



The Commercialization of our DNA

A qualitative study of attitudes regarding ancestry DNA tests

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EXECUTIVE SUMMARY

This thesis focuses on DTC genealogy testing and consumer attitudes regarding these tests. DTC genetic ancestry tests have become popular among Norwegian consumers, as technological development has made them easily accessible and relatively affordable today. By sending in a sample of your DNA for a genealogy company to examine, you are now able to track down your heritage and receive an overview over where in the world you have genetic connections. The amount of people purchasing this service has led privately held genealogy companies to possess databases that contain some of the world's largest collections of human DNA. They are profiting on people's interests in genealogy. It is therefore sensible to call this a commercialization of our DNA.

This phenomenon poses both positive and negative consequences for society. Databases can be used to improve public health by contributing to medical research, as well as improving national security by allowing law enforcement to search through databases in their investigations. However, for-profit companies possessing large pools of human DNA information poses risks and ethical dilemmas, such as privacy issues, exploitation and sales to third parties.

We have provided relevant background information regarding these tests and the market they operate in. Further, we have presented some of the relevant terms from the companies' consent forms, included laws and regulations that are essential in this context. Relevant literature on topics such as holism and ethics of happiness and meaning has been examined before being applied to our analysis.

Through interviews with 10 people, we have been able to attain a broad span of thoughts and beliefs regarding DNA ancestry tests. This has helped us to understand what people feel about these tests, their hopes and concerns, and possible motives to conduct a test. Main reasons for wanting to conduct a test comes from positive influence by friends, curiosity of the results and the need for entertainment.

Our findings show that the main reasons why people refrain from taking these tests are distrust in motives of the companies. Several worry that they are exploiting people for money. Another essential reason is that several do not trust the accuracy of the tests. An interesting finding is that our sample did not seem to care particularly about privacy issues. This was not an essential

reason from refraining from taking a test. We have tried to stress that this could be a common trait among Norwegians, as social trust in Norway is high. This could also explain why our respondents clarified that they would rather share their data with governmental institutions in Norway than in the US.

We have concluded with providing a list of commandments for people considering conducting a DTC genealogy test. As further research is the aim of this whole thesis, we have focused on this in the concluding chapter. We hope our thesis can be a starting point for future research on the topic, as we believe issues regarding genetic testing will become even more relevant in the coming years.

ACKNOWLEDGEMENTS

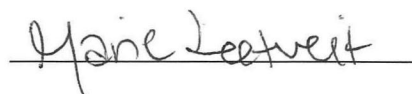
This master thesis is written as a final part of our master's degree with a specialization in Strategy and Management at the Norwegian School of Economics (NHH). We wanted to study a subject that is both something relevant and interesting. We have found a high interest in Courses such as Sustainable Business Models, Leader psychology and Digitalization. Therefore, we wanted to conduct a study with an essence within emerging digital markets with a sustainable and ethical view. Through studying this field of DTC genealogy testing, we have found such a topic. This is not the regular thesis for Economy students to write, but we find it highly valuable to broaden the limits of our knowledge even further. We find that this sort of topic gives us a great possibility to learn more, and to understand more of the existential dimension of our selves. We find it highly valuable to understand how people think and make arguments. This has given us an even broader view into leadership psychology and how we more effectively could understand other people and manage more comprehensive. We have in this thesis touched upon fields of study that we had little knowledge about earlier, such as Psychology, Law, Medicine, Sociology, Philosophy, and Ethics. This has made us realize the breadth of the economics and business discipline.

This could not have been managed without extremely valuable support and help from our supervisor Knut J. Ims. We would like to express great gratitude for the time Knut has spent with us, discussing deep ethical and societal issues as well as guiding us in our work. We would also like to express gratitude to Truls Petteresen from Bioteknologirådet, who made time for an interview with us to discuss DTC genetic testing. He helped us understand the core issues of our topic, brought us further insight into why this issue is highly relevant in today's society.

Bergen, December 2019



Anniken Sofie Brauti



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1. INTRODUCTION

IDENTITY

In today's society, we struggle to find ourselves. We get lost in thoughts about how society wants us to act, what is cool and what is not. We seek confirmation and approval from others, while repressing our own actual values and identity. We strive to reach achievements and fill the role society puts us in. The entry of social media has created role models and ideals on how you should be present almost every second of the day. There is so much that it is easy to lose the grip of yourself. To know who you are is a human need for affiliation. Kjøe 2019, thinks the modern human needs to have a "core identity," and that this is what raises the curiosity in us for genealogy tests. *"A need for a point of departure in a time when identity has become fluid and volatile - a project you are responsible for succeeding"* (Kjøe, 2019). An ancestry test claims to tell you something substantial about the essence of yourself, to give you a reference point and group affiliation. The commercialization of DNA testing has made this possible for regular consumers around the world.

THE SURVEILLANCE SOCIETY

"We were offered personalized medicine. Instead, we got Facebook for our DNA."

(BuzzfeedNews, 2019)

Some believe that we are moving further into a Surveillance Society. This implies that big companies gather a lot of information on the individual, also called big data. It is argued that the reason for the success of companies like Google, Amazon, Facebook or Apple is firstly, because of technological development, and secondly, because of the way they manage to harvest and harness the immense power of data (Medium, 2019). Some now consider data to be the most valuable resource in the world, with an even higher value than oil and gold.

We live in a world with fast evolving technologies, especially within the field of biotechnologies and big data. Governmental laws and regulations have troubles keeping up the pace. Where should the line be drawn between personal and public information? Issues have risen especially after it was revealed that Cambridge Analytica were using social media and big

data to tamper with the US election (The Guardian, 2018a). Where is the line drawn between whether nudging and data collection is standard in marketing, and when should the individual be protected? The same question applies for genetic technologies. They have an enormous potential to store information and knowledge that must be used carefully - if used at all.

You may have been worried about sharing things on Facebook and may have changed your privacy settings to protect your data. What about protecting your DNA? Do you find it more vulnerable to experience a naked photo of yourself or your DNA information being leaked? What would be worst in terms of consequences?

We all have an urge to know more about ourselves, but when could it become more harm than good? We would argue that we are in a paradigm shift, where we look at how society could end up, and look at where we do not want society to be. Where is the individual's right compared to societal rights? Are we stepping into the Surveillance society?

1.1 BACKGROUND AND MOTIVATIONS

Although the industry has existed since the late 1990s, consumer DNA testing is more popular now than ever before, as it has been simplified and made more accessible for consumers over the past years. High evolvment in the technology has led to extreme cost cutting for sequencing genomes (National Human Genome Research Institute, 2019). The lower price has opened up for a new kind of market, with companies that operate outside of the regular hospitals. Now, the price for such a test is only around 500-1500 NOK, and you can easily order it online. After you receive the testing kit, you only have to send it back with a sample of your saliva. After some weeks you will get the results online or in a document.

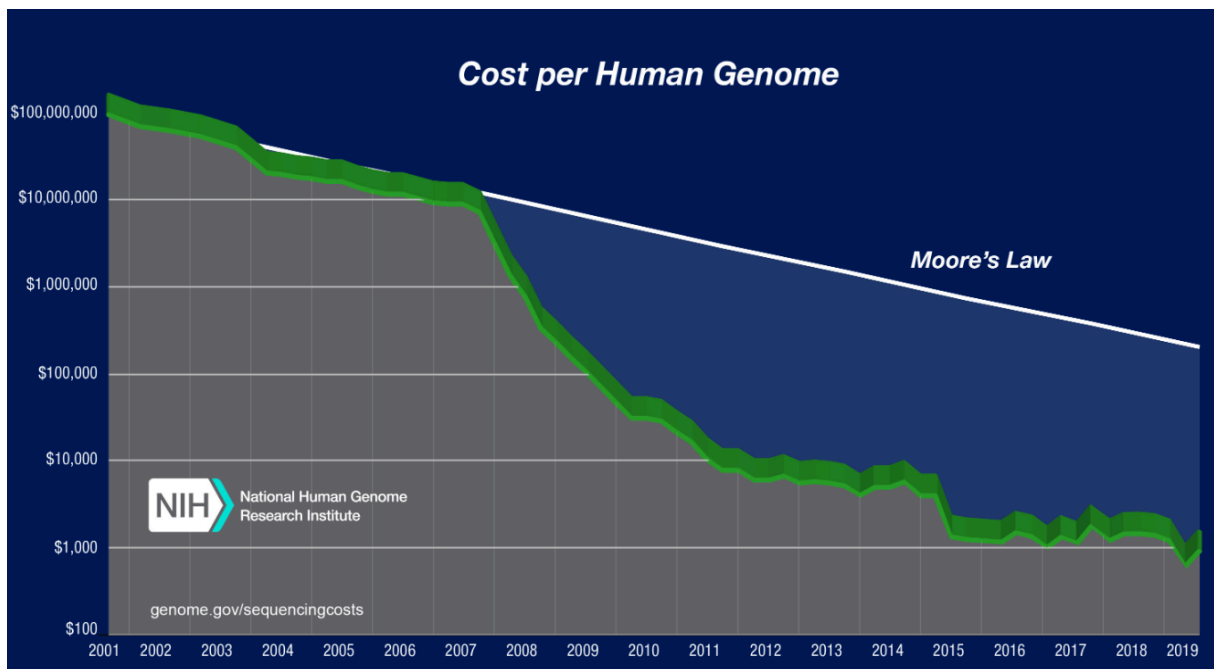


Figure 1: Cost per Human Genome (National Human Genome Research Institute, 2019)

Genetic testing has also been highly promoted through TV and online marketing efforts. According to a recent study by MIT, more than 26 million people had by the start of 2019 taken an at-home ancestry DNA test from at least one of the four major consumer genetics companies. It is estimated that in two years, more than 100 million people will have taken ancestry tests (MIT Technology Review, 2019). With the high speed of technological advances, the cost of highly professional medical devices suddenly becomes affordable for the everyday citizen.

According to My Heritage, Norway is one of their most attractive markets (BT, 2019). Norway is a country with traditions in genealogical research. Most Norwegians you encounter have someone in the family who have made a family tree. This makes a family legacy for future generations to investigate. When it is possible to get all these answers just by sending in a DNA sample, it makes it easier accessible. Because of the strong tradition for genealogy research, My Heritage chose to arrange their first consumer conference to Oslo in 2018.

DEFINITIONS:

DTC	Direct-to-Consumer
Genealogy test	Testing DNA to explore ethnicity

1.2 RESEARCH QUESTIONS

To understand this phenomenon in a deeper context we want to understand the attitudes towards DTC-genealogy testing. Therefore, our Research Question is as followed:

“What are the attitudes regarding Direct-to-Consumer Genealogy tests?”

1.3 OUTLINE

Chapter 1 contains a presentation of the thesis. In chapter 2 we present the context of our thesis. This includes a presentation of Direct-to-Consumer Genetic Testing, the Norwegian market, the companies within the market, their implications for society, and lastly, prior research done on DTC genetic testing. With this, we intend to provide the reader of this thesis with essential insights into the topic, as well as giving an overview of what research is done, and what is lacking. Excerpts and discussion around the terms and conditions of the major companies are then discussed, before we provide an overview of laws and regulations regarding DTC genetic tests. We also present a model for personal privacy that can describe issues of conflicting interests between individuals and society. As we are conducting our research in Norway, on Norwegian consumers, we also find it beneficial to portray some of the main values and traits of Norwegian society.

Chapter 3 includes the literature that is relevant for answering our research question. Firstly, we present theory about the hermeneutic circle, to be able to look at both parts of the problem and the whole to understand the deeper meaning. Secondly, we present Mitroff’s framework for holistic problem solving, which is essential for the analysis of our findings. Further, we focus on the existential dimension of Mitroff’s framework by presenting theories within ethics. These theories aim to provide a better understanding of the existential dimension. The Balanced Identity theory is also presented, as we believe this gives valuable insights into the meanings of our interviewees.

In chapter 4, we present definitions of relevant terms. This is also the chapter where our research model is presented. This model will be used as a foundation for our analysis.

Chapter 5 consists of our methodology. We start off by introducing our chosen research philosophy as a backdrop for the rest of the methodological choices. Further, we present our research design, our data collection and our data analysis. An overview of our interviewees and their initial stands towards DTC genealogy testing is presented in this section. We continue by evaluating our data and method in light of its validity and reliability. Further, we discuss the ethics related to our research method, before we conclude the chapter with a discussion of weaknesses and limitations of our study.

We present our findings in chapter 6. This will be presented through portraits of our interviewees, where we try to provide a picture of them and their attitudes and beliefs regarding DTC genealogy testing. The last section will sum up our findings, and present key differences and similarities among our sample.

In chapter 7 we will conduct our analysis through our chosen framework/research model. Different aspects of DTC genealogy testing that emerged during our interviews will be discussed in light of the four dimensions of the Mitroff framework. In chapter 9, we conclude our thesis by providing an answer for our research questions. This is followed up by recommendations for possible consumers, based on what we have learned. We conclude the chapter by presenting our thoughts on possible future research relating our topic.

References and appendix are found at the end.

2. CONTEXT

To understand the market and environment DTC genealogy tests operate in, we need to understand the context. This chapter will provide an insight into the Norwegian market, how companies operate, and a review of what prior research is done in this field. Then we will go through critical terms and conditions as well as laws and regulations that apply to the Norwegian market. We also introduce some parts of what privacy means for the individual and society, as well as some relevant aspects on Norwegian culture. After the context chapter, we will present existing literature and ethics we find sensible to use during our analysis.

2.1 DTC GENETIC TESTING

Each person has a unique genetic material, called DNA. In a sample of one's saliva, there is biological material that can be analyzed to reveal information about one's family history, ethnicity, risks and predispositions to get several different diseases, music preferences, what kind of sport one is most likely to succeed in, among many others (NIH, 2019).

Consumers can now order a genetic testing kit from a genetic testing company, receive their kit in the mail, and then send a sample of their DNA back to the company by spitting into a tube or conducting a cheek swab. After a few weeks, they will receive their results online. Consumers can now access information about their genetic data without involving institutions like health care providers or health insurance companies (NIH, 2019). The companies promote their ancestry test with declarations like *"Discover your genetic heritage," "Trace your DNA. Find your roots," "Explore your genetic roots," "What is your tribe."* (Wagner, Cooper & Sterling, 2012).

However, these tests come with limitations. One important note is that results are different for women and men. Women, who have the XX chromosome, can only trace back their maternal line. Men, who have the XY chromosome, can trace both the maternal and paternal lines and are therefore able to see the whole picture (PC Mag, 2019).

Most companies present their results with a description of how many percentages that matches with various ethnicities and/or countries. In general, the motivation for conducting a DTC genealogy test is to receive this information (Su, Howard & Borry, 2011). However, Duster (2015) criticize the presentation of the results as being "dangerously seductive and equally misleading."

2.1.1 THE NORWEGIAN MARKET

According to the Director of PR and Social Media at MyHeritage, the Norwegian market is among the most attractive markets globally. Norwegians are among the global leaders when it comes to purchases of DTC genetic tests, and usage is increasing (VG, 2019). From 2017 to 2018, the usage increased with 80 percent, according to Yael Beck, the director of MyHeritage

Norway (NRK, 2018). Bioteknologirådet (the Norwegian Biotechnology Council) has communicated that ancestry tests are the most popular tests among Norwegian consumers (2019).

2.1.2 COMPANIES

This chapter will provide an overview of the four different genetic testing companies.

Currently, the market for DTC genetic testing consists of two superpowers: Ancestry from Utah and 23andMe from California. These privately held companies now have some of the world's largest collections of human DNA (MIT Technology Review, 2019). The other two major players in the industry are FamilyTreeDNA and MyHeritage. Figure 2 outlines some important key facts about the companies.

