So at first I was like disappointed in somewhat, but then I was happy because I actually knew Jewish people. So I felt like I was part of a community… I definitely excite, just to like have an answer and be like I belong to this subset of people. Kind of like a belonging or like a knowing your history. Like most people around you around me know at least vaguely but not specifically like we're from this place in Italy or where we're from, you know, eastern Russia. It's like not knowing at all, like what my dad's side was. (Don – Genealogy Group)

> You know, there are a couple things I think that we need a little bit more knowledge on, some of the genes where they really placed. But overall I really think it's amazing what they have done so far with it. To pinpoint a condition that

> doctors had been having a hard time with me for 12 years trying to figure out what it is. So yeah, I really think that they should be using it a little bit more. (Robyn – Sequencing.com Health Group)

> This is something that would give me a lot of information on what I could use to help knowing if my genetics are affecting how my ability to lose weight… what we've been doing is because I've just had some major surgery. So for the physical therapy we've been instituting the short bursts and exercise. Yeah. (Erin – Sequencing.com Health Group)

> I have changed my diet and I've made tweaks with my diet and also increase my activity level and developed an exercise plan. (Brenda – Sequencing.com Health Group)

Interestingly, among the participants who did not find it useful, the concepts of accuracy and/or applicability seemed to stand out as the cause for concern. The latter is interesting because, in the study, it was found that only two participants from the genealogy group made use of the social networking features within the DTCG websites to connect with other users, and only two participants out of the health group changed their health behaviors after getting the results.

For the participants who felt the results were not useful, Tracy who is passionately trying to understand her past was the most skeptical, given the changing percentages of ethnicity she has experienced in the results over the past year.

> The funny thing is that when I first got the results back last year… and then I just used the test today because I got another email…. The numbers have changed and so now... I guess I don't think the test is accurate at all now because I have two different versions... So that tells me I don't have any faith in this, in this DNA system anymore. It doesn't, it doesn't hold well if yield two different results in a years time. (Tracy – Genealogy Group)

Other participants were less critical about the results themselves, but acknowledged that they are often not directly applicable at this time, or felt that they were not useful enough for them to seek to change any behaviors.

No, I mean that was like the first step, you know, is like paying the money, getting the results, like understanding that, getting familiar with the website, talking to other people and the next step of like talking to my friends, getting their contacts and then have the medical professionals. But I haven't done that yet. (Don – Genealogy Group)

I think that for the average person who gets this task, they have access to a lot of data that they don't necessarily know how to interpret and I think if it came, it would be a lot more useful to someone who doesn't have the background if it came with like a primmer or like a, this is what these numbers mean in practical terms. Don't freak out. I have the experience of I'm trying to explain this to my father. I showed him some of my data because he was interested in looking at a few things and trying to. He jumped to conclusions or wanted to analyze data or draw conclusions from data in a way that was not meaningful when you clearly didn't understand what kind of conclusions could be drawn in terms of risk. And so I think an explanation of what the statistics mean and how meaningful it is on an individual as opposed to a population level is necessary, and could be done much better… As the field of genetics progress, if we're able to draw much stronger conclusions or meaningful conclusions from the data than we can now I can proceed doing so. (Sophia – Sequencing.com Health Group)

I don't know if I would say directly useful, but I'm happy to have the information and I'm hoping it will be more useful as time goes on. (Claire – Sequencing.com Health Group)

I want to meet with the doctors and, and make sure that I'm going in the right direction because I'm not a genetic specialist by any way, shape or form. And I do rely on their expertise in medical knowledge over mine. (Robyn – Sequencing.com Health Group)

No, I don't think so... There's not really much I could do to help myself and I don't have anything bad going on at the moment. (Scott – Sequencing.com Health Group)

I don't think there was anything that specifically like stood out to me that needed to be a behavior change. (Ian – Sequencing.com Health Group)

No, cause I already, I already knew about that risk factor in my family, so I already take steps to avoid that. (Alex – Sequencing.com Health Group)

Given the findings, the user experience of current platforms is called into question. While the desired utility of the DTCG consumers appears to be well defined, that is, to better understand their family history and/or health identity, the experience

today appears to fail in consistently delivering on that promise. The problem was found among both groups, however it does appear to be more widespread within the health group. It is theorized the major stumbling issues are lack of information, consumer literacy and their ability to understand the information presented, and the applicability of the information.

5.6 Genomic Literacy and Consumer Perceptions of Risk in the Bioeconomy

Given the high levels of trust in DTCG tests, and user experience shortcomings that result from lack of consumer literacy, consumer safety also needs to be discussed. Social scientists have called attention to a number of risks associated with consumers exchanging their genomic data, or biocapital, with private DTCG companies, and the use of that data by companies (Hogarth and Melzer 2008). Consumer advocates have often stated that consumers lack sufficient genetic literacy regarding genomics and information technology, and subsequently opt into contracts that allow the companies unprecedented control over the use of their biocapital because of how the consent process is structured.

The reason for this is because the purchase of a DTCG test is structured to be relatively frictionless. A consumer typically goes to a website and orders the test with a few clicks like almost any other e-commerce experience. While efficient, some believe it is also dangerous because consumers are opting into a contract that often has large ramifications related to their personal DNA and what the DTCG companies may or may not be able to do with that data (Phillips and Charbonneau 2015). The concern is grounded in the way the legal terms are delivered. The legal terms are often able to be

found via a link from the homepage and are also typically displayed in some format during the purchasing process. However, the concern is the way these terms are shown, and the complexity of the terms themselves. Most of these legal agreements that DTCG consumers opt into are in the format of a wrap contract. Wrap contracts, which are often called shrink wrap contracts because they are often inconspicuously packaged with products, can be defined as a unilaterally imposed set of terms which the seller states are legally binding, on use of the product (Kim, 2013).