COMPANY NAME	SERVICES	LOCATION	USER BASE
23andMe	Ancestry and health testing	California, US	Globally: 10 million
Ancestry	Ancestry testing	Utah, US	Globally: 15 million
Family Tree DNA	Ancestry testing	Texas, US	Globally: 2 million
MyHeritage	Ancestry and health testing	Or Yehuda, Israel (HQ) California, US (offices) Utah, US (offices)	Globally: 3.7 million Norway base: 1.1 million Website profiles: 109 million

Figure 2: An overview of the major players in the DTC genetic testing market (Phillips, 2018; Janzen, 2019)

ANCESTRY

Ancestry was founded in 1997 and launched its consumer DNA testing service in 2012. They are considered to be the global leader in family history and consumer genomics, and the largest

for-profit genealogy company in the world (Business Wire, 2018). According to Ancestry, over 15 million people have bought a DNA test from their website (Ancestry, 2019).

23ANDME

23andMe was founded in 2006 and is a privately held personal genomics and biotechnology with Google as one of their big investors. Their saliva-based DTC genetic testing business was named “Invention of the year” by Time magazine in 2008 (23andMe, 2019a). According to their website, they have more than 10 million customers and ship their products to more than 50 countries worldwide (23andMe, 2019a). Google Ventures is one of the companies investing large sums in 23andMe.

MYHERITAGE

In 2016, MyHeritage launched its genetic testing service MyHeritage DNA. In May 2019, they launched their MyHeritage DNA Health+Ancestry tests, which includes comprehensive health reports (Reuters, 2019). It is considered the third most popular DTC genetic testing company worldwide. MyHeritage was founded in Israel in 2006, and its laboratories now lie in the US. As their service supports 42 different languages, they have a broad global presence (MyHeritage, 2019). They market themselves as “*the only consumer DNA company that has pledged never to sell data to insurance companies*” (MyHeritage, 2019).

FAMILY TREE DNA

The DTC genetic testing service of Family Tree DNA launched in February 2010 as a division of the commercial genetic testing company Gene by Gene (FamilyTreeDNA, 2019). With a database of more than two million people, it is the fourth most popular company within DTC genealogy testing (Janzen, 2019).

2.1.3 IMPLICATIONS OF GENETIC DATABASES

With so many people conducting DNA tests, large pools of genetic data is gathered. These databases of DNA can be used for the public good by law Enforcement and medical research. As discussed, they could also be sold to other third parties.

LAW ENFORCEMENT

In 2018, FamilyTreeDNA discovered that the FBI had been accessing and using their web service and databases for an undisclosed amount of time. It raised concerns about privacy issues among their users. At the start of 2019, FamilyTreeDNA admitted that they, as a compromise, had allowed law enforcement to access their databases to use genetic data to investigate rapes and murders. This can be done by comparing DNA samples from crime scenes with DNA in the databases, and further to use the closest matches possible to build a family tree and identify the likely suspect. Before this, law enforcement had used a public database called GEDmatch for these kinds of investigations (Science News, 2019). This is a freely accessible ancestry database, where people submit DNA to find relatives. Although users may not have given informed consent to allow their data for this cause, users now have the option of opting out of ‘Law Enforcement Matching.’ All EU residents are automatically opted out due to laws and regulations within the EU (FamilyTreeDNA, 2019).

Law enforcement were in 2018 able to identify a serial killer named the “Golden State Killer” who murdered at least 12 people in California between 1974 and 1986. Using GEDmatch they were able to identify the serial killer (MIT Technology Review, 2018). Since then, more than 30 rapists, killers, and victims’ bodies have been identified the same way (MIT Technology Review, 2019). FamilyTreeDNA even used this as a sales pitch in their marketing efforts by asking customers to share their genetic data to help law enforcement solve crimes (MIT Technology Review, 2019).

MEDICAL RESEARCH

DNA databases are used in medical research. As long as companies’ Terms of Service do not explicitly prohibit it, they can conduct research on the genetic data in their databases (Consumer Reports, 2019). They can even sell it or share it with third parties. According to experts, 23andMe has quietly evolved into a driving force for medical research (NBC News, 2019). They are using their massive database of genetic data to conduct research in their therapeutics laboratories, as well as providing peer-reviewed publications (NBC News, 2019). In 2018, 23andMe received 300 million dollars from the pharmaceutical company GlaxoSmithKline in exchange for access to the data from 23andMe’s DNA kits. The DNA sales included information on 5 million people, and possibly thousands of Norwegians (Dagbladet, 2018). This collaboration shows how the DTC genetic testing companies can work together with third

parties to innovate research and drug discovery with the use of their enormous databases. However, some accuse 23andMe of profiting off of customers' genetic material in an unethical manner (NBC News, 2019)

SHARING WITH THIRD PARTIES

The sharing of genetic information with third parties presents a risk that somewhere in the process, the information could be used in ways that are harmful to the person who submitted their data for testing, or even for their relatives (Consumer Reports, 2019). Concerns have been raised about future discrimination based on genetic information. This includes, for example, people being denied insurance or discriminated in a job application process because of one's predisposition to developing some disease (Consumer Reports, 2019).

In 2019, Ancestry received a German 'Big Brother Award,' a negative recognition "*for exploiting interest in genealogy to entice people into submitting saliva samples*" (Weichert, 2018). The company was accused of abusing people's interests in genealogy to "*pile up a treasure trove of genome data for commercial research because that is their actual business model.*" Further argumentation stated that "*Ancestry is the top dog, and it has no scruples concerning data protection or basic human rights*" (Weichert, 2018).

SECURITY

In June 2018, the company announced that it had experienced a security breach in 2017, in which data of 92 million users were leaked (Vice, 2018). They claimed that no sensitive data in the form of credit card information or user DNA data was compromised. However, this shows just how many people could be affected in the event of a security breach into the database.

2.1.4 PRIOR RESEARCH

There has been conducted some prior research concerning DTC genealogy testing. We find that, in general, there is a more significant overflow of DTC health-related studies rather than ancestry. According to Bioteknologirådet, there are no studies of DTC genealogy tests and Norwegian consumers (2019).

Blell and Hunter (2019) have studied if the increase in DTC genetic tests is a move toward personalized medicine, and if it constitutes a risk for the individual and/or racialized ethnic groups. To understand this, they have looked at the way this information could misrepresent human genetic diversity (Blell & Hunter 2019). We will sum up their research:

VALIDITY

There are several problems with DTC genetic tests regarding the validity and reliability of health results (Tandy-Connor et al., 2018), transparency issues (Knoppers 2010), and privacy issues (Laestadius, Rich & Auer, 2017). “*There is a definite mismatch between what consumers think that they are getting from these tests and what the companies themselves state they are giving to consumers of their products,*” (Blell & Hunter 2019). Various articles examine the validity of the tests, which shows that they lack prominent evidence (Science New, 2018; Gizmodo, 2018; The Guardian, 2018b; National Public Radio 2018). Studies have been done on identical twins (The Register, 2019), and the same person at different points in time (CBC Nova Scotia, 2018), which have both shown inconsistencies in the results (Blell & Hunter 2019). A report from the US Congressional Research Service claims that the results could not be independently verified because there is widespread use of proprietary databases (Sarata, 2008). There are various reasons why the results may vary. Via et al. (2009) point out that there are three main factors determining ancestry results; they can be self-identified, identified by an observer, or estimated from genetic data. Ancestry results can then be estimated by one or multiple factors, which again could lead to many downstream complications (Via et al., 2009)

IDENTITY

Horowitz et al. 2019, have discovered that the (dis)-interests for Genetic Ancestry Tests (GAT) differs according to the roles of race, immigration, and ancestral certainty. Further, he suggests that a pre-existing sense of ancestral certainty shapes it, leading some individuals to decline GAT, even if it were free (Horowitz et al. 2019). Their study also showed that 93% of people asked said they would be interested in taking a DNA ancestry test if it was free. However, respondents who self-identified as Asian were more than twice as likely to express disinterest (Horowitz et al. 2019).

A longitudinal study has been performed by Janet et al. (2018) to understand the feelings around racial identity. Their findings imply that there is “*a curious combination of anticipation and*

satisfaction, yet no discernible impact on their sense of self or racial identity. (Janet et al. 2018)”, meaning that most people reported that getting to know new information about themselves did not make them feel different.

Currently, a professor at the Eastern Connecticut State University is surveying to understand public attitudes towards DTC genetic testing, including genealogy services such as Ancestry, 23andMe, and MyHeritage. This study aims to understand what people feel about their DNA results and about sharing these results with others. As this is an ongoing study, it will be interesting to view the results when they are done (The DNA Geek, 2019).

2.2 TERMS AND CONDITIONS

To go into the depth of the DTC genealogy test, we have looked into the contracts of the most prominent players within this market. The consumers are supposed to read through and agree to the terms and conditions before purchasing a test. However, it has proved to be hard even for lawyers to interpret the extent of these terms (Hansen, 2019). Despite this, we will in this chapter try to provide our understanding as business students of the terms and conditions. We will present our most essential findings from the contracts, as we find this to be valuable background knowledge for the reader of this paper.

Ancestry’s contract has been described as problematic by Bioteknologirådet (VG, 2019). He explains that this company can redistribute the data, and one's saliva, to third parties such as research projects and pharmaceutical companies. Many consumers consent to this without knowing (VG, 2019).

A study of the privacy policies by DTC genetic testing companies in the US in 2018 showed that these policies fall short of the ideal of informing consumers about how their genetic information will be used and secured, with whom it will be shared, and other issues (Hazel & Slobogin, 2018). However, it is essential to express that these policies are regularly changed and updated. In 2019 companies have updated their policies several times a result of pressure from customers and authorities (The New Economy, 2019). Updates are usually not notified to the customer, and many companies have stated that any changes to their policy would be reflected on their website and that it would be the customer’s responsibility to keep themselves updated on their policies (Hazel & Slobogin, 2018).

STORING DATA

MyHeritage expresses in their Terms and Conditions that: *“you explicitly waive any laws or regulations relating to DNA samples, DNA Results and/or DNA reports and their storage from the state or jurisdiction in which you reside. One agrees that the DNA samples will be stored in the United States as provided in this Agreement”* (MyHeritage, 2019). In general, all of these four companies keep the DNA sample stored indefinitely, except Family Tree DNA, who claims they store DNA for a minimum of 25 years (Janzen, 2019).

SHARING DATA

MyHeritage clearly express that they do not misuse their customer’s data. They claim never to have sold, licensed, or shared DNA information, either personalized or anonymized, to any third parties (Hansen, 2019). They also pledge to never sell data to insurance companies in the future (MyHeritage, 2019). In their Terms and Conditions, they specify that it is their policy to resist law enforcement inquiry to protect the privacy of their customers unless a court order is obtained (MyHeritage, 2019). However, they also write that *“by providing DNA samples and/or DNA Results to us, you acquire no rights in any research or commercial products that may be developed by us that may relate to your DNA”* (MyHeritage, 2019). This implies that although they do not redistribute data to third parties, they may use data information in internal research projects.

MyHeritage also warns customers about sharing genetic information about themselves with others, and indicate that *“information could have greater meaning in the future as discoveries are made. In the future, businesses or insurance companies may request such information from you”* (MyHeritage, 2019). These same statements are also made in 23andMe’s Terms of Service (23andMe, 2019).

OPT-IN OR OPT-OUT

In January 2019, it was discovered that FamilyTreeDNA had quietly changed their Terms and Conditions so that law enforcement had access to their database containing their customers’ DNA information. This made all customers automatically opted-in to share data with law enforcement and caused dissatisfaction among customers. They changed their Terms and Conditions in March 2019 from having the choice to opt-out, i.e., to being able to actively

refrain from sharing data. However, this action has been criticized for not attending to customers' rights, as opt-in was still the default option. Failure to opt-out will then be considered consenting, although this may not be the customer's intention. It is argued that there should be explicit, informed consent in these situations. As for FamilyTreeDNA, the opt-out option is automatically the default option for customers in the European Union - but nowhere else. It is suspected that FamilyTreeDNA made this decision specifically to avoid lawsuits based on EU privacy laws. However, if they launched opt-out as the default option everywhere else, they would run the risk that nobody opted in and that their databases would be useless for third parties (The DNA Geek, 2019).

Both 23andMe, Ancestry, and MyHeritage now use the opt-in option concerning using data for scientific research for all their customers. 23andMe also ensures customers that they will not provide data information to insurance companies or employers (23andMe, 2019b). However, 23andMe states in their Terms of Service that *“regardless of your consent status, we may also include your data in aggregate data that we disclose to third-party research partners who will not publish that information in a scientific journal.”* Both FamilyTreeDNA and Ancestry have stated that one does not need to consent to use their products or services.

DELETING YOUR PROFILE

23andMe, Ancestry, and MyHeritage all allow you to delete your DNA information from their database. FamilyTreeDNA does not provide this option for their customers - this can only be done through contacting customer service (McKnight, 2019). However, Ancestry writes in their 'AncestryDNA Informed Consent' that they do not remove your information from research that is in progress or completed (Ancestry, 2019). 23andMe writes in their Privacy Statement that *“Please note that you may not be able to delete User Content that has been shared with others through the Service and that you may not be able to delete information that has been shared with third parties.”* (23andMe, 2019b).

MyHeritage writes in their Privacy Policy: *“where you or we delete the content of your account, copies of that information may remain viewable elsewhere to the extent any such copy has been shared with others, was otherwise distributed pursuant to your privacy settings, or was copied or stored by others”* (MyHeritage, 2019). This implies that although one requests the DNA information to be deleted, it might not be that easy. Your data could already be used in research

that is in-progress or completed. Besides, both 23andMe and MyHeritage have expressed that they may keep some record of data for ‘regulatory purposes’ or because it is ‘required by legal obligations’ (Consumer Reports, 2019).

2.3 LAWS AND REGULATIONS

Regulations for DTC genetic tests could be problematic to control. The companies within this field work across borders and under different authorities. Some countries, like France, have a strict prohibition for sales of DTC genetic tests. Other countries, such as Norway, do not have any laws prohibiting overseas companies from conducting sales in the country. The fact that the technology is entirely new and evolving at a record pace makes it even harder to control. We do not yet know what kind of consequences or implications this kind of product will have for the future. The fact that it affects not only the person taking the test but also family members and future generations makes it especially problematic. In this chapter, we will take a closer look at the regulations regarding sales of direct-to-consumer genetic tests in Norway today.

2.3.1 NORWEGIAN LAWS

Genetic tests for governmental hospitals are widely regulated, but these kinds of regulations are not transferred over to the direct-to-consumers test, yet. At the hospital, it is easier to follow a framework, and the healthcare personnel has a strict privacy confidentiality agreement to follow. One of the laws that regulate genetic engineering in Norway is Genteknologiloven (The Genetic Technology Act) from 1993, which regulates plants and animals and the use of genetically modified organisms (Lovdata, 1993). The other one that is slightly more relevant concerning genetic testing in hospitals is Bioteknologiloven (The Biotechnology Law) from 1994. This law regulates the human medical use of biotechnology, which occurs in hospitals. It regulates assisted fertilization, prenatal diagnosis, cloning, and genetic therapy (Lovdata, 1994).