As e-commerce increased, this idea was expanded into web-wrap, click-wrap, or browse-wrap license agreements that function in a similar way, however, they are possibly even more inconspicuous since they sometimes only required a scroll of the mouse or a click of a button to easily agree to the terms of the contract. Of the three methods, the clickwrap and browsewrap are the most commonly used. Clickwrap contracts require that a user scrolls through terms and click "I Agree" at the end. Browsewrap contracts typically don’t even require the user to scroll through the terms, and instead display a hyperlink to the agreement, thereby making it possibly for a user to click "I Agree" without ever viewing the terms. With that in mind, a 2015 study reviewed the contracts of 248 DTCG tests and found that they are often long and complex, and typically make use of the common implementations of either clickwrap or browsewap contracts (Phillips and Charbonneau 2015). This raises the question, do consumers of DTCG tests even read the contracts, and if so, are they clear on what they are consenting to?

The question of what a consumer is consenting to is steeped in medical and legal issues. From a classical medical perspective, the doctrine of informed consent is a

cornerstone of ethical practice in research that is built on the promise of beneficence in a clinical relationship (Spector-Bagdady 2015). It is something that both academic and clinical researchers take very seriously given the past history of harm, like in the Tuskegee Syphilis and the Milgram experiment. Traditionally, the process of informed consent requires that subjects are provided sufficient information about the research to be able to make an informed decision as to whether or not they wish to voluntarily participate in the research. However, in the case of DTCG testing, this process is substantially less rigorous than traditional academic standards given the way the tests are purchased. Furthermore, the future of the industry is full or potential, but still not well defined. Since the long-term goal of many of the DTCG companies is to monetize the data they are collecting, and because most of the applications for that data are yet to be determined, it is nearly impossible to draft a contract that is able to accommodate all potential uses cases for the data in contracts today. To handle this issue, many of the contracts reviewed in the study include a unilateral change of terms clause which often allows companies to change their terms without direct notice to the consumer. Consent to clauses of this nature are generally realized through the continued use of the website or service, even if the updated terms are never again encountered by the user in the course of that use

Thus, the terms governing how a consumer's DNA can be used may change over time, and the consumer may continually opt into the updated terms without even realizing it simply through continued use of the service (Phillips and Charbonneau 2015). The result of this could mean that the consumers' data can be used for purposes they never understood, nor ever could anticipate based on the terms of the

contract they initially opted into, such as their personal biobanked data being sold to any unforeseen third party for uses that they never anticipated, or comfortable with. However, the consumer would no longer have control over their own data.

5.6.1 Consumer's Trust in Exchanging Their Biocapital

To gauge consumers' perceptions about exchanging their biocapital for results, study participants were probed to gain a sense of the trust they held in the companies and the potential harm of the data being in the hands of the companies. They were asked specifically if they trusted the companies and why, and about the data being stored on webservers and the potential harm they see in their data ever being compromised. These questions built on the previous questions which probed the participants to gain a sense of their trust in the scientific claims. Similar to those findings, the majority of participants were found to trust the companies enough to exchange their data with them to get the results they wanted. In some cases, the participants were hesitant but felt they had no other option if they wanted to get the knowledge they hoped to get based on the scientific claims.

Of the participants, Vanessa, a young millennial, was the most trusting of the companies with her data. While she acknowledged that cyber security was an issue, she was not that concerned.

> I've thought about that. I'm not really like a conspiracy theorist or anything. So yeah, I do trust them. I don't think they are going to do anything with that, that I wouldn't want them to do… Yeah, I guess it does because hacking is so common, but it's a very minor concern. (Vanessa – Genealogy Group)

Other participants were less overt in their trust, but also similarly not concerned about security.

I just, I've never heard of anything negative happening, you know, people say, oh, what if they like stop you from getting healthcare in the future and um, like that's like the only concern, but I'm just like, I don't think that's going to happen in my lifetime and you know, if it does the world is that messed up, that's what happening by then. There's probably a lot of other bad stuff too. And like I'm not going to be worried about that. (Don – Genealogy Group)

That's just the risk that we take, given the world that we live in today. So, I try not to worry too much about it. Just hope the information isn't misconstrued in any way or use for anything other than what was supposed to be used for. (Sarah – Genealogy Group)

Yeah, um, yeah, I mean, as much as I guess I would trust, you know, um, Experian, Equifax and whatever else with my social security number, you know, or banks... If somebody knew this information, I don't think it would, you know, I don't think there's any value to a hacker or a dark web, somebody fishing on the dark web. I don't think there's any kind of a value to this, so to speak. (Tom – Genealogy Group)

As much as I can, I try to have the, I assume the best in people and, and hopefully it's safe. I sort of like the consent form said, do you know anyone using the Internet takes a certain amount of risk and the seems worthwhile. (Claire – Sequencing.com Health Group)

I'm fairly confident that it won't get out. However, if it were critically important to me, if I believed truly that it was extraordinarily important to that data never get out, I wouldn't trust them enough to have it. If I thought they were going to release it to everyone with my name, I probably wouldn't have given it to them. I have a reasonable level of confidence that they will not publicly link it to my name, but not absolute confidence that it won't get attached to my name outside of them… I do but I don't I think the risk is that large. But that's more than, I don't think the information is that meaningful and I don't think, you know, it's a lot of data so it's not something that someone is going to. It would be very hard to leak 30 gigabytes genome for every person in your database and no one is going to care enough to collect that much data. (Sophia – Sequencing.com Health Group)

“I was looking through privacy policies and things and when they send stuff back to you, your names aren't used on the files... I'm just not worried about it the way it is and I would hope that they would do more good with it then bad. I know that sounds horrible, but it's just like, well, it's not my social security number.” (Robyn – Sequencing.com Health Group)

Yeah. I trust those companies that have it. I don't think they are going to sell it or use it in and identifying way… I think they're taking as many steps as they can, but I also am not concerned that somebody is going to hack in and steal all of the genetics data per se. I mean, I don't know what would be the goal of somebody

> to do that. So I guess I'm not super concerned. (Alex – Sequencing.com Health Group)
>
> I don't think it's significant because I don't know. It's just life. It's not my address or my social security number. I don't feel like I could have a monetary loss on this one so I can affect my health. I mean I don't understand how my DNA being in the hands of somebody is going to hurt me. (Scott – Sequencing.com Health Group)
>
> Personally I think my DNA data is anything too much to get excited about. (Erin – Sequencing.com Health Group)
>
> I guess I would have to. There's not really an option to not put otherwise I wouldn't have the data that I do have without it. (Ian – Sequencing.com Health Group)

5.6.2 Consumers' Perceptions of Ownership and Fair Use of Biocapital

In speaking with the participants, about half indicated that they looked at legal policies of the DTCG testing companies. However, of that group, very few read it in any great detail, and so the majority seemed to lack a sufficient amount of literacy to speak about the ramifications of the contract. Given this and building on previous research concerning the unilateral change of terms clauses that show up in the contracts, the consumers were probed further to get a greater sense of who they feel should own the data, and what constitutes fair use of it given the nature of the contracts they have opted into.

The majority of participants believed they should own their biocapital however, but some of them also acknowledged that they may have granted the companies rights to it as a result of taking the test. Of those in the latter group, they somewhat begrudgingly acknowledged the reality of the exchange, but typically wished they still had some right to own the data. Over the nineteen participants, only two felt the companies should own the data.

Surprisingly, despite the overwhelming interest of the participants to own their own data, they were also quite comfortable with the data being used for research if used appropriately. However, the concept of what was appropriate, or fair use, was most often based on them granting consent for the data, which paradoxically, many did not realize they already did. Other factors that contributed to the concept of fair use for the participants were grounded in the purpose of the research. Most participants wanted the research to be for good use, such as academic or non-profit research but were more concerned if it was revenue generating.

By contrast to their comfort with sharing data, most participants had significantly stronger opinions regarding ownership and fair use. James, a confident-talking millennial with an undergraduate education and full-time employment with earnings that put him in the middle class, broadly summarized the sentiments of the group. He stated that he wished to own the data but acknowledged that he signed away his rights. However, he did feel he should be made aware if the data was going to be used.

> I feel like I should own that data, but since I did sign the privacy agreement with them, they should have the data but not for like to broadcast to the world anything, but just to have in their database… I feel like they should contact me first because it's my data. I mean if they're going to use my stuff or research or they should let me at least give me the courtesy to know that they're going to do it and let me agree to information everywhere. I feel like that's something you got to have consent for. (James – Genealogy Group)

Most of the other participants echoed James in the sense that they wished to own the data; however, they acknowledged that a business transaction had occurred, and just hoped the data was used appropriately.

> I would say me, but I'm not sure who does legally…. Like I don't know if in the fine print it signed off my DNA to them as, as the data to them as owners, but if they are assuming that ownership, I would want a more explicit and clear right to give that to them… I'd be fine with that. I would just hope that they would ask

permission, but I'd be more than happy for them to use it if it could help other people or help research. (Toby – Genealogy Group)

I think us as the consumer should, however we're releasing our information to these people so… I'm ok with research that's the way that we learn. So I'm OK with research. I like to do research. That's how we learn new things in technology and genealogy and all that good stuff. We're in the world now where that information is so readily available why not take advantage of it now that we have the source. (Sarah – Genealogy Group)

I think it's yours, I think it should be the person who's it is and if they want it destroyed, you know, or taken out of the database then they should have that right to do that… If it's for academic or nonprofit research, I have no problem with it. If it's going to incorporate like a for-profit corporation or some kind of entity like that than I would have been. I wouldn't really be OK with that. Like if they're selling to, you know, some list. So you get on some list for mailings and whatever else or email then that, that kind of that's not good or I think that kind of sucks. (Tom – Genealogy Group)

Well, I've given it to them. So my giving them my information, we both own it. They own it because they have it and I own it because it's my information… I wouldn't mind if my, you know, like I have seventeen percent of Irish blood in me or whatever. I wouldn't mind if that was used for a research because I don't know that they would be disclosing each person's name individually. If it just the background facts of to add to their research. (Ruth – Genealogy Group)

I mean it's like my information, but they're the ones who are finding it out for me. Like without them, I would never know what it is… So it's like, I mean, I think it's both, I guess… Like I said, like I wouldn't know anything about me if they didn't research other people's genes. (Don – Genealogy Group)

I think that I should own the data about my health information and they should own the proprietary technology in terms of how they got the information and how they obtained it. (Amy – Genealogy Group)

I personally, I think I should own it. Because it's mine. It's me... I think we need to be able to use stuff like that for research because if we don't, how are we ever going to get ahead? (Erin – Sequencing.com Health Group)

Well me, but you know.... it's my health data. It's my kind of who I am… You know I'm actually OK with that. I go with the assumption that my personal data is kept confidential. That I would be like Jane Doe or 1591 or whatever. (Brenda – Sequencing.com Health Group)

> Well, I should own it.... It isn't mine. It's about me… If you're doing some research then I don't care. Let me sign a consent in a waiver and you know, all that good stuff. (Sandy – Sequencing.com Health Group)
>
> I think ultimately the individual owns their own genetic data, whether or not that's done through, like if you pay for somebody to test you or if you sign up for research, I think ultimately you own your own genetic data… Yeah, I think as long as I knew about it that would be fine, and it was anonymized. (Alex – Sequencing.com Health Group)
>
> I think, I guess I ultimately should own the data, but I guess there's a play a part in each one of those that does own the data. (Ian – Sequencing.com Health Group)
>
> I think they can own the right to profit from distributing that data. I don't think they own the information itself or should be allowed to own the information itself. (Sophia – Sequencing.com Health Group)
>
> It should be mine, but I have shared it with a company… As long as they talk to you and say, hey, we want to do this or not going to expose your name or anything else like that, then I would be OK with them using it or whatever we needed to. (Robyn – Sequencing.com Health Group)