§ 1-1 The purpose of this law is to ensure that medical use of biotechnology is utilized for the benefit of people in a society where there is room for everyone. This shall be done following the principles of respect for human dignity, human rights, and personal integrity and without discrimination based on genetic material based on the ethical standards embodied in our Western heritage. (Bioteknologiloven, 2019a)

When people that have no health issues or possible genetic inherited predisposition take a genetic test, it is called a predictive test. § 5-1 in Bioteknologiloven tells us that genetic testing is strictly regulated when it comes to predictive testing. If you want to sell genetic tests from Norway, you have to apply for authorization from the Health Administration, and you need special authorization to sell predictive tests. For the predictive tests, the customer has to apply to Bioteknologirådet for acceptance to take the predictive genetic test and give consent. It is also illegal to test others than yourself without consent. In other words, genetic testing in Norway is strictly regulated, and violations can lead to prison sentences (Lovdata, 1994). None of these regulations applies to companies that operate from abroad, such as DTC genetic testing companies that offer both ancestry and predictive health testing.

Another essential note in Bioteknologiloven is that there is other legislation for clarification on how other players in the Norwegian market is allowed to use data from genetic tests: *“Information from genetic tests should not be used by others, for example, insurance companies and employers. They cannot ask for such information, nor use it if the person personally gives them access to such information.”* (Bioteknologirådet 2019a)

2.3.2 IVD REGULATION

In 2017 the EU commission changed a law concerning in-vitro diagnostic medical devices (IVD) for clarifications on genetic testing. The regulation is for *“devices intended to an examination of human body samples for medical purposes.”* Not all of the DTC tests are accounted for as a medical device, but in 2017 the US Food and Drug Administration (FDA) authorized the first DTC genetic tests as an approved medical device. Some authors have called this the start of a phase called DTC 2.0 (Allyse et al., 2018). The changes in the IVD regulation will apply to Norway in 2022. By getting a broader European law, it will give us less national leeway, but at the same time, international regulations will make it easier for the companies to comply. In this law, DTC genetic tests for health are regulated. The new regulation will make sure that the quality of the laboratories is at a certain standard, that the validity of the tests is marked, and make sure that the company selling to the European market has an office within Europe.

Bioteknologirådet has interpreted the new laws. In this interpretation, they find some aspects that appear unclear as to where they could be controlled, watched, and implemented in a reasonable way. Some of the concerns are that there exists both health, traits, and ancestry tests and that all of these tests have overlapping usages that could make it hard to know if the laws apply or not. In a consultation statement, Non-medical tests is mentioned, see excerpt below:

“If the test is not specific or targeted, for example, by whole-genome sequencing, the test could yield findings that are not limited to a specific condition. (...) Another concern is that companies that sell tests for clear non-medical purposes also ask the customer’s consent to do further analysis. It may include tests for illness, and it is unclear what the procedure is for reporting these results back to the customer. Thus, customers who purchase an ancestry test may end up being tested for predictive illness. (...) This will also apply to companies that sell tests in bundles.” (Bioteknologirådet, 2019b)

In the hearing about this regulation, the concerns are also pointed to whether it is discriminating only to have regulations for Norwegian companies and if this as well violates the principle of free trade.

2.3.3 GDPR

The importance of a law that ensures data protection emerged in the wake of the Second World War. This was due to both advances in computer sciences, and the use of surveillance technology by totalitarian regimes to commit crimes against humanity. Data protection has increased in importance over the last decades. There are people advocating for more rights to own you own data, especially after the Cambridge Analytica scandal where 87 million Facebook users were targeted to receive advertisements for President Donald Trump’s 2016 campaign (Business Insider, 2019).

GDPR (General Data Protection Regulation) is an international law from the EU, which counts for the all the countries in the European Union. GDPR was a new official law in Norway from 20th of July 2018. The law was created to ensure the safety of personal data and protect people from big corporations collecting data about the individual. It presents a legal framework for how to address new technology has changed our society (Business Insider, 2019). In sum, it

expresses that *“the processing of personal data should take place in a way that ensures, as far as possible, predictability and proportionality for the individual”* (European Parliament, 2019)

The law has a couple of principles illustrated from the European Parliament (2019). The ‘lawfulness, fairness and transparency principle’ means that data should only be processed ethically, and that companies need to comply to the laws and regulations, as well as providing transparency for outsiders. ‘The purpose limitation principle’ entails that the data should only be used for its specified, explicit and legitimate purpose, and not for other incompatible purposes. ‘The data minimization principle’ means that personal data must be used adequately, and that it must be relevant and limited to only what is needed for the process. ‘The accuracy principle’ refers to the fact that data must be accurate and kept up to date. ‘The storage limitation principle’ states that data must not be stored for longer than required if it contains personal data that can be identified. Lastly, ‘the integrity and confidentiality principle’ entails that personal data must be kept with integrity and that companies need to work to prevent security breaches (European Parliament, 2019).

In July 2019, the European Parliament Research Service published a study of how GDPR changes the rules for scientific research. Here, they look into how the rules transform into genetic data. *“The authors criticize the definition of genetic data in the GDPR as not adequately reflecting the ‘exceptional nature’ of genetic data, hence a differentiation between different categories of sensitive data might be required”* (European Parliament, 2019). It is difficult to know how they identify between medical and non-medical tests when talking about whole genome sequencing. Without any further clarifications it is hard to know how the laws acts in practice.

2.4 PRIVACY

Ims 1992 presents a model that visualizes the privacy issue where the individuals' interests are compared to the interests of society. Looking at these two stakeholders and their interests, we find that there are several issues of contradictory interests. See figure XX below.

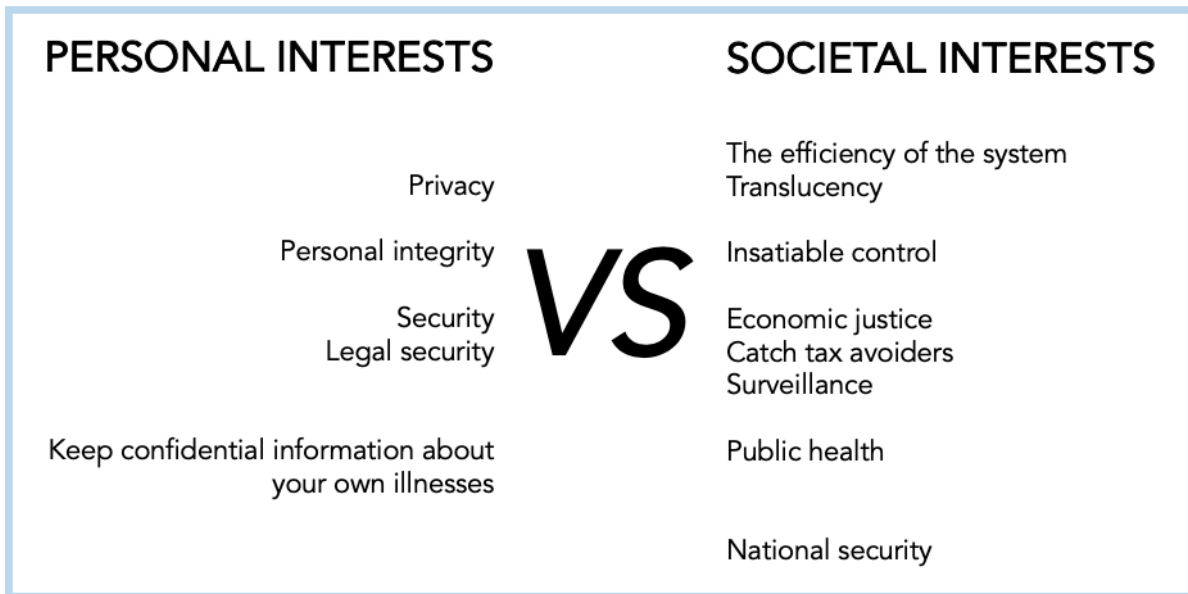


Figure 3: A model of privacy as conflicting interests (Ims, 1992)

Ims 1992 describes privacy as a possible interest for the individual to be able to have control over the information about themselves. The individual interests for privacy are discretion, completeness, to be informed, having a “Citizen Friendly Administration,” to avoid excessive control, and to avoid premature interference with privacy (Ims 1992). He also emphasizes that these factors only say something about the actual usage and that it is just as important to bear in mind the fear of use/abuse of data. The threat of possible use/abuse use could affect our self-perception and our self in the most profound sense (Ims 1992). *“The more information stored about a person, the more likely it is that some of the information will leak, be misused, or otherwise get lost (Gudmund Hernes: Ims, 1992).”*

2.5 NORWEGIAN SOCIETY AND VALUES

As we plan on doing our research in Norway and conduct interviews with Norwegian consumers, we find it useful first to present some background on Norwegian society and culture.

Norway is an individualist society that places importance in the self and the concept of intellectual freedom. Personal opinions are valued and expressed. Norway also stands out as being the second most feminine society in the world after Sweden, which implies that dominant values in society are caring for others and quality of life. Equality is a fundamental value in our society and trying to be better than others is neither socially nor materially rewarded (Hofstede Insights, 2019). The focus is on well-being rather than showing off one's status.

The "Concept of trust" is a determining factor in the Norwegian society. A report by SSB in 2016 stated that Norwegians are among the most trusting people in Europe when it comes to political institutions, with the police being the most trusted institution. Research has also shown that people in Nordic countries, in general, are unusually trusting on a world scale (Forskning.no, 2017).

Social trust is defined as the belief in honesty, integrity, and reliability in other people (Pew Research Center, 2007). This is also an essential aspect of the Norwegian culture, and it correlates with several other variables that are considered highly desirable for most people. People who believe that most other people in their society, in general, can be trusted are also more inclined to have a favorable view of their democratic institutions, as well as having a more optimistic view of their possibilities to influence their own life and to be more happy in general (Leung et al. 2011; Helliwell 2006; Dinesen 2013; Delhey and Newton 2005; Uslaner 2002). Norway is among the societies with the highest rates of social trust globally, with around 60 percent of people believing that most other people can be trusted (Rothstein, 2013).

2.6 CONTEXT SUMMARY

This deep dive into the different contexts provides a backdrop for our research topic. We have now discussed characteristics of the market for DTC genealogy test, while looking at the companies, issues and some prior research regarding the topic. This helps us understand the market for these types of business models. We have taken a look into the terms and conditions, as well as laws and regulations. All summed up, it is challenging to conclude on any regulations or terms and conditions because of their ambiguity and newness, but we find it valuable to have in mind how the context for this market is when looking at what kind of attitudes our interviewees have later on.

3. LITERATURE

In this chapter, we will present existing theories and ethical perspectives to help us understand the deeper issues surrounding DTC genealogy tests in the analysis. This theory is what we use as our framework for the rest of the study. Firstly, we will present the Hermeneutic Circle to give a picture of how our process towards answering our research question. Secondly, we will look into Mitroff's framework for holistic problem-solving. Thirdly we will look into ethical theories discussing Aristotle's thoughts on flourishing, followed by Epicurus's thoughts on happiness through pleasure before describing the Balanced Identity Theory.

3.1 HERMENEUTIC CIRCLE

The Hermeneutic Circle aims to explain how we interpret the meaning of something. To understand the hermeneutic circle, we need to understand holism. Holism argues that the whole is more than the sum of its parts (Poynton, 1987). The parts need to be understood for understanding the whole, and the whole need to be understood to understand the parts. Transferring the holistic view to our interpretations of the meanings about genetic testing would be to look at the details within each participant to gain a greater understanding of the whole. However, we will never know when we have reached an understanding of the whole, as the context of meaning is unlimited (KILDE).

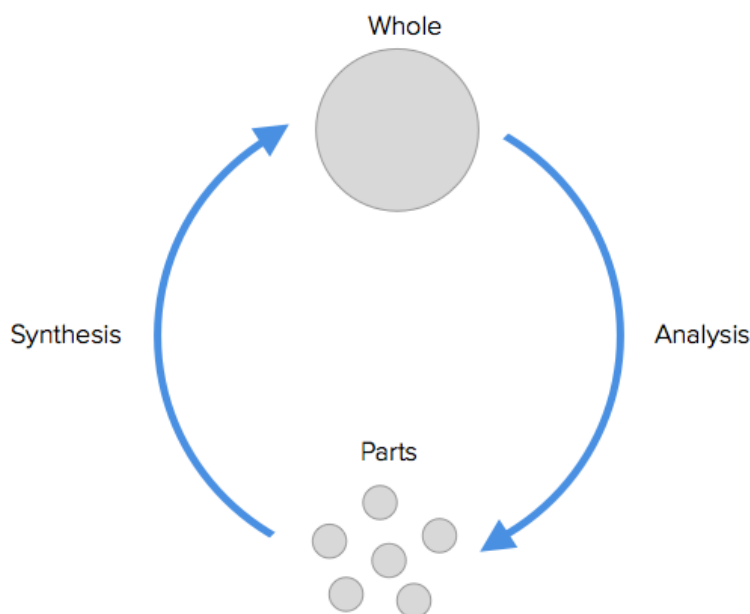


Figure 4: *The Hermeneutic Circle.*

The hermeneutic circle tells us that people interpret things by going from the specific to the general and back again (Gadamer, 1975). Specific details can help us understand the general. The iterative process through which one reaches a new understanding of a whole reality consists of exploring the details of existence. Philosopher Hans-Georg Gadamer applied this to the socio-cultural context. Gadamer got inspiration from Aristotle: “*Truth is not reducible to a set of criteria*” (Gadamer, 1975). There is a need to look into the cultural, historical, and literary context to analyze the interpretation of the meaning.

3.2 HOLISTIC PROBLEM SOLVING

Mitroff's framework for Problem Solving could be helpful when analyzing decisions, problems, and consequences (Mitroff, 1998). By using this framework, we can analyze all the potential issues and look at it as a whole to give us a deeper understanding of the problem or phenomenon. Mitroff presents four different perspectives. These are the Scientific/Technical Dimension, The Systemic Dimension, The Interpersonal/Social Dimension, and The Existential Dimension, as presented in figure XX below.

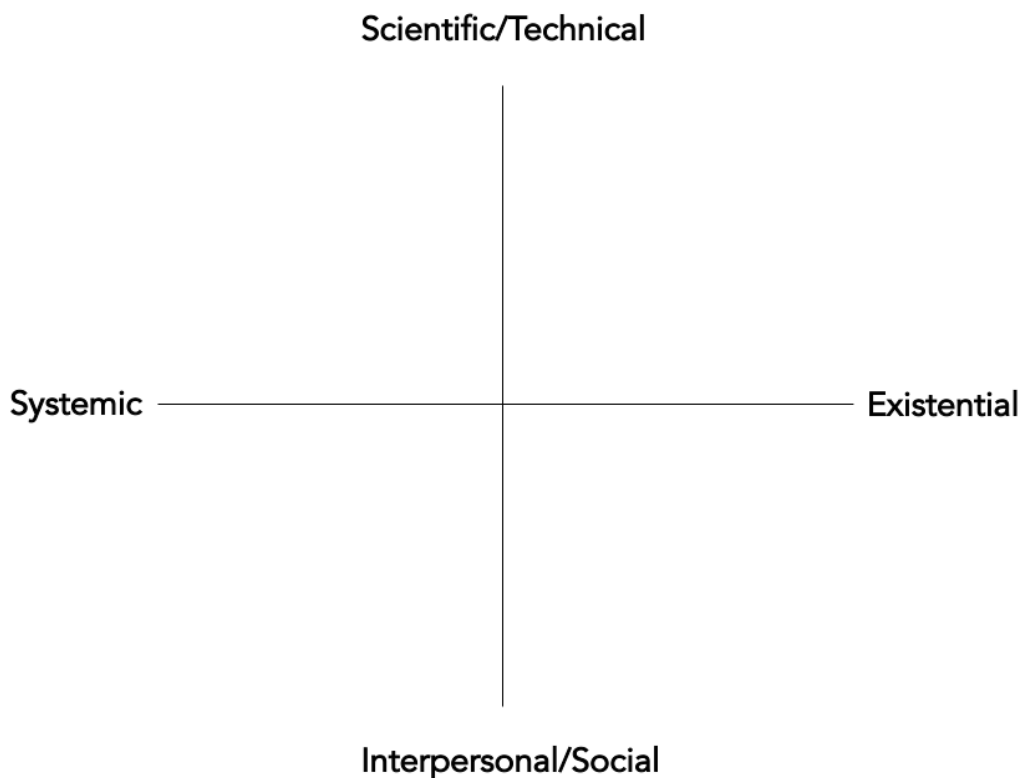


Figure 5: Mitroff's Framework for Holistic Problem Solving.