Based on the findings, the research theorizes that that previous literature is correct in its assessment of DTCG consumers. They do appear to lack sufficient literacy to make completely informed decisions when purchasing a DTCG test, and as a result, do not have a complete understanding of what they have opted into. Likewise, it is being suggested that the process of consent is made more explicit and that consumers are given more control over the use of their data. Control over the data may include restricting it from being used for research or sold, as well as giving them the ability to delete the data should they wish to no longer have it part of the database. Furthermore, since customers wish to own their own data, a model should be considered where consumers do own their data, but essentially can license it to the DTCG companies in exchange for the ability to use it as part of research. This would support both parties assuming the role of producers within the bioeconomy.

CHAPTER 6

CONTRIBUTION AND REFLECTION

The thesis project involved exploratory research to understand the beliefs, attitudes, and behaviors of consumers who have used DTCG genealogy and health tests. Exploratory research was used because it is “useful for developing original product and service ideas or finding new applications for existing and emerging technologies” (Squires 2002, 104). To accomplish this, ethnographic research was conducted through the lens of design anthropology. Consumers of both types of types of DTCG tests participated in qualitative research. The research sought to uncover new dimensions about the forms of sociality that influenced their decisions making to adopt DTCG tests, and to learn more about their everyday practice with the tests, and the meanings they ascribe to them. (Wasson, 2000; Wasson, 2016).

The objective was to understand how consumers became knowledgeable of the tests, why they chose to adopt them, and what are their perceptions of the tests after taking them. The findings were qualitatively analyzed using thematic analysis to produce rich ethnographic insights. These insights were then mapped to the Diffusion of Innovations (DOI) theory to gain a sense of factors influencing the diffusion process from a sociocultural perspective.

The analysis supplemented the DOI with extensions to the original DOI as well as other theories. Specifically, disruptive innovation theory was employed because innovations such as DTCG testing can result in competence-destroying discontinuities that require new skills, abilities, and knowledge in the process of delivering a new product class (Christensen 1997). Likewise, the dynamics of diffusion and adoption for

these types of innovations are critical to understand because as Geoffrey Moore's *Crossing the Chasm* model theorizes, specific steps must be taken on the part of a business to overcome the chasm, which is a hurdle in achieving critical mass adoption of new disruptive innovations. Two of Moore's techniques that this research focused on were defining a target market and whole product concept.

Defining a target market involves understanding and focusing on a specific customer segment, their needs or wants, and the sociality that occurs between members of that segment. Defining the whole product concept involves fully thinking through your customer's problems and potential solutions (Moore 2014). Likewise, Sequencing.com must make strategic product decisions that can satisfy the correct customer segment at the correct time along the adoption curve. However, accomplishing this is challenging as they need to correctly make critical product decisions under conditions of scarce resources (Jantunen, et al. 2011). Thus, a series of tradeoffs often need to be made thereby creating a business challenge that is difficult to sustainably navigate.

The goal of this research was, therefore, to address this business challenge by using design anthropology methods to produce actionable ethnographically informed insights that Sequencing.com can use to define their target market and create a whole product concept that is mutually beneficial to their business model, as well the consumers that adopt the innovation.

6.1 Summary of Findings

The following table details a summary of the key findings based on the themes uncovered in the course of the research.

Table 1: Table of Summary Findings

Socialization and Diffusion	Advertising and social influence, particularly of kin, are both effective for producing knowledge of DTCG testing. To that end, both have assisted in the diffusion of DTCG testing to date. However, there appears to be a great opportunity to improve the rate of diffusion. It is suggested that both methods be used in combination. Specifically, advertising ought to be directed to the kin of previous adopters.
Trust and Adoption	Consumers have demonstrated that they derive trust in DTCG tests in a number of ways form scientific claims, social influence, and promises of future-oriented knowledge. However, previous research has also shown that there are reliability issues with some testing given methods, data sets, or the science used for multigenic prediction. Given this, it would be advised from an ethical perspective to call attention to shortcomings in methods, datasets, and or scientific claims, and make it easy for consumers to find information about the methods and date the results are based on.
Narratives of Identity and Adoption	Learning more about the concepts of identity appears to be one of the most motivating factors for choosing to adopt along with the social influence of kin. Likewise, appealing to this desire is likely an effective strategy when targeting consumers. However, as noted with the trust concept, this ought to be done in such a way that is not based on faulty assumptions or overstated promises.
A Rite of Passage and Sharing to Influence Future Adopters	Sharing can represent an action in time, but also a larger symbolic concept of passing into the biosocial. It is spoken of very fondly by consumers, even if they don't frame it as a rite of passage specifically. Catering to this need may help satisfy this ritualistic need, while at the same time increasing the opportunity to create new instances of social influence among kin to drive the next round of adoption.
Towards a User Centered Design	The user experience of DTCG is still lacking. Specifically, it was found that a lack of information, consumer ability to understand the information presented, and the ability to apply the information appears to be the cause. To address those shortcomings, more flexibility should be granted to the user to accommodate the needs of varying degrees of proficiency. The focus ought to be on the usability of the results, as that appears to be negatively impacting the usefulness of the features or utility that exists currently.

Conceptions of Risk and Future Opportunities	There is an opportunity to empower the exchange of biocapital between DTCG companies and consumers, that does not have to harm the companies but can protect consumers than they currently are. This opportunity should be leveraged, by providing more clarity and control to consumers who are not trained in genetics since they need assistance navigating the DTCG industry. To accomplish this, the consent process should be simplified, and the consumer should be given more control over their biocapital. Allowing the consumers also to own and license the data is a significant opportunity to ethically flatten the playing field in the bioeconomy and do well by doing good.