In the Scientific/Technical Dimension, we look into the problem with a view that is typical within the field of business, science, and technology. One typically looks at it through testing for hypotheses, using theories, frameworks, models, and calculations. This is a common way of analyzing the problem and it provides several guidelines on how to solve it. In this thesis, we will use this dimension to discuss, for example, the validity and accuracy of the tests. However, one must not forget the other dimensions, as they will also provide essential insight into our phenomenon.

The Systemic Dimension looks into the problem as a whole and examines what kind of consequences the decision could have on a larger whole. It relies on the assumption that everything is interconnected; countries, governments, the planet, future generations, and society in general. In this thesis, and according to the DTC genealogy tests, we will use this dimension to broaden our view and look at the possible consequences DTC genealogy tests could have on a larger scale.

In the Social Dimension, one looks at the problem in a social context. We often see that some problems have social influence and that the perceived problem may not be the root of the problem. This can be identified by asking the right questions. To enlighten this aspect, one can be beneficial to ask questions such as: “What would others think of this decision?” “What would happen if everyone made the same decision as me?” and “How will this influence people around me and me?”. In this thesis and relation to the DTC genealogy tests, we will use this dimension for analyzing the possible problems that can occur within one’s social environment, such as family relations or relations to others. We will also use this dimension to illuminate issues concerning the marketing and promotion of companies, as we consider this to affect the relationship between the consumers and the company.

In the Existential Dimension, we look into the bigger picture and the spiritual aspects. We view the problem from a perspective of self-realization, search for meaning and happiness. According to Mitroff, it is essential to see people as human beings and not as objectives. We need to look into the lifeworld of each person. He also points out that this dimension is one of the most crucial ones for actually understanding the problem. Therefore, we will focus on ethical, emotional, and existential impulses. In this thesis, we will take a deep dive into how our interviewees seem to value themselves according to self-esteem, identity, and what that is meaningful for them in their life. We want to take a closer look into this dimension through the theory of what different relevant philosophers find valuable within the existential context. We believe this phrase describes the essence of this dimension well:

“Man is not as a utility maximizer, but more in line with the conceptualizations in modern motivational theory, where the inherent pleasure of the task, or the experience of the flow, are motivators of activities that are intrinsically valuable for the actor” (Zsolnai & Ims, 2006).

3.3 ETHICS

To analyze Mitroff's existentialism dimension, we need to take a deeper dive into what could identify existentialism within the field of ethics. The next section provides ethic theory as a background for our reflection on how we could interpret the existential dimensions in our analysis.

We will take closer look at two perspectives on well-being: Epicurus' egoistic hedonism and Aristotle's eudaimonism. Current theories on happiness have derived from these two perspectives, and evidence has shown that well-being is probably best conceived as a multidimensional phenomenon that includes aspects of both the hedonic and eudaimonic perspectives on well-being (Deci & Ryan, 2001). We will, in this chapter, provide an overview of these two perspectives.

3.3.2 ARISTOTLE: EUDAIMONISM

"Knowing yourself is the beginning of all wisdom"

Aristotle

The ancient Greek philosopher Aristotle (384 - 322 BC) believes that happiness is the highest good. In Aristotelian virtue ethics, the term is called "Eudaimonia" and consists of a state of happiness, contentment, and fulfillment. Eudaimonism bases virtue in human flourishing, where flourishing is equated with performing one's distinctive function well. As opposed to Epicurus, Aristotle identifies happiness with a life of virtuous activity, and his idea of well-being can be described as 'happiness plus meaningfulness' (McGregor & Little, 1998). The eudaimonic perspective is one that mainly focuses on meaning and self-realization (Deci & Ryan, 2001). Eudaimonia is attained when one's life activities are consistent with deeply held values (Deci & Ryan, 2001). Aristotle believed that all actions have an aim and that they aim at some good, either for their own sake or for the sake of other things. The ultimate goal is eudaimonia or human flourishing.

Central to these theories of virtue ethics is the fact that they do not aim to identify and generate universal principles that can be applied in any moral situation, as opposed to other ethical theories. Virtues are justified because they are constitutive elements of eudaimonia, which is good in itself (Sachs, 2019). Aristotle emphasizes the importance of freedom of choice, and writes in his work Politics: *“This, they say, is the privilege of a free man, since, on the other hand, not to live as a man likes, is the mark of a slave.”* This freedom is, according to Aristotle, tied to happiness and virtue. Thus, it is one’s own choices that can lead one to find meaning and achieve self-realization and, therefore, happiness.

3.3.2 EPICURUS: EGOISTIC HEDONISM

“Pleasure is the first good. It is the beginning of every choice and every aversion. It is the absence of pain in the body and of troubles in the soul”

Epicurus

Epicurus (341-270 BC) was a philosopher from Ancient Greece and was the founder of the school of philosophy that is now called Epicureanism. According to Epicurus, happiness is the main goal in life, and achieving happiness is the proper goal of all conduct. It can be achieved through pursuing pleasure and avoiding pain, but also by taming one’s desires and being content with the simple things. Ultimately, what is pleasurable is morally right, and what is painful is morally wrong. Epicurus focused on happiness rather than virtue, as he saw humans as pleasure-seeking beings by nature (O’Keefe, 2019).

Epicurus’ ethics is a form of ‘egoistic hedonism,’ which is a concept that arguably has been misinterpreted in our time. The term Hedonism stems from the Greek word ‘hedome’, which means pleasure, and some mistake Epicurus’ hedonism as a way of attaining pleasure through indulging the senses (O’Keefe, 2019). Although he recognized that overindulgence might be pleasurable for a while, he saw that in the long run, it only causes pain, in such amounts that it overshadows the pleasure derived from the activity in the first place. Epicurus recommends a virtuous, moderately ascetic life as the best means to attaining pleasure. The main aim is not the positive pursuit of pleasure, but rather the absence of pain, a neutral state he calls ataraxia. This can be translated to tranquility, and in that sense, it could be less misleading to call Epicurus a ‘tranquillist’ rather than a ‘hedonist’ (O’Keefe, 2019).

The meaning behind egoistic hedonism is that the only intrinsically valuable thing is one's own pleasure - anything else that has value is valuable merely as a means to attaining pleasure for oneself. According to Epicurus, friendship is especially valuable as it is one of the most excellent means of attaining pleasure. Anxiety about the future, on the other hand, is, according to Epicurus, the greatest destroyer of happiness. If one can banish fear and pain, and face the future with the confidence that one's desires will be satisfied, then one will attain ataraxia (O'Keefe, 2019).

To attain pleasure, one must follow a hierarchy of desires in which Epicurus explains what pleasures we should and should not pursue. This hierarchy contains three levels of desires. These are 1) Natural and necessary desires, 2) Natural and non-necessary desires, and 3) Vain desires. He argued that seeking to fulfill the needs for natural and necessary desires is favorable towards attaining ataraxia, as these desires have a natural limit, which makes them comfortable and possible to satisfy fully. These needs are basic needs like food and shelter. Secondly comes natural and non-necessary desires such as luxurious foods or expensive cars, which are a bit harder to satisfy. However, Epicurus argued that the state of contentment we feel after the fulfillment of these needs is the same as for the state of contentment we get from fulfilling natural and necessary desires. 'Vain desires' are desires of power, fame, and extreme financial and material wealth, which are impossible ever fully to satisfy. Epicurus discouraged the pursuit of these unnatural desires as they are based on opinion, meaning that they are what society makes us think that we need (Einzelgänger, 2019).

"We call 'Vain pursuits' the types of life that do not tend towards happiness"

Epicurus

According to Epicurus, one is better off eliminating a desire rather than working too hard to satisfy it. Living in today's consumerist societies with a high focus on material wealth, we might want to ask ourselves the following question: why suffer from the constant chase of fulfilling desires for money, fame, and power, when attaining a life of happiness, contentment and tranquility is so easily achievable?

3.4 BALANCED IDENTITY THEORY

The balanced identity theory is formulated as a ‘unified theory of implicit attitudes, self-esteem, and self-concept’ (Greenwald et al., 2002). It defines two cognitive constructs: stereotype and self-concept, and two affective constructs: attitude and self-esteem. We choose to focus on the affective constructs as we believe this is more relevant to our study.

We have developed our model based on Greenwald’s model of balanced identity. Our model describes the relationship between the affective constructs and the three concepts: the self, social groups, and their attributes. The affective approach relates to valence, or attractiveness, of the attributes. This implies that the attribute one relates to a group will be defined as an attitude and that the attribute one relates to the self will be defined as self-esteem. An example of attitude could be that one has an attitude towards American companies that entails suspiciousness, a negative attribute. An example of self-esteem is when a person ascribes the attribute of intelligence to themselves, a positive attribute. This enhances their self-esteem, and therefore also the self. The model visualizes how all of this concept relate to each other.

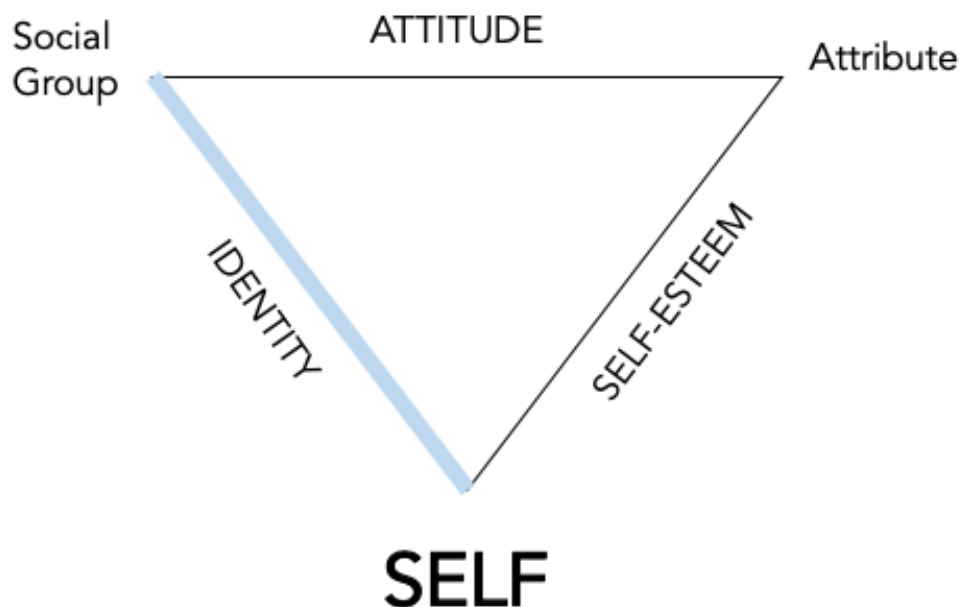


Figure 6: A model of relationships in affective constructs of the self.

The self is identified as a central entity (Greenwald et al., 2002). Identity is an essential part of the theory as it is defined as “the association of the self with a social category” (Greenwald et

al., 2002). One can associate the self with social groups like Norwegians, students, health care workers and so on, and this can therefore be defined as your identity.

The theory predicts that the attitude towards a social group should be equal to the valence (attractiveness) of the self. One prediction of this model is that when both self-positive and self-group identification exist, a positive view of the group is expected to develop. This is due to the balance-congruity principle (Greenwald et al., 2002). The idea behind this theory is that these concepts need to be balanced. The in-group attitude should be a multiplicative function of the strengths of in-group identity (self-in group association) and self-esteem (self-positive association).

Attitudes towards genetic testing could also be transferred into attitudes for yourself/the self. To understand this concept, we need to look into the identity according to a social group, and self-esteem towards different attributes considered relevant for genetic testing.

4. MODEL

4.1 THE RESEARCH MODEL

As presented in the literature we will use several models for trying to explain our research question, on what the attitudes for DTC genealogy tests is. We will use the Hermeneutic circle to look at both the parts and the whole to understand the problems. Our holistic view would be presented with Mitroff's framework to understand at all the dimensions. The main focus will be in the existential dimension, which will overlap to some of the other dimensions when looking at balanced identity theory.

4.2 DEFINITION OF TERMS

We will, in this chapter, provide definitions of terms which we will refer to throughout our study to give a deeper understanding of the concepts we are studying.

4.2.1 LIFEWORLD

The German philosopher and sociologist Habermas uses the concept of 'lifeworld' in his social theory. He describes the term 'lifeworld' as "*the background environment of competences, practices, and attitudes representable in terms of one's cognitive horizon*" (Habermas, 1987). It relates to our ability to understand nature, society, and ourselves through communication with each other (Fairclough, 1991).

4.2.2 THE SELF

We understand the self as a unified being intrinsically connected to consciousness, awareness, and agency relating to an individual's thoughts and actions. We want to focus on three aspects of the self: the perceived self, the real self, and the ideal self (Rogers, 1961).

The Perceived Self refers to one's own assessment of oneself and how one believes to be perceived by others.

The Real Self refers to how the person actually is.

The Ideal Self refers to how the person would like to be.

4.2.3 IDENTITY

The concept of 'identity' is essential in this study. We will use the definition from Greenwald (2002), which describes identity as the association of the self with a social category.

4.2.4 ATTITUDES

As we aim to explore and understand the attitudes of our interviewees, we believe it is essential to define this term. One definition of attitude we find useful is that it is 'a person's beliefs or feelings related to a certain idea, object, person, or situation, and their resulting behavior tendency.' Taken together, favorable or unfavorable evaluative reactions toward something define a person's attitude (Olson & Zanna, 1993). It is crucial to emphasize that unlike observable behavior, attitudes only exist in a person's mind: it is only a mental state.

4.2.5 SELF-ESTEEM

We will, in this thesis, use the definition of self-esteem that refers to the extent to which we like, accept or approve of ourselves, or 'how much we value ourselves.' Thus, self-esteem will always involve a degree of evaluation. We may have either a positive or a negative view of ourselves (McLeod, 2008).

5. METHODOLOGY

This chapter will introduce our research method and describe the methodological choices in our study. The choices are all based on the objective of answering our research question. We will start by presenting our chosen research philosophy as a backdrop for our chosen research design. Further, we will present our process of collecting and analyzing data. A quality evaluation is presented through a discussion of the reliability and validity of data. We will also present the research ethics of our study and discuss the research constraints of our methodological choices.

5.1 RESEARCH PHILOSOPHY

Before deciding on a research design, it is beneficial to choose a research philosophy to build the rest of the methodological choices on (Saunders et al., 2016). The research philosophy refers to the system of beliefs and assumptions about the development of knowledge in a particular field (Saunders et al., 2016). We have chosen the research philosophy of interpretivism, which is based on a subjectivist perspective. This is a view that incorporates assumptions of the arts and humanities, claiming that social reality is made from the perceptions and consequent actions of people (Saunders et al., 2016). Interpretivism emphasizes that humans are different from physical phenomena because they create meanings (Saunders et al., 2016). Researchers within the interpretivism research philosophy, therefore, aim to study these meanings. This choice of research philosophy is in line with our objective of trying to understand the lifeworlds of the respondents in our study - we want to understand how they create meanings and what is meaningful to them. This will allow us to obtain valuable insights into the field of study.

Interpretivist researchers need to be aware of their role as interpreters in the research process. This requires us as researchers to adopt an empathetic stance, to be able to enter the lifeworlds of our respondents, and to understand the world from their point of view (Saunders et al., 2016). We will, therefore, have an emphasis on our respondent's dignity and to avoid any judgment of their meanings throughout the process.

5.2 RESEARCH DESIGN

The research design provides an overall plan on how to answer the research question (Saunders et al., 2016). We have chosen an exploratory research design for our study, as we aim to seek new insights into the relatively new topic of DTC genetic testing. This design allows us to keep a broad focus and provides flexibility throughout the research process as it allows us to adapt to change. This is necessary when studying this topic which lacks prior research and understandings.

With interpretivism as our philosophical research background, it is suitable to conduct an inductive research approach to our study. This approach entails collecting data to explore a phenomenon, identify themes and patterns, and generate and build a theory on that basis (Saunders et al., 2016). There is currently a lack of previous studies of DTC genetic testing,

especially in the case of ancestry DNA tests. Therefore, our aim of this study is to provide knowledge within this field of study.

Further, we have found it beneficial to conduct a qualitative method of research in our study. This type of method is associated with an interpretive philosophy, as well as an inductive research approach (Saunders et al., 2016). We will collect non-numeric data from our respondents, and at the same time we intend to study our respondent's meanings. The use of a qualitative method will provide textual descriptions of how people experience a given research issue (Mack & Woodsong, 2005). An essential aspect of the qualitative method is that it is an iterative process that allows us to shift our focus back and forth between the different components of the design. This is also corresponding with the hermeneutic view from our literature.

We are using a cross-sectional approach since our empiricism is a collected form a specific moment in time. If we were to use a longitudinal approach, this could give the study an even broader view and intel on how the attitudes change over time. Since this is a time-limited master thesis, it would not have been beneficial for us to do it over a more extended period.

Lastly, we have decided on a research strategy, which is a plan of how we, as researchers, will go about to answer our research question (Saunders et al., 2016). In our case, we found it most beneficial to conduct a Narrative Inquiry. This type of research strategy seeks to capture personal and human dimensions of experience and takes account of the relationships between individual experience and cultural context (Clandinin & Connelly, 2000). The purpose of Narrative Inquiry is to derive theoretical explanations from narrative accounts while maintaining their integrity (Saunders et al., 2016). Our role as researchers is to listen to the respondent who will act as the narrator in the process. At the end of the process, we will be able to compare and contrast these narratives to get a deeper understanding of the topic. The depth of this process is likely to produce thick descriptions of contextual detail and social relations (Saunders et al., 2016).

5.3 DATA COLLECTION

This chapter presents the processes of our data collection. Our primary source of data collection is semi-structured interviews, which is a common data collection technique within qualitative studies (Saunders et al., 2016). The semi-structured interviews aim to provide an environment in which we, as researchers, get insights into the lifeworlds of our interviewees, without needing to follow a strict layout. Ultimately, this will provide a basis where we can collect rich primary data through understanding the reasons for the decisions that our research participants have taken about genetic testing or the reasons for their attitudes and opinions on the topic.

SAMPLING

We have used several types of sampling methods to find our sample. We have used a combination of maximum variation sampling from a purposive sampling method and convenience sampling.

We have chosen to conduct a purposive sampling method, which is a method within non-probability sampling techniques. This means that it will not be possible for us as researchers to make statistical inferences about the characteristics of the population (Saunders et al., 2016). This method is beneficial for an exploratory research design, as it supports the developing of knowledge in the early stages of a new topic, and allows us to gain in-depth knowledge from a small number of cases. This method also requires subjective judgment by us as researchers, to enable us to select cases that will help us answer our research question (Saunders et al., 2016).

We aim to interview a group of people with different attitudes to be able to achieve a broad perspective of variations within the attitudes towards genetic testing, and further to reveal and illuminate critical themes. We will, therefore, conduct maximum variation sampling in regards of their initial standings. To ensure maximum variation within our sample, we have included diverse characteristics as sample selection criteria before the selection of our sample. This requires us to look for people that are both positive towards genetic testing, people that have not already taken a stand, as well as people that are negative towards genetic testing. According to Patton (2000), a small sample containing cases that are entirely different has their strength, as any patterns that do emerge are likely to be of particular interest and value and represent critical themes. The fact that we are interviewing wide cross-sections of participants with highly contrasting opinions could increase validity as we can cover a breadth of meanings.

Our way of choosing a suitable sample also has traits of convenience sampling when it comes to the actual individuals. According to Saunders (2016), convenience sampling often ends up meeting purposive sampling criteria that are relevant to the research aim. Although we chose our interviewees on the basis that they had some stance (positive, unsure, or negative) on genetic testing, we found these candidates based on convenience. We talked to people in our environment, asked them about their stance on genetic testing, and subsequently requested them to be part of our study. We wanted to include all stances on the topic, so it was important for “fill up” all categories. We ended up with a sample that contains good variations within attitudes, but they are rather homogenous when it comes to personal characteristics. All of our interviewees are in their 20s, they are Norwegian and most of them are students or new graduates.

The most important issue when deciding on suitable sample size is keeping in mind the logical relationship between the sample selection technique and the purpose and focus of the study (Saunders et al., 2016). According to Saunders et al. (2016), a suitable sample size for semi-structured interviews is between 5-25 respondents. In our study, we have found it favorable to interview ten people to gain insights on their attitudes towards genetic testing.

We ended up with a sample that included ten people; eight, which are students within a range of different fields of study; law, economy and business, molecular biology and media and communication, and two which are working within health care. Eight were girls, and two were boys, and they were all between the ages of 20 to 28 years old. In short, we will characterize them as young adults. Our final sample is presented in the table below.

INTERVIEWEE NUMBER	INITIAL STANCE ON GENETIC TESTING
Interviewee 4	Positive, has conducted a test
Interviewee 9	Positive, has conducted a test
Interviewee 5	Positive, wants to conduct a test
Interviewee 6	Positive, wants to conduct a test
Interviewee 3	Unsure/positive
Interviewee 10	Unsure/positive
Interviewee 2	Unsure/negative
Interviewee 7	Unsure/negative
Interviewee 1	Negative
Interviewee 8	Negative

Figure 7: Display of the variety of attitudes among the interviewees of our sample.

PREPARATIONS

The respondents were given information about the specific topic of the research and were asked about their current standing on genetic testing. Other than this, we wanted to give them as few prerequisites as possible to not risk influencing their answers in any way.

INTERVIEW GUIDE

Ahead of the interviews, we had prepared an interview guide that included questions within different topics related to genetic testing. These questions were both open-ended and closed. Our main objective was for the interviewee to talk as much as possible about their reflections, so that we could get a deep understanding of their lifeworlds. Different themes and related questions were, therefore, only planned to be used as guidance throughout the interview if needed. We found it essential that the interviewee could let the interview flow in the wanted

direction, and followed up with more questions on given topics if we found the meaning to be of extra value.

5.4 DATA ANALYSIS

By using an inductive approach we have started by collecting data, and further aim to explore them to see which themes or issues to follow up or concentrate on, in line with recommendations by Saunders et al. (2016).

PREPARATIONS

After the interviews were conducted, we made use of the audio recordings and notes from each interview to transcribe our collected data word by word, in their native language. Using both of these methods leads us to emphasise both *what* our respondents said and *how* they said it. Transcription was started as soon as possible after the end of each interview, and was finished within the following day. This to ensure that our recollections of the interview were fresh in mind, and that we did not confuse different interviews with each other.

NARRATIVE ANALYSIS

To analyze our data, we chose to conduct a *Narrative Analysis*. This is not a specific analytical technique or part of a wider methodological approach as other methods are, it is instead a collection of analytical approaches to analyse different aspects of narrative (Saunders et al., 2016). This method enabled us to preserve data within their narrated context to maintain the sequential and structural element of each case, and to subsequently analyse these narratives as a whole (Saunders et al., 2016).

Both inductive and deductive approaches were used in our Narrative Analysis. We had already developed codes and categories based on theory and previous research, but we also allowed codes and categories to emerge inductively from each narrative. In line with the purpose of Narrative Analysis, we have not followed a procedural outline during our analysis, but rather used collections of analytical approaches which we found suitable to analyse our particular data. We have found it favorable to conduct a *Thematic Narrative Analysis* as it will help us identify themes within our narratives and to focus more on the content of the narrative than the way it is structured. According to Saunders et al. (2016) this method is used when you wish to

analyse multiple narratives individually. This helps to illustrate how variations in context affect the actions taken and outcomes recorded, or to illustrate how and why differences in the actions taken and outcomes recorded may vary in spite of contextual similarities.

5.5 VALIDITY

The validity of a study is based on the validity and relevance of the data to be able to answer the topic we seek to explore. It refers to the appropriateness of the measures used, accuracy of the measures used, accuracy of the results and generalisability of the findings (Saunders et al., 2016). We will in this section discuss aspects of validity in relation to our research.

INTERNAL VALIDITY

The internal validity concerns whether one is able to measure what is intended to be measured and if the study provides credibility in its results (Johannesen et al., 2011). We would argue that the fact that we have a relation to our interviewees would strengthen our internal validity, because it is easier to be honest when you do not feel judged. At the same time, this could make the interviewees having an incentive to act differently than their meaning because they want to act as their ideal self. Asking them to elaborate also helps increase our internal validity, as well as asking them if we have understood their meaning right. Thus, qualitative studies with semi-structured interviews like ours are able to achieve a high level of validity/credibility when it entails a process of using clarifying questions and probing for meanings (Saunders et al., 2016).

CONSTRUCT VALIDITY

Construct validity relates to the identification of correct operational measures for the concepts being studied (Yin, 2014). Do we measure what we intend to measure? It could be hard to be certain of whether we are measuring the correct attitude of our respondents because it is such an abstract concept.

To enhance our construct validity, we apply *communicative validity* techniques. Our choice to present our data through personal portraits entails that we aim to describe other peoples lifeworlds. This is a demanding process that require a deep sense of understanding from us as researchers as we attempt to interpret the communication accurately. One way to test the durability of the portraits is through communicative validation. This is tested through asking the portrayed people if they recognize themselves, or if they feel alienated by our descriptions

of them (Ims, 1987). To test this in our study, we sent each of our interviewees their finalized personal portraits to get their feedback on it. This was considered as crucial to finding out whether our interviewees felt like our description on them and the interview is applicable to their own perceptions.

EXTERNAL VALIDITY

Qualitative research is often cited as being too specific on a particular social setting to be generalizable to a wider world (Pandey & Paitnak, 2014). Qualitative research should be understood as an effort to seek *depth* rather than breadth. The external validity in qualitative studies like ours refers to whether the results of the study is *transferable* and can be *generalized*. As explained above, qualitative studies cannot be used to make statistical generalizations about an entire population where our data are from a small non-probability sample. However, this does not mean that qualitative study is less valuable than a quantitative study. A qualitative study is more suitable for our research as it aims to explore, explain and provide insights that can be used to develop theory, rather than to provide statistical generalisations. Our study could be used as a point of departure for future studies within this topic.

5.6 RELIABILITY

The reliability of a study refers to the *dependability* of the study, and relates to whether a researcher is able to replicate our research design and data collection and achieve the same findings as us (Saunders et al., 2016). For qualitative studies, there are in general concerns about reliability as these studies lack standardization in the research process. Semi-structured interviews can therefore provide a threat to reliability.

Firstly, our study can suffer from interviewee bias, which is caused by interviewee's about the interviewer, or perceived interviewer bias. This could lead to a situation where the interviewee refuse to answer questions that could reveal sensitive information, or where they provide wrong information that is more 'socially desirable' to make themselves look better (Saunders et al., 2016). We will try to solve this by ensuring anonymity for the respondent, as well as we will provide a safe environment that facilitates openness and sharing.

Secondly, as researchers we run the risk of researcher bias. Since qualitative researchers are very close to their research settings and subjects, issues of biases and subjectivity in

interpretation of the results are often raised. Objectivity is one of the major challenges in qualitative research (Pandey & Paitnak, 2014). Researcher bias relates to the comments, tone or non-verbal behavior of the interviewer, and can be avoided by not asking guided questions, to be sure to not influence our respondents answers in any way and to try to not interpret their meanings based on our own conviction. To provide reflexivity in our study, it is also beneficial that we are two researchers involved in the whole process, and that we both participate together in each interview. This can help develop complementary as well as divergent understandings of our data, and further allow discussions of the interpretations (Panday & Paitnak, 2014).

5.7 RESEARCH ETHICS

When conducting qualitative research, it is crucial to think about the integrity and respect you have for the people you gather data on. They could be sharing sensitive information, and it is, therefore, necessary to take caution when both gathering the data and handling the data. It is vital to have in mind that we all have our values and boundaries of what we are comfortable in sharing. Many may find the interview situation to be scary or intimidating. Our job as researchers is, therefore, to ensure a safe environment and respect the person willing to participate in an interview.

The Danish philosopher K.E. Løgstrup (1905 - 1981) introduced the concept of ‘the Zone of Untouchability’ and used it to describe a fundamental human need (Christoffersen, 1999; Tremoen, 2018). He claims that all human beings have their own zone of untouchability, and that this is something that needs to be considered when interacting with others. If we are to communicate with another individual, it is essential to respect the distinction between reasons and motives. He emphasizes that we are free to attack or disapprove of any *reasons* of our counterpart. However, one should be particularly careful with ascribing motives to others. He believes that when attributing suspicions to the motives of others, we cross the line into their personal zone, ‘the Zone of Untouchability’. Thus, communication with others enables us to hide our motives, and this is a possibility that should be respected. Some have argued that this is in contradiction to the openness of speech. Løgstrup agrees on this point, but explains that these tendencies are ‘unifying contradictions’ because they mutually condition each other. The zone of untouchability would without the openness of speech lead to isolation. Without respect for the zone of untouchability, the openness becomes thoughtless and tactless (Christoffersen, 2019).

Since we know the identities of our interviewees, it means we are in possession of sensitive data. We have, therefore, sent a notification form to the Norwegian Centre for Research Data (NSD). Approval from NSD is attached in appendix 4.

To ensure the interviewees that we value and appreciate their contribution, we wanted to gather the data in an orderly manner with informed consent. Informed consent relies on giving all the information needed about the purpose of the interview. We informed that we were looking for personal meanings and thoughts and that there are no right or wrong answers. We expressed that the interview is voluntary, approximately how long time the interview would take, and that we would send them the text back for their validation. More of this is in appendix 3, where you find our information paper given to the attendees.

We wanted to do data collection with consent from the participants, so we also made sure of having written consent for us to conduct the interview and use their data in our thesis. By consenting, they also can withdraw at any time if they want to. This gives incentives to feel safe and that it is not possible to say something stupid that could have consequences in the future. We highly value our participants' anonymity and rights.

5.8 RESEARCH CONSTRAINTS

This study, as several other studies, have research constraints. The main weakness lies in the sample. One weakness of the study is that it is hard to generalize. Generalizable results on statistical grounds on this topic could be fascinating. However, since it is such a new phenomenon, we believe that our research could help other researchers study this moving forward. A limitation would be that we could have increased our sample size if we had more time for the study. Some of the interviews were conducted over FaceTime; this could be a weakness because it is harder to create a safe environment for the conversation. However, we know these interviewees well, and do therefore not view it as an essential problem.