6.2 Critical Insights

The findings of the research illuminated six critical insights related to DTCG health testing which Sequencing.com needs should be aware of when defining their target market, whole product concept, and strategic intent. The insights are:

1. DTCG genealogy and health tests appear to be at different points on the adoption curve, which is producing some differences between the genealogy and health group consumers.

2. Social influence plays an important role in influencing the diffusion and adoption of DTCG tests, and particularly, the influence that comes as a result of kin.

3. Consumers base their sense of trust regarding the science claims on either a belief in science, others, or the promissory language of the marketing efforts of DTCG companies but appear to lack the ability to validate the claims.

4. The test results consumers receive generally leave them wanting more information or additional support. This effect of this appears to be lessened for the genealogy group, however for the health group, the perceived usefulness of the test results is quite low. The genealogy group does appear somewhat satisfied to learn anything about their family history, though most participants still wanted more information. However, the health group generally finds the data to be more of a novelty that is not ready for application yet.

5. Consumers are far less concerned about sharing their DNA with DTCG companies than is often discussed in the literature, however, they also want more control over their biocapital, such as the ability to delete it from the database or delete it.

6. Sharing the data with other people, such as kin appears to be compulsory in the sense of a rite of passage. This applies to the health and genealogy group, and the genealogy group often takes this step further and also frequently shares the data with friends, coworkers, or even the public internet.

Those insights translate into a few broad concepts that need to be considered when crafting specific product management recommendations and business strategies.

6.2.1 Point on the Adoption Curve

It appears that that DTCG genealogical testing was further along the adoption curve than health testing. This is supported by estimated sales figures, previous research, and the qualitative ethnographic research conducted as part of this study. Sales estimates put genealogical tests significant ahead of health testing with the leading genealogy company, Ancestry, representing about 62% of the total DTCG market. (Forbes 2017). Given this, the needs and wants of the customers appear to be different, as do their levels of literacy. Likewise, each group needs to be approached differently.

6.2.2 The Importance of Social Influence

Social influence was the most significant factor influencing the diffusion and adoption of DTCG tests, but interestingly, it also influenced consumer's perceptions about the test experience. Specifically, it was shown that influence of kin had the most profound effect for motivating users to take the test. The sociality of kinship contributed to this, as well as the desire to learn more about one's genomic makeup, which is a factor of kin. The latter was pertinent to genealogical and health knowledge, and thus

applied to both groups. The importance of social influence mirrored previous findings related to the DOI and TAM.

6.2.3 Customers Lack Literacy, Respect Them

Customers today lack a sufficient amount of literacy to fully understand the process DTCG testing process. This applies to how they derive their trust in the science, how they interrupt the results, their understanding of the contracts and what they consent to, and the importance of their data being stored safely. As a result of this, the consumer should be respected; and care should be taken to protect them because to some degree, the current adopter group is not fully able to do this for themselves.

6.2.4 Extra Care Needs to be Given to Design

In the Technology Acceptance Model (TAM) usefulness is a strong predictor of continued adoption. Unfortunately, the majority of participants stated that the tests were not useful, with many citing concerns about usability that contribute to usefulness. While this is not unexpected given that disruptive innovations which involve competence-destroying discontinuities like DTCG testing require new forms of knowledge from consumers, it still creates unfavorable perceptions among the users. Given their low level of literacy, and the varying abilities, more effort needs to be made to increase the usability of the tests and provide greater flexibility to the users to enhance utility. These will contribute to usefulness, and thus the experience.

6.2.5 Blue Ocean Opportunities

It was found that the participants are not concerned with their biocapital being used for research. However, they do wish that they would own the data. Given their literacy, and in the spirit of being fair to the consumer, there is an opportunity to create a model that gives the consumer more control over their own data, potentially, even allowing them to own their data, and license it for use.

Furthermore, given that sharing results with kin and others was so compulsory, there is an opportunity to leverage this ritual to satisfy the needs of the consumers, but to also create a feedback loop that furthers the diffusion and adoption of DTCG testing to create a hurricane within the concept of *Crossing the Chasm.*

6.3 Adoption Model for the Current DTCG Health Test Adopters

Based on the research, the most critical factor that mediated the experience was social influence, and in particular, kinship. In general, social influence played a significant role in diffusing DTCG testing, influencing decisions to adopt, and perceptions of the experience once a test was taken. Particularly, though, kinship acted as the largest driving force given its relationship to sociality, trust, and identity.

Thus, kinship ought to be leveraged when defining the target market and deciding on features to create a whole product concept, however, the power of targeting users who will be influenced by kinship should not be abused. This group is very receptive, but also, as the research demonstrated, many consumers in the early days of adoption lack a sufficient degree of literacy to be able to understand what they are opting into and getting out of the test. Therefore, while kinship ought to be used to

define the target market, consumers should also be made fully aware of what they can expect to learn about themselves and their kin by taking a DTCG test.