It could be hard to draw a conclusion when the sample is in such a spread. When we have such different perspectives and few people having the same meaning, we only get a glance of the different meanings and attitudes out there. This can make it hard to conclude, and make it difficult to know if the deep meanings we explore counts for more people, or if it is just for that

one individual. We cannot know for sure that each person is representative of their meaning in a larger context.

That we only have two males, could also be a weakness of the study, but might as well bring forward the view from the females' side. It could be interesting to compare our results with a similar study, but only on more male participants, to see if the results vary or not. At the same time, we did find it easier to recruit females, probably because we are females ourselves.

One other weakness could be that we have a relationship with the interviewees; this can affect the way they respond. They could respond with dishonest opinions because they want to build a specific relationship with us in other areas. Nevertheless, it could also be a strength, because it could be easier to open up to people you know will not judge. It is also a strength because it is easier for us to interpret the truthfulness because we know how they react and act usually.

Another research constraint is that it is hard to know if what people think they would do correlates with what they actually do. In the same sense, it is hard to know what they express they feel is what they actually feel. To limit the extent of this bias, we have tried to ask questions from different angles and followed up with questions if we feel the information they give is contradictory.

6. FINDINGS

6.1 PORTRAITS

In this chapter, we will present our results and findings. To give a good picture of our interviews, we will start by presenting the different people in personal portraits. This will provide the critical essences of their attitudes and describe what separates them. The portraits will be presented based on our main take from the interviews and will give a sense of what kind of opinions that circulate regarding DTC genealogy tests. Data from our findings are presented in a table in appendix 1. At the end of this chapter, we will present the similarities and differences in thoughts and attitudes. We will also sum up what we found to be their biggest worries concerning DTC genealogy testing.

6.1.1 The Susceptible Discoverer

The Susceptible Discoverer was the first person we interviewed who had taken a DTC genealogy test. He explains that his main reason for taking it was to be entertained and describes it as a fun Sunday activity. Commercials had been popping up everywhere, and that caught his attention. He felt like this was something that everyone was doing, and that contributed to his choice. *“The way they market these tests, you get very convinced that it is accurate, and that you will learn something new about yourself, so I got excited.”*

He already knew that he had some ancestry from other countries and was excited to get this confirmed in the results as this would enhance his feeling of being unique and not 100% Scandinavian. The results, however, showed him that he was 100% Scandinavian. He found the results unsatisfactory. *“I thought that the test would explain my whole DNA, but I feel that the results were too shallow. I do not feel any more certain of my ancestry after the test, but I was quite sure before taking the test. I got kind of disappointed; it would have been fun to be more exotic than just to be 100% of something. I did not take the test to know that. I wanted to know something more, like that I had genes from other nations.”*

“I do not think my trust in the test is reduced even though I do not completely agree with the outcomes. I believe this is because I do not understand the process good enough. I have just accepted the results without having any further thoughts about it. The answer is not something that defines me. I still think I have some connections or relatives in other countries.”

He does not really care about privacy issues; he cares more about the accuracy of the results. He acknowledges that he “should” find it crucial to think about the safety of his DNA. *“I am insignificant in a global context. I have nothing worth protecting. However, it is just me. Had I been a slightly more influential person, then I would have been much more concerned about it.”*

“I would say that: Ignorance is a bliss.”

The Susceptible Discoverer is fully aware that he is easily influenced and would be a perfect target for marketers to reach, but he finds it more relevant to figure things out while doing it, rather than overthinking possible outcomes. *“If you know too much it can easily become an*

undesired stress element.” One potential risk he sees for the future is that we will be using more biological codes as identification, such as the way fingerprints are used for unlocking phones. “*As long as it has no noticeable consequence for me, it is not that important what kind of information they are sitting on.*”

The Susceptible Discoverer trusts that his information is safely kept. He got information about the process of the test, from how they handled his sample to how they were analyzing it. He is positive in sharing his DNA with medical researchers but would like to know about it up front if they are planning on using his DNA. At the same time, he may have consented to it when he ordered the test - he is unsure. He did not read the terms and conditions because he did not bother. He has never wondered about what he may or may not have given the company permission to do. “*I think I thought that it is so little they can figure out from my DNA, but now I think that it may be more than I have thought of.*”

He would have trusted the validity and accuracy of his results regarding what they state if they had confirmed his former beliefs. As this is not the case, he has less trust in the accuracy. His trust in the accuracy of the results after conducting it is roughly 70%. Even though his trust relies on the answers, he still thinks it is worth the money. “*It is always nice to know. I think it is a curiosity thing to understand yourself, and a fun fact to tell others.*”

The Susceptible Discoverer enjoyed reflecting over privacy factors as this is not something he had speculated about earlier. He would still have taken a genetic test, but now feels more reflected over his values and that DNA is a part of his identity.

6.1.2 The Ambivalent Discoverer

The Ambivalent Discoverer has conducted a DTC genealogy test from MyHeritage. However, she did not purchase the test herself, she got it as a gift from her friend. That made the barrier for taking the test even lower. *“When it is a gift, you feel like you have to take it. However, it was something I wanted, as well. I thought it was a fun gift to receive”*.

The fact that two of her friends had already taken the test has greatly influenced her choice. *“Since my friends have already taken this test, I feel like they are going down with me if something happens to our DNA information.”* This has made her less concerned about taking a test.

She initially had no hope of getting any new, surprising information from the results of the test, as she sees herself as 100% Scandinavian. From what she knew, she had no family or relatives in other countries. She explains that her motivation for taking the test was initially to confirm this belief. However, when receiving the results, the test showed that she was 78% Scandinavian and 22% Irish, which was surprising to her.

After getting the results, she claims that she now identifies as both Norwegian and Irish. *“I feel a bit less Norwegian and a bit more Irish after the test.” “Before, I thought I was 100% Scandinavian, or Norwegian. I feel a bit more special now. I am definitely a lot more interested in Irish stuff, and I started watching Peaky Blinders, for example. If I see an Irish TV series, I feel a bit patriotic”*. She admits that she feels more unique and exciting as a person after this finding.

What is unique about The Ambivalent Discoverer is that she felt more confident in her knowledge about her heritage and identity before taking the test, than she felt after getting the results. *“Because I have not gotten any explanation of why I am 22% Irish”*. According to her, her parents did not know about any Irish heritage, and the test has not provided her any answers on where the Irish heritage stems from either. She is also skeptical about the accuracy of the tests, and only believe them to be about 60% accurate.

She thinks it is harmful the way companies make money off people’s curiosity. *“I think I could have seen more if I had paid more. I would expect to see everything, because it is quite*

expensive, and you give them access to personal information, your DNA and your family. When they already know all that information, it is a bit annoying that you cannot see everything”.

She admits that her trust in these companies vary from which country they are from. *“It is hard to say because in the US you know that they are probably very good at what they are doing, that they have a lot of technology and a good system. Nevertheless, the US is very economic-based. A lot is just about making money”.* *“I trust Norwegian companies more. They have many laws they have to follow, and probably privacy regulations that are a lot stricter than in the US. Moreover, maybe they do not focus as much on the money”.*

She admits that she has thought about the fact that the company might know more about her than what she ordered from the test. *“That is what they want to get paid for, among other things. It is a bit scary that there are people out there that know more about me than I do myself. I don’t like that. That is a bit challenging”.* Although she was aware of this, she still took the test. *“I guess it is just the curiosity and the fact that you do not think about the consequences in the exact moment of action.”*

She says that she has read the Terms & Conditions, as she cares about privacy to some extent. However, she admits she only skimmed through the text. *“I just tried to see if something caught my attention so that I knew I did not sell my soul.”* She could not recall anything catching her attention, and to her recollection, she consented to everything. When asked if she cares about what she has consented to, she says: *“Yes, now I do.”* She admits she did not care too much about it when she took the test. *“No, I did not think it over. I was kind of blinded by curiosity”.*

When reflecting on the conversation at the end of the interview, she admits that there were many questions she had never thought of. The new information that made her more concerned. *“That they could use my DNA for medical research, and that they can share your DNA with others. That you consent without reading through everything”.* *“I feel like I am a bit more critical towards sharing my data now.”* However, she claims she would still have taken a test if she had not already done it. *“I would read carefully through the Terms & Conditions. I would pay extra attention to words like ‘medical’ and ‘sharing’”.*

6.1.3 The Optimistic Globalist

The Optimistic Globalist is also positive towards taking a DTC genealogy test. She describes that the motivation behind it is that it is both fun, interesting and exciting, and it can be used as a fun fact in the future.

“I have seen videos of people that have done it that have relatives all over the world, and I think it is exciting to see that everyone comes from the same place, that everybody has a little bit of everything inside themselves.” This globalist view is also one of her main reasons for wanting to take an ancestry test. Despite this, she has still not taken a test. The main factor for why she has not done this yet is the price aspect of the tests. *“It depends on how much it costs. If I could do it for a reasonable price I would do it. If it was free I would take it without a doubt”*.

She says that she has watched several commercials promoting these types of tests.

“I was watching YouTube when one of these commercials appeared. It displayed people that had taken an ancestry test for their heritage, to find out where in the world they were from.” She believes this have influenced her towards taking a test. *“Before I saw that I did not really know that it was possible. It made me aware of it, and that of course made me more interested”*. She believes people her age could easily be influenced to taking these tests. *“I think there are more people in their twenties getting influenced by bloggers and influencers than others, because we use social media more, and we read more about these things”*.

The Optimistic Globalist in general see positive consequences and implications of taking ancestry tests. *“If you have an idea that you belong to a certain type of people, it could maybe break with that idea, and I believe that is a good thing – that you get a feeling of global unity”*. She sees both benefits and disadvantages of ancestry tests. *“It is a benefit that you get to see yourself in a bigger context. It could be a disadvantage if you find out that you are 100% from Scandinavia, and if you have racist tendencies, maybe that would enhance that. But I believe you will have results from here and there. I think it is very rare that you are 100% from one place. So, in general I think it would be a positive thing”*. This expresses her optimistic, globalist view. *“It is kind of dull if it turns out I am entirely Scandinavian. I hope I do not get that result”*.

She does not think discrimination will be a very realistic consequence. *“People live everywhere now, the world is a lot more globalized than it used to be. So I do not really think it would have a big negative impact. Maybe 100 years ago, or 50, or even 20. But I think we evolve in that way that we live different places and because of that become more tolerant”*.

When asked about how she perceives the big players of this industry, she has to reflect upon their motives. *“I wonder how much money they make. I think it is a little bit odd to start a company like that. But they probably saw a need for it. That people want to do it. But at least, I feel like since I have heard about them and that I have seen them when I have not even tried to do it on purpose, it gives them some credibility”*.

Regarding the trust of the companies, she believes she would trust Norwegian companies more. *“At least a Scandinavian country, because then you know that they have strict regulations. Maybe England too. I immediately get more skeptical when it comes to the US, because they have this market strategy, they are very exaggerating in their advertisements. You do not always know if you can believe everything they say. I think it is easier to be tricked by US companies because of their market strategy”*.

She claims that she cares relatively much about privacy, but only to an extent. She is not too concerned about sharing her DNA with a foreign company. *“I am not really certain what DNA can actually say about somebody. What you can really get out of it”*. *“Right now, I do not think there are many people that would get something out of possessing my spit. Because I am a student. If I was a prime minister or something, maybe I would be more interesting”*. She does not see hacking of the databases as a particular threat. *“I do not really get why people would hack it. Why they would want that information, at least right now. But of course - it is a personal thing”*.

Consenting is important to her. She is positive towards sharing her DNA with third parties if it involves medical research or solving crimes, but it is crucial that this is informed explicitly, and that you have the choice to opt-in by for example ticking off a box if you consent to sharing. *“I am guessing that they cannot really do anything more with the data, without me consenting to it, but I am not specifically concerned about that. I do not think I would share my DNA unless there was a consent form to sign. I would be skeptical if there was not”*.

After the conversation, she does some reflecting over the questions and aspects of what we have discussed. *“There were quite a few questions I had not thought about before. I think I had more or less the same opinions before, but now I have reflected more around them”*. When asked if she is still pro ancestry tests, her answer is yes.

6.1.4 The Curious Globalist

The Curious Globalist has not taken a DTC genealogy test yet but wants to do it. She mainly wants to do an ancestry test to figure out where her ancestry is from and to see if her heritage reaches outside of Scandinavia. Although she does not know exactly where her family is from, she would mainly take the test for fun and of curiosity, not because she needs to know something in particular.

Another reason *The Curious Globalist* supports ancestry tests is that she thinks it breaks down barriers. “I think we all are much more connected than we think. By getting the results of these tests, I think it will disprove that I am 100% Scandinavian. I think it could give people a broader global mindset, that it opens up people towards other cultures and nations.” Therefore, we have given her the name *The Curious Globalist*. However, she also sees the risks of these tests affecting people to become more nationalistic and more racist if they find out that they are 100% of a particular ethnicity. “I am trying not to identify myself with a thought, feeling, education, or lifestyle. I am only identifying myself as a feeling that this is me”. *The Curious Globalist* want to identify herself as only herself and felt a change of mind regarding her identity when she traveled the world some years ago. Before that, she felt that Norwegians are one type of way and that people from other countries are a different type of way. After broadening her perspective through her travels, she came to find that people are people, and that thinking about what identifies us could lead to dangerous misinterpretations of human beings.

If *The Curious Globalist* had figured out that she has roots from another country, she thinks that she would have been more curious about that specific place. “*I think I would have looked at myself a little differently if I had roots from another country. I would have been more interested in history and the people living in the country. I think I would have identified myself more with that place just because I learned that I am partly from there*”.

The way the ancestry test has come to her mind is through commercials and friends she has talked with that received exciting results. One of her friends found out that she was her fifth cousin. “*That was kind of interesting, but we just laugh about it.*”

It is crucial for *The Curious Globalist* that the quality of the tests is high. “*If many Norwegian people are using these tests, this strengthens my belief in the accuracy and privacy issues*

related to them. It is stupid to pay for a result if it is only a 50% chance that it is right. I want it to be accurate". She would have consented to allow law enforcement to use her DNA in the database for criminal cases. "It would have been suspicious not to do it, like you are hiding something. I think it is more important to find a criminal person rather than to maintain the security of my data privacy. Especially for the police, which I place high trust in".

The Curious Globalist feels that the companies get a lot of relevant and sensitive information and is skeptical about the fact that private companies can profit from that. "The World Bank should store this information; it would have been more legitimate. Alternatively, another public organization, who is not profiting from it. Another thing is that it is voluntary to do this. If there is a willingness to pay, it should be okay to have a company for profits as long as you think through the consequences and read the terms and conditions first."

"If I go voluntarily into a website, like YouTube, I have no problem with them gathering some of my data. I am doing it fully aware, and have no problem with them collecting my data because I get something back. If you pay for a voluntary test about yourself, you should be able to keep it private."

"Before this interview, I would never have thought about deleting my data or reading the terms and conditions, unless I had discovered an article or something that warned me about these issues. Nevertheless, now I would delete my data and read the terms". The Curious Globalist believes she has changed her attitude towards DTC genealogy testing. Not in the way that she will not take one, but in the way that she would care more about the privacy issues now, as opposed to before the interview when she did not care about it.

6.1.5 The Pending

The Pending is not firmly against DTC genealogy tests, she is only a bit skeptical. The biggest problem she sees is if people are skilled enough to read the results without misinterpreting it. She is anxious about whether people misread the results, and thinks this could become a public problem. *“The test results do not necessarily have to tell the truth.”*

“It could be fascinating to get knowledge of things that you were not aware of before. However, sending away DNA, which contains so much information, is the main problem.” Her concerns lie in not knowing what the company can use it for. *“Today, there are many commercials on TV that make me suspicious about their motives. I just get the impression that this is something someone aims to make money out of. I think I would rather trust a hospital or the academic environment in this area.”*

“If I know exactly who I am? I do not know if I know that myself, no, but I do not think a genetic test would give me those answers. I would probably not feel more confident about who I am after taking such a test, and I do not really need to know who I am genetically either.” She thinks people probably do the testing because they are curious, especially people with a concern for something. *“I would rather have taken a health or personality test than the ancestry test because I do not find ancestry that interesting.”*

The Pending finds it strange that the DTC tests being sold to Norwegian consumers are not regulated. *“They do deal with people’s DNA. There is much information in this. I am positive about the fact that there are so many companies; the only thing to be questioned is how well these various companies are being controlled. There should be regulations on this.”*

The Pending is excited about the fast-moving evolution of science. She sees more positive consequences than negative. One positive effect of ancestry tests is that it could lead to a more open mind. *“The benefits can be, of course, that there are quite a few who are extremely nationalistic and think they are so much better off being Norwegian than being from another country, for example. So, I think it is good that it can help increase transparency. I think many do not understand that you are not just from one place. After all, you are a mixture of different genes. In that sense, it is a matter of understanding and that people understand a little more of their genetics.”* She thinks there could be adverse effects if one is surprised or disappointed

over the results. *“If you find out that you are not completely Norwegian as you thought, you could have a complete identity crisis, but I do not see it as a major drawback.”*

Concerning privacy, The Pending is not so worried. *“I think it is important, but in general, in everyday life, I do not really that care about such information. So, I can say I care, but then I do not think much about it.”*

Reflections over the interview at the end shows that The Pending is still on the ‘maybe’ side. She is pending in the sense that she plans to conduct a test once the regulations are in place *“I feel like I got some good reflections and new views on the different sides of DTC genealogy testing.”*

6.1.6 The Concerned

This person stands out as the person that is the most concerned about privacy and security of his personal data. We have therefore given him the name *The Concerned*. In general, he is curious about his own heritage and would be interested in taking an ancestry test to find out more. He mentions price as a barrier to taking the test, as he thinks it is too expensive at the moment. However, his main reason for not taking one is his concern of the privacy tied to these tests. *“It depends a lot on the data security and privacy, but I would probably take the test had I known for sure that the data was not shared with anyone”*.

He explains his view on privacy: “That is of course very important. You do not want to be exposed to identity fraud, and that has actually happened to me. I had lost my card, and somebody ordered a bunch of stuff in my name, and I got a lot of bills. That was a really stressful”. This happening a couple of years ago has made him more concerned with privacy than he used to be. “I am very concerned with privacy now, in all areas. 3-4 years ago I did not think too much about it, but the latest years I feel like it has become more and more important. And harder and harder to be safe, due to the digitalization”.

The Concerned has some knowledge of the companies offering ancestry tests. He specifically recalls to have heard about MyHeritage and 23andMe. He is not quite sure how they got to his attention, as he has not been seeking out these companies or done active research on them. Therefore, he believes they have come to his attention through influencers on social media, through advertisements and through articles in the news.

He is quite skeptical towards companies from the US, and claims that his trust towards the company depends on what country the company is from. *“That definitely matters, because it makes you think about everything you have heard in the news about the US - the Facebook Scandal, Cambridge Analytica. It makes you think they might do something with your DNA”*.

He is also skeptical towards Chinese companies, and he says that he trusts Norwegian companies more. *“If it was a Norwegian company I would take them more seriously, I would have more trust in them”*. The Nordics in general has his trust, and he justifies it through the cultural aspect. *“I feel like the society is a bit different here. That it is built up the same way, and that we have good security systems around these things”*.

Despite his current concerns about privacy, he believes that these issues will be reduced in the future. “I believe that if I do the test in 5 years, it will be better. I think people will become more aware of privacy issues, and the companies will not be able to make money if the privacy of their customers is not good enough. So I think it will be safer in the future”.

In general, he seems to have a positive outlook on the future of technology. He believes privacy will be improved and that hacking of databases will become less of a threat. He also points out that the growth of the supplying companies in this market will create competition which could lead to lower prices for consumers and a general improvement of all aspects of the service. He is positive to the fact that these tests exist and emphasizes the importance of people having the freedom of choice. *“If people want to know a lot of different stuff about themselves I think they should be allowed to”.*

At the end of the interview the interviewee reflects on our conversation. He explains that he is still open to take an ancestry test, although he is even more worried now about the possible privacy issues tied to it. *“I am probably a bit more skeptical now. Before I was more like ‘maybe-maybe yes’, now I am more ‘maybe-maybe not’. I am still not totally against it, I would have to look at the privacy part of it. I have reflected more on what the DNA can be used for - that it could be misused”.*

6.1.7 The Ponderer

The Ponderer has not yet taken a final stand on whether to conduct a genetic test or not. She feels like she has control over her family tree and ancestor history and does not see any reason why she would do it, other than the fact that it could be fun. Her biggest concern is if there are possibilities for her data to be misused or used for other purposes. *“I am a 100% Norwegian and I know all about my ancestors, so I do not need to take a test. I am not interested in getting to know all my distant relatives”*.

“It is important to know where you are from, and what kind of values your family has.” *The Ponderer* thinks this shapes you as a human being, and allows you to be a part of a community. Had she not known her family, she would have considered doing it. If she had taken a genetic test and figured out that she was, for example, 10% Swiss, her only reaction would have been: *“Insanely funny that I am 10% Swiss, where is this from?”*

The Ponderer has written a paper about genetic testing as a school project. She experienced to get a lot of advertisement for the tests after that. Before writing the paper she did not know much about genetic testing. *“I trust that the privacy policy is there to protect us. However, it is quite scary how cookies work, and that the data you leave behind can be misused. In Norway, we have very good privacy laws, so I trust them to a certain extent.”* In her regular life it differs how much she cares. *“It varies whether I care or not, sometimes I think a lot about it, while other times I do not think about it at all.”*

“It’s hard to trust the company and their incentive to keep my data safe when it is a company working for profits. Sure you agree to the terms and conditions, but you will always wonder just a little.” She is still positive towards her data being shared for medical research, but she has to be asked. *“I trust that if there would have been any trouble with the safety of these tests, or if there have been any safety breaches, we could have heard about it through the media.”*

“Regarding the terms and conditions, I would like to read it because I have heard so much about it. Nevertheless, if I had not had some knowledge of it, I think I would have consented right away. It is just saliva, somehow. One is not educated in DNA testing. You do not know the consequences, and that can be a bit of a problem; it is easier for people to do this if they do not know the consequences. You think it is just a saliva test - it is just some spit.”

6.1.8 The Disinterested

The Disinterested is also open towards taking a DTC genealogy test. However, she says she is quite sure of her ancestor history, and explains that she would mainly conduct the test to seek confirmation of her former beliefs of her heritage. She feels that taking an ancestry test is less scary than taking a health test or a personality test, but if they were all for free, she would take all of them. *“I could just not choose not to look at them”*.

One of the main reasons for why she is not specifically interested in taking an ancestry test just now is that she already has a good overview of her family tree and ancestry. *“We actually used MyHeritage in school. We made a profile and created our family trees. So I have a user there, I get emails from them all the time.”* *“I do not think I discovered something new from doing that, because I had already done some research on my family tree when I was younger. So I kind of know my ancestor history”*.

Privacy is in general a very important aspect to her. When it comes to data from ancestry tests, she does not consider it to be particularly sensitive data, although she claims it could be for other people. *“It is very vulnerable to give your DNA away to strangers. You never know what it can be used for”*. However, she would consent to sharing her DNA if it was used for medical research, or even to assist law enforcement. *“I feel like if you say no you would seem suspicious”*.

Regarding what she thinks would be worst if was spread, a naked picture versus her DNA, she says: *“I feel that a naked picture, people do not really care about that. But at the same time I think that depends more on self image and self confidence. I do not think that would be fun. But I feel like over some time it would be worse if my DNA was shared”*.

She is not too concerned about the potential implications these large databases could have. *“I am actually not sure. Heritage and stuff like that, people know that from before. That is not new”*. When we ask her about the future and her thoughts on the Norwegian society and democracy, she is hesitant to answer. *“I do not like thinking about the future. It’s scary”*.

She is a bit negative towards the marketing efforts by commercial genetic companies.

“I feel that they advertise a lot for it on YouTube and other social media, so you hear about it quite often. It can be a bit much maybe”. “I think that people that want to do this do not need to be pushed. It can become a bit intrusive”.

She definitely thinks people her age can be influenced by bloggers and other influencers into taking these types of tests. She is also open to admit that she could be influenced herself. At the same time, she claims that it would probably not be too interesting for herself to get the results, as she expect that there will be no new information.

Regarding her identity and if she feels like she knows who she is, she answers: *“A little. Kind of”*. She does not see herself as special heritage wise, and claims that she feels very ordinary. She does not think taking a genetic ancestry test would change her feelings about that, whether she received an unexpected result or not. *“I would be a bit surprised, but I do not think it would really affect me, I think if i had heritage in another country it would probably be Sweden or something. And I could have guessed that. If it was from further away, I would be surprised - but it would not really affect me”*.

6.1.9 The Science Advocate

This person has been assigned the title the *Science Advocate*, as she is fundamentally concerned with scientific reliability in general. She questions the evidence of the tests and how accurate they are. Our conversation conveyed that her biggest concern was her trust in the companies selling these DTC genealogy tests, regarding their motives and the accuracy of the tests. This, including the fact that she felt no need or inherent curiosity towards discovering her heritage, are the main factors for not wanting to take a DTC genealogy test.

“We have this enormous need for information about everything today. That is not necessarily negative, but I think there are other ways of fulfilling that need. I am also concerned about if you can trust that the results are true? That is very important to me. I am very concerned with not lying or deceiving anyone. It is important that the information is true, and that is what I do not know if it actually is. I have this presumption that it is not adequately tested whether this type of genetic ancestry test is actually accurate.”

The Science Advocate strikes us as a confident person who is well grounded in herself and clear in her opinions, values and beliefs. *“I feel very confident in who I am”*. Although she is confident in herself and her own identity, she is not fully aware of where her heritage is from. *“I am not sure where my dad’s side is from, and I do not have a big need to find out about that either, if I had I would have done it earlier. But I feel confident about my mom’s side”*.

She is disinterested in discovering the part of her ancestry that is currently unknown to her. On a question about whether it would matter to her where her ancestors were from, she says: *“No. After all, they are dead”*. She does not inherit a curiosity towards finding out more about her heritage. *“It has not been a great need, and I still do not think it is.”*

When it comes to being influenced, *the Science Advocate* does not believe that anybody could impact her decision towards taking a genetic test. When asked if she believes she could be influenced by bloggers or influencers she says: *“I do not read blogs, and I only follow influencers that give me a positive vibe and who contribute to something good in society”*.

Even when presented with the question of whether she believed she could be influenced by recommendations from friends and family, she is clear in her opinion. *“No, the scientific*

evidence comes first". She also adds: "*The older you get, the more information you get, the more skeptical you become*".

In general, she believes people could easily be influenced by bloggers and influencers, especially younger generations. "I think that the younger you are, the bigger influence these bloggers and influencers have on you. I also believe we in general are very trustworthy as people, we believe that people are good instead of bad the first time we meet them". She also emphasizes that she believes different types of societies will have an impact on the level of people's trust in others. "I think people in general believe more in the good than in the bad. But then again, we live in a very civilized society here in Norway, so I assume it is easier to have a positive attitude towards others in our type of society."

Regarding privacy issues, she explains that she is more concerned about openness than about her own privacy. "I think it is important. But personally, I do not care too much about it. I do not want to be scammed or to discover that someone has stolen my identity. But at the same time, I believe that one of the success factors of a good society is openness. For my part I think it is crucial to be open and honest." She is not particularly concerned about privacy issues regarding her DNA. "What I am thinking is, what are they going to do with it? I feel like it is worse to send a naked picture of yourself."

This interviewee stands out as one of the more skeptical towards the companies that sell DTC genealogy tests. "I find it strange that a company suddenly just decide that they want to do research on your relatives and your genes. What is the evidence that this is true with great certainty? Especially if it is a foreign company, then there are not very strict requirements towards them. In general, I have bigger trust in Norwegian companies."

"I assume that these companies are US based. And when I know how the pharmaceutical industry and the health industry is built up in the US, it makes me wonder if this is just a pretext to make even more money off people? Is this pure profit to them? Is this a way of making good money off people's curiosity? Considering that we are 7-8 billion people in this world, I assume you can make quite a lot of money on this."

The Science Advocate is fundamentally skeptical towards profit organizations selling DTC genealogy tests for home use. "*I feel like this resembles alternative medicine.*"

She is also concerned about the accuracy of the tests. “If I had taken a test and it had given me totally different answers than I thought, I would just think it was wrong. I know where my mom is from, and where her parents are from. I am not 100% sure about my dad, but I would probably think that it was not true”.

The conversation has conveyed that *the Science Advocate* is not necessarily concerned about privacy issues, especially regarding herself. Her main barriers for taking a genetic test is that she has no need for it, and that she puts little trust in the companies and the results of the test. Although she has done a lot of reflection on new aspects of DTC genealogy test, *The Science Advocate* has been firm in their opinion throughout the interview, and she is still negative towards taking this type of test after finishing the interview.

6.1.10 The Confident Opposer

We have chosen to call this interviewee *The Confident Opposer*. We perceive her as extremely confident in her opinion about withdrawing from DTC genealogy testing. One of her main motivations is that she is confident in herself, and she does not need anyone telling her who she is. At the same time, she has control over her ancestry and feels entirely Nordic. *“I am not willing to pay for something I already know.”*

The Confident Opposer thinks the reason other people take these tests is that they are curious and are insecure about themselves. *“It is human nature to be curious about yourself and your roots. You always want to learn more about yourself”*. In that way, it is great to have the possibility to explore with this sort of test, she adds. *“Maybe the test can help others find themselves.”*

The Confident Opposer knows one person who has conducted a test. She got a result that showed her that she was 97% Northern European and that the rest was Southern European. *“I think she got it as a gift, so luckily, she did not throw away her own money by wasting it on those uneventful results.”* *The Confident Opposer* never wanted to do the test anyway, so she did not get influenced towards taking a negative stand on the tests by her friend’s results. She has never seen celebrities promoting the tests, but she has seen several commercials on YouTube on how people get to know their true selves, with just spitting in a cup. *“I cannot understand and comprehend that you want to pay to get a confirmation that you are from Northern Europe. I do not get it.”*

“I do not think the results have anything to say for who you are. I think there are only weak, desperate people taking these DNA tests. Because they just want to know what their DNA says about them, to make excuses for themselves, and act dishonestly.”

The Confident Opposer is open to taking a test solely to help medical research or law enforcement, rather than sending her DNA to private companies. *“I think the companies have found an area where one is curious and gullible, and then try to exploit people. I believe the money goes to individuals who own the company.”* She does not fancy the way it seems that the company is running its business. *“They have found a way to take advantage of people’s urge to know more about themselves. This, I think, is unethical.”*

For privacy concerns, The Confident Opposer is worried about misuse. “If it is not sensitive information or protected, rumors could be spread without me being there to verify it. That is not good.” At the same time, she is not so worried about herself and private policies in regular life. “No, I do not think much about privacy. I do not even cover the webcam on my computer. If anyone wants to see me lying down eating chips with three double chins, yes, please be my guest.”