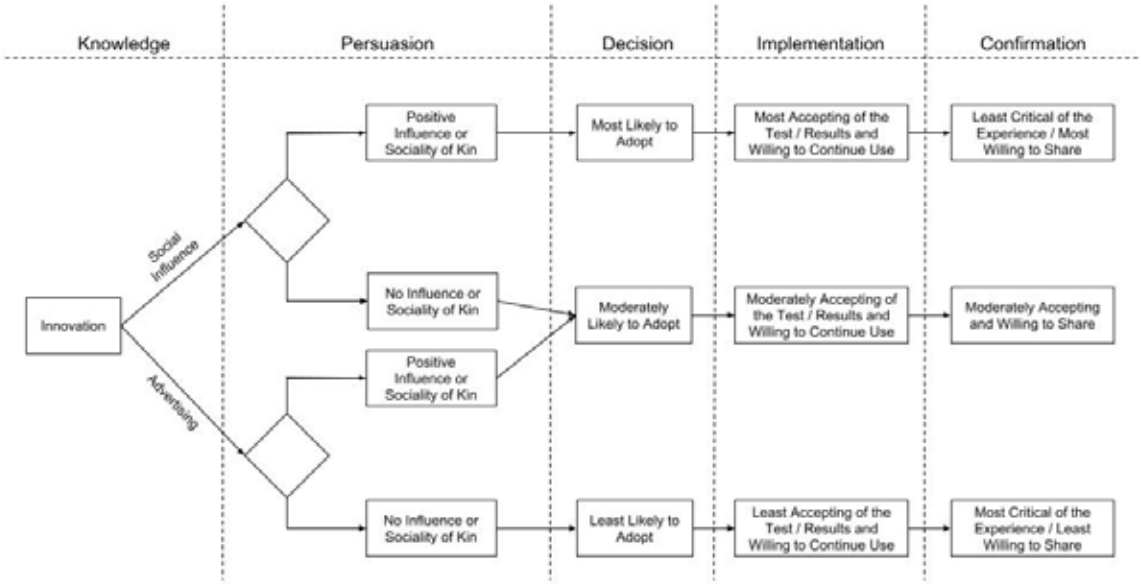

Figure 18: Adoption Model for the Current DTCG Health Test Adopters

6.4 Contributions to Client

Based on the insights learned from the qualitative ethnographic research and analysis process, as well as my user experience, software product management, and business strategy experience, the following recommendations are suggested.

6.4.1 Defining a Target Market

Based on the insights of this study, it is recommended that Sequencing.com's immediate target market be defined as consumers who are related to previous users. This will support the diffusion process, as well as the decision to adopt and also help to positively influence the perception of the experience.

Furthermore, given the lack of applicability participants reported, it is also being recommended that Sequencing.com focus on a subset of consumers. That subset should involve consumers who are who interested in tests that can accurately be reported on, appreciating that most DTCG consumers are using data they get from ancestry-based testing services, which means they are not whole genome sequences and thus many results for multigenic conditions cannot be reported on accurately.

Likewise, based on that fact, and the recommendations of Geoffrey Moore in C*rossing the Chasm*, it is recommended to focus on consumers with problems that can concretely be addressed in the current state of DTCG health testing. This will produce the greatest sense of usefulness, which according to TAM can lead the users to recommend the product, and thus support diffusion and adoption.

6.4.2 Defining the Whole Product Concept

Based on the insights of this study, it is recommended that an immediate effort should be placed on building mechanism for kin to recommend the product or specific apps to their family in a referral-like system.

Related to that, clear and easy mechanisms ought to be made to allow users to share their results with other people, through various modalities to satisfy their desire to share, but also to enable the hurricane effect to amplify diffusion and adoption.

The results consumers are provided should also be made easier to understand, but enhanced functionality also needs to be built in to offer more flexibility and access to more elaborate data on request. Many of the users made positive comments about Promethease which links to SNPedia, which allowed them to explore as little or as much

as they wished, but in either case, it provided greater flexibility to meet the varying degrees of needs.

Building on the shortcomings in results, an emphasis ought to be made to make the results directly actionable, as the health participants overwhelmingly discussed this as a shortcoming. Concepts of nudging from behavioral economics can likely be leveraged to increase the likelihood of application and continued use.

Given consumers' willingness to share their biocapital for use in research, but their desire to own it, Sequencing.com ought to consider putting their Altruist Center functionality on a blockchain that allows users to contribute their DNA to help science, in exchange for cryptocurrency that they can be exchanged for value within the platform to buy more apps.

Finally, given the fact that consumers often make use of multiple testing services and or analysis services, Sequencing.com may want to consider offering test kits so that participants can start the process with Sequencing.com. Furthermore, it should increase the number and depth of integrations with app providers. To the degree that Sequencing.com can keep the user within one ecosystem, instead of requiring consumers to go elsewhere for extra services, will enhance the stickiness factor of the product.

6.4.3 Establishing a Strategic Intent

When speaking with participants, it was clear that today they lack a single source of truth for genomics. Most participants have had their DNA tested by multiple DTCG companies, and then they have independently analyzed that data at a variety of

websites like Sequencing.com, Promethease, DNA Land, GED Match, and others. Given this gap in the marketspace and based on the fact that Sequencing.com is already an established app market, it is suggested that Sequencing.com stretches to become the *hub of consumers' genetic life*. This does not imply that this would be done overnight, but it is meant to be a long-term goal in the spirit of how "Komatsu set out to encircle Caterpillar, Canon sought to beat Xerox, and Honda strove to become a second Ford-an automotive pioneer" (Hamel and Prahalad 2005, para. 13).

6.5 Directions for Further Research

The research demonstrated there are differences between the two groups. However, the sample size was not large enough to determine what exactly were the differences and why they occurred. It is theorized they may be a representation of the characteristics of different adopter groups based on the respective points along on the adoption curve that genealogical and health tests are, or it may be a result of the different types of products attracting different customers. Either way, more research should be conducted to determine how and why the groups are different, and if possible, those characteristics should be mapped to the DOI adoption curve to help better define the target market and whole product concept.

Building on that, the research may also wish to observe consumers in their natural environment instead of remotely to gain a greater sense of the user, and their context of use. In the current remote interviews and observations, only audio and a screen capture of users using Sequencing.com was recorded, and thus there is still a

significant opportunity to learn more about the users, and how their use relates to others, especially kin in the case of users who live with family.

Furthermore, research ought to be conducted with non-users. Developing an understanding of why consumers have not chosen to adopt either type of test would likely provide useful insights for developing a better understanding of the market at large.

6.6 Reflection

As a result of this research, I learned that conducting ethnographic research is by no means a straight line. From the outset of the project to writing this reflection, I have been consistently amazed by how frequently things deviated from the ideal plan. In retrospect, I suppose that should not be surprising, after all, humans are a complex animal. But none the less, it was eye-opening.

It also has become very clear to me that the analysis of rich data is a complex and nuanced process that is more than theory and methods. It, of course, involves those. However, it also involves the researcher and everything they bring to the table as a person that is a product of their own culture. From the topic we select, the research questions we think to ask, the scripts we use to guide our interviews, to the way we interpret the data; it is all subjective. As such, I think it is worth noting that we are as much part of the process, as we are part of the outcome.

To that end, my anthropology training certainty contributed to me being able to carry out this project, for it is in the UNT program that I learned of the methods and theories that I employed in the project. Methods that allowed me to uncover data that I

may not have been able to otherwise, and theories that allowed me to situate it in a larger sociocultural context. However, it should also be noted that my previous biology and business education also came into play as a subjective researcher, which is why they are so present. And why should I not invoke those other disciplines and use them as additional lens to factor into the ethnographic process? After all, they are part of my worldview, and maybe more importantly, they are also a part of our social fabric and cultural identity as a group of people living in a world that offers products like direct-to-consumer genomics (DTCG).

So what did anthropology add to the outcome? For me, the most important thing was the acceptance of other worldviews, be they of another group of people such as the participants in this study; or another discipline such as sociology or information systems. Of course, it also overtly contributed methods and theory, but what is more important to me, was its holistic nature for understanding and doing. Much like the DA design anthropology model, it allowed me to be reflexive yet prescriptive, and at the same time, openly accepting of that. From the outset, the goal was to understand the past, to design a better future, and for that, it was applied.

CHAPTER 7

CONCLUSION

This study set out to achieve a few goals. First and foremost, as an academic exercise, it sought to develop me as a design anthropologist by applying the knowledge I learned at the University of North Texas to a real-world project.

The project I selected was to gain an understanding of how the DTCG market is maturing. I attempted to do this by developing an understanding of why DTCG health tests are adopted, how and why they diffuse, and what needs to be done to ensure we design the DTCG experience in a way that is beneficial, useful, and respectful of consumers.

To accomplish this, I conducted ethnographic research to understand the differences between consumers who have previously used DTCG genealogical tests, and those who have used DTCG health tests. I made use of design anthropology methods to produce actionable ethnographically informed insights that could benefit my client, Sequencing.com.

These insights were intended to help Sequencing.com define their target market and create a whole product concept that is mutually beneficial to their business model, as well the consumers that adopt the innovation. I also suggested a conceptual, strategic intent: to be the *hub of consumers' genetic life.*

Finally, I wanted to apply design anthropology to product management and business strategy. Design anthropology, though often discussed in the context of user experience design, is currently underrepresented when discussing these other disciplines, yet it represents an ideal complement to those disciplines. Likewise, I plan

explore the intersection in further publications, as I believe it is an area of scholarship that is lacking and offers tremendous potential to place the human back at the center of the equation of technology management and business strategy.

APPENDIX A

IRB APPROVED SEMI-STRUCTURED INTERVIEW GUIDE GENEALOGY GROUP

You will be asked to participate in a genealogy genomics interview and an observation session that will take approximately 30 minutes to 1 hour. The interview will be conducted via a conference voice line. During the interview, we will ask for permission to record the audio. The audio will be used to create accounts of your expectations and experiences. Your identity will be kept completely confidential. Pseudonyms will be created and used for all individuals who participate in this research. Signed consent forms will be required to be signed prior to starting the research. The signed consent forms and analysis documents will be stored in separate locations. Video, audio, and/or still photos will be stored in a locked cabinet after it is recorded. Computer records will be password protected. The confidentiality of your individual information will be maintained in any publications or presentations regarding this study.

1. How did you first learn about the concept of genetic tests for genealogy?
2. What did you think when you first learned about it?
3. Can you tell me about the specific genetic genealogy tests you have taken in the past?
4. How did you hear about that test(s)?
5. What was your reaction when you learned about the test(s)?
6. What made you interested in taking the test(s)?
1. Did you have any specific goals or outcomes you wanted to achieve?
7. Did you trust what you heard about the tests, be it verbally, in print, online, etc?
8. Did you review the company's website? What did you think?
9. Did you read any of the privacy policies or terms of use? If yes, what were your thoughts?
10. What did you expect to learn the test? Learn about ethnicity or relatives?
11. What was your reaction to the ethnicity analysis?
12. How did you feel after the test?
13. Did it help you better understand yourself and your personal identity in anyway?
14. Did you use any of the social networking features to interact with relatives (distant or close)?
15. Did you contact any of the matches, and if yes, what were your interactions like?
16. How did it feel to learn of potentially new relatives?

17. Did learning about these relatives help you better understand yourself in any way?
18. Do you think that the sequencing and analysis of your data was accurate?
19. Did you understand the results that you received?
20. If yes, can you tell me more about how you used the results? Would anything have made them more usable?
21. If no, can you tell me what may have helped you to better understand the results? A different type of reporting, educational videos, professional articles, professional consultation with an expert?
22. Did you share the results with anyone, be it on the screen, in print, via email, etc?
23. If yes, what made you want to share the data?
24. How did you feel after you shared the data?
25. Do you trust the company with your data?
26. Who do you think should own the data, you or the company that provided the test?
27. Do you have any concerns about the data being on public servers?
28. How do you feel about your data being used for research?
29. How would you feel it the company sold or turned over genetic data to marketing companies?
30. How would you feel it the company sold or turned over genetic data to pharmaceutical companies?
31. How would you feel it the company sold or turned over genetic data to insurance companies?
32. How would you feel it the company sold or turned over genetic data to employers?
33. How would you feel it the company sold or turned over genetic data to law enforcement?
34. Do you think you should be compensated in some way if your data is sold or turned over to some other group or company?
35. Did you know that you could download your raw genetic data? (Applies to some services only. Asking this depends on an earlier answer.)
36. If yes, have you ever done it or do you think you would ever do that, and why?
37. Do you think the government should regulate what types of test should be offered?
38. Do you think the government should regulate what the company can do with your data?
39. Is there anything I didn’t ask that you want to tell me?

APPENDIX B

IRB APPROVED SEMI-STRUCTURED INTERVIEW GUIDE SEQUENCING.COM HEALTH GROUP

You will be asked to participate in a health genomics interview and an observation session that will take approximately 1 hour to 1.5 hours. The interview and observation will be conducted via the internet using a conference voice line and a screen sharing application. During the interviews and observation session, we will ask for permission to record the audio and the video of the screen sharing software. Both the audio and video recordings will be used to create accounts of your expectations and experiences. Your identity will be kept completely confidential. Pseudonyms will be created and used for all individuals who participate in this research. Signed consent forms will be required to be signed prior to starting the research. The signed consent forms and analysis documents will be stored in separate locations. Video, audio, and/or still photos will be stored in a locked cabinet after it is recorded. Computer records will be password protected. The confidentiality of your individual information will be maintained in any publications or presentations regarding this study.

1. How did you first learn about the concept of genetic tests for health?
2. What did you think when you first learned about it?
3. Can you tell me about the specific genetic tests you have taken in the past, including Sequencing.com as well as any other?
4. Do you know if you had a whole genome test, exome test, gene panel, or SNP test? If yes, which one(s)?
5. Are you generally interestested in Medical/Clinical (heart disease, cancer, etc), Wellness (sleep, diet, etc), or Lifestyle (taste preferences, ability to sprint vs. run long distances, etc) tests?
6. How did you hear about that test(s)?
7. What was your reaction when you learned about the test(s)?
8. What made you interested in taking the test(s)?
9. Did you have any specific goals or outcomes you wanted to achieve?
10. Did you trust what you heard about the tests, be it verbally, in print, online, etc?
11. Did you review the company's website? What did you think?
12. Did you read any of the privacy policies or terms of use? If yes, what were your thoughts?
13. What did you expect to learn from the test?

14. What was your reaction to the health analysis?
15. How did you feel after the test?
16. Did it help you better understand yourself and your health identity in anyway?
17. Do you think that the sequencing and analysis of your data was accurate?
18. Did you understand the results that you received?
19. If yes, can you tell me more about how you used the results? Would anything have made them more usable?
20. If no, can you tell me what may have helped you to better understand the results? A different type of reporting, educational videos, professional articles, professional consultation with an expert?
21. Did you share the results with anyone, be it on the screen, in print, via email, etc?
22. If yes, what made you want to share the data?
23. How did you feel after you shared the data?
24. Do you trust the company with your data?
25. Who do you think should own the data, you or the company that provided the test?
26. Do you have any concerns about the data being on public servers?
27. How do you feel about your data being used for research?
28. How would you feel it the company sold or turned over genetic data to marketing companies?
29. How would you feel it the company sold or turned over genetic data to pharmaceutical companies?
30. How would you feel it the company sold or turned over genetic data to insurance companies?
31. How would you feel it the company sold or turned over genetic data to employers?
32. How would you feel it the company sold or turned over genetic data to law enforcement?
33. Do you think you should be compensated in some way if your data is sold or turned over to some other group or company?
34. Did you know that you could download your raw genetic data? (Applies to some services only. Asking this depends on an earlier answer.)
35. If yes, have you ever done it, or do you think you would ever do that, and why?
36. Do you think a doctor / general practitioner should have been involved in administering the test or reviewing the data with you?
37. Do you think a doctor / general practitioner is capable of reviewing the data?

38. Do you think the government should regulate what types of test should be offered?

39. Do you think the government should regulate what the company can do with your data?
40. Is there anything I didn’t ask that you want to tell me?

APPENDIX C

IRB APPROVED SEMI-STRUCTURED OBSERVATION GUIDE SEQUENCING.COM HEALTH GROUP

You will be asked to participate in a health genomics interview and an observation session that will take approximately 1 hour to 1.5 hours. The interview and observation will be conducted via the internet using a conference voice line and a screen sharing application. During the interviews and observation session, we will ask for permission to record the audio and the video of the screen sharing software. Both the audio and video recordings will be used to create accounts of your expectations and experiences. Your identity will be kept completely confidential. Pseudonyms will be created and used for all individuals who participate in this research. Signed consent forms will be required to be signed prior to starting the research. The signed consent forms and analysis documents will be stored in separate locations. Video, audio, and/or still photos will be stored in a locked cabinet after it is recorded. Computer records will be password protected. The confidentiality of your individual information will be maintained in any publications or presentations regarding this study.

1. What made you want to use sequencing.com specifically? (if not already answered)
2. How did you first hear of sequencing.com? (if not already answered)
3. How long have you been using sequencing.com? (if not already answered)
4. Can you show me how you login to sequencing.com for me?
5. If not social login, why not?
6. If not 2 factor authentication, why not?
7. Can you show me a quick overview of the dashboard and explain to me all of the elements on this page?
8. Can you show me the apps you use and give me a brief overview of each?
9. Can you show me how you browse for new apps and tell me about what you think of the process?
10. Can you show me the apps you have used before and tell me if they met your expectation?
11. Can you show me how you view results for apps and let me know what you think of this process?
12. Can you show me a few reports and let me know if you understand everything in the report? If no, what might make you understand them more?

13. Can you show me how many times you have used the apps and let me know how you use this data?
14. Can you show me how you seek out help if you need support when using sequencing.com, and let me know what you think of the help?
15. Can you show me the altruist center, and let me know how you understand this area? What are your thoughts about it?
16. Can you show me your altruist points, and let me know what you think of the points and how they make you feel? (only applies if they had already opted in. I will know this based on previous screens I will see).

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