She believes companies should be more transparent in their information about what they do with the genetic information after one has received the results of the tests. According to her, one should not have to opt-out of consenting to terms or deleting data. *“If you physically have to delete the information, it is kind of like nudging. After all, many people would not bother to do so. Rather, it should be like one must physically enter and accept that they keep your DNA or use it for other purposes.”*

The Confident Opposer has not changed her mind throughout the interview but is even more sure that DTC genealogy testing is something she never would do. It is about her being confident in herself and having no need for others to tell her who she is or who she should be.

6.2 RESULTS

In this chapter, we will present the results of our portraits, where we look into the correlations and differences between the different groups of core attitudes. Firstly, we will start by comparing the people who have taken the test (*The Discoverers*). Secondly, we will look into the people who are planning on conducting a test (*The Globalists*). Thirdly, we will look into the people that are unsure of whether they want or not (*The Curious Pending* and *The NoNeed*). Lastly, we will look into the correlations and differences from the people not wanting to take a test (*The Opposers*). These illustrations will give a more exceptional picture of what attitudes we find that define the different groups.

6.2.1 The Discoverers

As explained, the two people who have taken a test is *The Susceptible Discoverer* and *The Ambivalent Discoverer*. In this chapter, we will illustrate the core elements of the most important attitudes we found after interviewing these two people.

INFLUENCE

The individuals that have conducted an ancestry test felt they did it because other people influenced them. *The Susceptible Discoverer* saw many commercials and had the feeling that this was something everyone was doing. *The Ambivalent Discoverer* had two friends that had done it. When she received the testing kit in a gift from her friend, she did not hesitate to conduct the test as well. Therefore, we assume that marketing was an important factor in their decision. They both experienced a defining moment, which resulted in conducting the test.

TRUST

Neither of them bothered to or needed to look closely through the papers of what they consented to. They have high trust in the company and were not particularly concerned with privacy. *The Susceptible Discoverer* does not think he has anything worth protecting and *The Ambivalent Discoverer* feels that the information she was seeking was already online in different genealogy trees. Therefore, we could say that they both are careless in terms of what interest the company could have in them.

EFFECTS

Both felt they knew their own identity already, but found it fascinating to get a confirmation. *The Susceptible Discoverer* felt special, but ended up being “normal”. *The Ambivalent Discoverer* felt she was “normal” but ended up feeling special. None of them confirmed their prior beliefs, they both got surprised and ended up with mixed feelings. *The Susceptible Discoverer* was disappointed with the results but argued that they were too shallow. The test did not affect him at all, as he blames the results to be vague. He also addresses the fact that the test could not touch or move him if it is not what he expects to see. He still thinks there are some other countries related to his genealogy, only that the test did not go as deep as he had hoped. Still, he finds it worthy. *The Ambivalent Discoverer* got disappointed because she needed to pay additionally to get more information on know her heritage. She received some information that just raised even more questions. In that sense, they both paid money for giving away their DNA, but ended up with the same or even new questions. Both of them still have the curiosity in them and claim they would have done it again, but after the interview, they feel more reflected and cautious about the terms and conditions.

IDENTITY

The most essential difference we found here, is the effect the test has had on their identity. *The Susceptible Discoverer* felt it did not affect him much since he does not believe in the answers. In that way, he still feels the same and wants to take a test that goes deeper next time because the results he got were not as expected. *The Ambivalent Discoverer* on the other side found a new identity, and started to engage more in TV shows and cultural aspects related to the newfound identity.

SHARING

Our focused individuals have different positions in terms of willingness to share their data with police and medical researchers in the future. *The Susceptible Discoverer* is open towards sharing his DNA data with research as long as he is informed about it. *The Ambivalent Discoverer* is negative towards future research and law enforcement getting a hold on the data. Interestingly, she is the interviewee that is the most negative towards sharing even though she is one of the few who have conducted a test. This could have something to do with her disappointment of needing to pay more and therefore not wanting to contribute to anything. It

could also be because she felt that she has risked enough by doing the test and that she does not have any need in taking more risks. She would however be positive to sharing her data if the test was done by Norwegian health authorities.

6.2.2 The Globalists

Our findings show that both *the Curious Globalist* and *the Optimistic Globalist* are positive towards conducting a DTC genealogy test. They also share a specific view, which we will call ‘the globalist view’. We find this interesting, and will therefore present the main similarities and differences between these two individuals in this section.

THE GLOBALIST VIEW

The most significant similarity between the Globalists is obviously that they both have a global view on the tests. They believe that genetic ancestry tests will bring the world closer, bring people together, and make people less racist. They predict that there would be increased tolerance in the world would if people find out that they have roots in various nationalities. These thoughts are originating from the fact that they both believe people will get results which shows that they are more unique than they initially thought. This could have something to do with the fact that they both have seen different commercials with people showing unique results.

TRUST

They both think the highest of the accuracy of the tests, they believe it to be 90%. They are positive towards the companies commercials, and agree on being easy to influence. Both worry about the intention of the companies, as to whether they have a hidden motive. They do not want people making money unfairly. Even though this is a worry, they are open to agreeing on sharing their data with third-parties as long as they get a clear option to consent to it.

IDENTITY

One thing that seems to be important for both of our globalists is the way they identify themselves. They want to be looked at as individuals, not as a Norwegian, nor a student from a specific place. They feel it is dangerous to put people in boxes.

One thing that separates them is that the primary motivation for *The Optimistic Globalist* seems to be to do it for fun. *The Curious Globalist* is more curious about the results and want to know what it says. This could have to do with the fact that *The Curious Globalist* has a particular uncertainty about her heritage, and could therefore possibly find out something interesting that could have an impact on her life. The result for *The Optimistic Globalist*, however, would not have a great deal of impact on her identity. She would mainly think of it as a cool fact to tell people.

6.2.3 The Undecided

Four of the people we interviewed have still not taken a definite stand on DTC genealogy testing. We can divide these further into two groups of people. Both *The Curious Biologist* and *The Concerned* are hesitant for more regulations, as they worry about potential consequences of taking the tests. *The Ponderer* and *The Disinterested* are undecided because they do not feel a need to take the test, as they feel certain about their ancestry knowledge. Both of these groups will be presented with similarities and differences in the next two sections.

THE CURIOUS PENDING

The Curious Biologist and *The Concerned* are both curious about taking a test. They do not feel like they fully know themselves, but they have some concerns regarding the tests. They want the tests to become more regulated first, and they do not want to be a first mover. They prefer waiting until they fully know what kind of consequences it could have to take such a test. *The Curious Biologist* is leaning more towards yes. We, therefore, put her in the ‘Maybe/Yes’ category, whereas *The Concerned* leans more toward no, and we, therefore, put him in the ‘Maybe/No’ category.

The most significant difference between the two is that *The Concerned* find how they handle his private information to be his primary concern. He is worried about the risk of security breaches after reading about various scandals involving privacy issues lately. If he feels content with the companies’ privacy regulations in the future, he would want to conduct a test, as he has some uncertain elements in his ancestry. *The Curious Biologist*, however, wants to know more about the regulations and how the companies will ensure the correct handling of the test. She does not have the same need as *The Concerned* to find out about her ancestry, but finds this kind of service interesting. *The Curious Biologist* views the tests as a positive thing for society,

such as the globalists, as she believes it will make the world closer. In sum, they are both pending, and waiting for the right regulations to be in place before conducting a test.

THE NEEDLESS

The Ponderer and *The Curious Receptive* feel no need to take a test. One of the primary reasons why they do not feel this need is because they both know their families. At the same time, they are skeptical towards the possible consequences of genetic testing. *The Curious Receptive* believes it could be fun to take a test, and therefore, we categorize her as at ‘Maybe/Yes’. *The Ponderer* is more concerned about the possibilities of misuse, and is leaning more towards ‘Maybe/No’. *The Ponderer* finds it essential to know her family and believes she would have conducted a genetic test if she did not already know her family. She would have done this test to figure out her values, as she finds it fundamental to be aware of her family history and values.

6.2.4 The Opposers

To present a picture of the core attitudes of the people generally negative towards taking the test, we want to illustrate the similarities and differences between them. These are *The Science Advocate* and *The Confident Opposer*. As mentioned, these two would not take a DTC genealogy test. The most significant similarities we find are a high degree of self-esteem, their concerns related to commercialization, their lack of privacy concerns, and their care for society.

COMMERCIALIZATION

Both *The Confident Opposer* and *The Science Advocate* have significant worries regarding the companies intentions with these genetic tests. They seem to look at it as a great business model with excellent potential for earning a great deal of money for a few people, which they do not support. They find the companies’ way of doing business both suspicious and unethical. It is emphasized that the companies should be more transparent on their motives. The arguments conform to the companies taking advantage of people's insecurities, which none of them find acceptable to do. They both feel very confident in themselves and in who they are, but supports people having the possibility to take these tests if they want to. This could be interpreted into that they feel the companies are exploiting the weak and taking advantage of people's curiosity . They assume that people with a high degree of insecurities have a greater need to take the test, which then makes it unethical exploitation. If the results do not help them become more secure

about themselves, but rather the opposite, should it then be okay for some people to make money on exploiting the weak? Or is this only a misinterpretation of the companies' brands and way of marketing?

IDENTITY

Two main differences are identified between our two negative people. One of these differences is how they identify themselves. As mentioned earlier, both of them are quite confident with themselves. However, one of them feels unique, and one of them feels to be quite normal. *The Confident Opposer* knows her ancestry and that she is "normal", and therefore have no interest in taking the test. *The Science Advocate*, on the other hand, feels unique, even though she does not have complete control over her ancestry. Nevertheless, she has no interest in figuring out her ancestry either

SOCIETY

One other thing that strikes us is the way they both seem to look at DTC genealogy tests. *The Confident Opposer* promotes talking about all the harmful effects of genetic testing and seems to look at it with cynical eyes, in contrast to *The Science Advocate*. She instead focuses on the positive sides of society and why we do not need this sort of testing. From this, we interpret that they look at society as a whole, and do not find the society needing this sort of test. They would rather have an open society that helps people be sure of themselves rather than building the society around insecurity and low self-esteem. They both promote a society that cares for individuals, and that hopes this sort of testing should be unnecessary for our community to grow and become even better and more stable.

7. DISCUSSION/ANALYSIS

We have looked into our portraits based on our empiricism, and we now want to take you with us on a journey to look at correlations and meanings to understand our core issue: What attitude exist regarding DTC genealogy testing?

In the last chapter on findings and results, we got to know people who have conducted a genetic test; *The Discoverers*. We have gotten an exclusive view on people wanting to take a test; *The Globalists*. We learned to understand people who are unsure but leans towards taking a test; *The Disinterested* and *The Pending*. At the same time, we got to know unsure people but leans towards not taking a test; *The Reflected Ponderer* and *The Concerned*. Lastly, we learned to understand why *The Opposers* do not want to take a test.

To look into their deeper values and get a good understanding of their lifeworlds, we want to analyze the empirical data within the framework of Mitroff (1998) we presented in chapter 3.2. We will use this tool to look at the issue with genealogy tests from all dimensions, to be able to illuminate different aspects relating to the choice of conducting or not conducting a genealogy test.

7.1 The Interpersonal/Social Dimension

In this section, we will analyze our findings within the interpersonal-social dimension of Mitroff's framework. This entails us to look at problems in a social context, and to try to discover what kind of thoughts exist about the social aspect of DTC genealogy testing. Our main focus within this dimension is how the marketing and influencers could affect the way people look at DTC genealogy testing. We will, therefore, value what our respondents say about their perception of the companies and their service. We will also take a look at family and relations.

7.1.1 Marketing

Wagner, Cooper & Sterling (2012) highlight the attractiveness of the commercials and the sales pitches. We have discovered that many of our respondents have experienced passively hearing about the tests, through TV commercials, YouTube, Instagram, Facebook, and other social media. The marketing has established some curiosity in them. Three of them are explicitly expressing feeling influenced by commercials, as well as positive towards taking a DTC genealogy test. It may derive from the wish to belong to the social group that the marketing promotes.

However, this view on the companies' marketing strategy is not predominant. *The Disinterested* and *The Pending* emphasizes that the marketing efforts of the companies can come off as too intrusive, and can, therefore, have an opposite effect - being perceived as spam. *The Science Advocate* mentions that these mails have made her more negative towards the particular company, as it makes the company look unserious. Thus, we see that excessive marketing could lead to negative attitudes towards companies.

The Cautious Globalist believes the commercials make her distrust their motives and make it feel like they want to make money off people. The focus on marketing has for some led to a distrust in the motives of companies. *The Confident Opposer* is also detrimental towards the marketing of these companies and does not understand how people could get influenced by it.

7.1.2 Influence

There is a high variation within our sample when it comes to susceptibility. *The Ambivalent Discoverer* felt even more confident about taking the test since two of her close friends had already taken it. *The Susceptible Discoverer* felt that everyone was doing it and got highly motivated from the commercials he saw. We also got to know that *The Curious Globalist* felt intrigued after knowing that her friend got exciting results.

We could explain this according to Greenwald et al. (2012) and a positive view on certain social groups who are conducting these tests. They may want to show that they belong to that particular social group, who have a positive attitude towards DTC genealogy testing.

Their choice to conduct a test could, therefore, strengthen their identity and further lead to a more balanced perceived self. In general, our findings point to the fact that friends have relatively high importance when it comes to influencing. Although some people had seen influencers and bloggers promote this in social media, found this as less trustworthy because they suspect it is just for money.

The two people who were negative towards DTC genealogy testing are also the two who claim they are not susceptible as they are confident and firm in their meanings: *The Confident Opposer* and *The Science Advocate*. This can imply that their confidence in themselves makes them less receptive to these influences, especially in the case of DTC genealogy tests.

7.1.3 Family and Relations

Our findings support Horowitz's (2019) theory that implied that the pre-existing sense of *ancestral certainty* is a significant factor in the decision to conduct a DTC genealogy test (Horowitz, 2019). Out of the people that did not want to conduct a DTC genealogy test, most of them explained their real certainty about their ancestry to be the main reason, and thus, did not possess a need to find out anything.

One of the main reasons for not wanting to take a DTC genealogy test is the fact that they do not need the results. This applies to both *The Opposers*, although they have different premises. *The Science Advocate* who have some uncertainty in her ancestry still felt no need. This is an interesting finding. We believe an explanation for this can be that she does not define her

identity based on social groups such as her ancestry. Therefore, this issue is of less importance to her identity and confidence in herself. *The Confident Opposer* also expresses her disinterest in these tests, and we believe it also could be based on the fact that she has a high confidence in herself and her identity. An implication of this could be that people who are confident and content in their identity, disregarding their pre-existing sense of ancestral certainty, seem to have a lower interest in these kinds of tests.

Several of our interviewees are considering conducting a test because they are curious and think they might find out something they did not already know about their family. Both *The Concerned* and *The Curious Globalist* reports this as a significant motivation for conducting a test. *The Ponderer* also claims that she would have taken a test had she been unsure about some of her ancestry, as she believes it is essential to know your family - she claims it shapes you as a human being and makes you feel part of a community.

We believe this desire derives from the need for self-realization. The desire to belong to a social group or a community could help towards having something to identify with and to achieve meaning in their lifeworld. According to Aristotle, this could be seen as a way of achieving human flourishing. This desire could be a spontaneous one that has not reflected explicitly upon, or it could be a nagging yearning after finding out something one does not know. Either way, fulfilling this desire and satisfying one's curiosity could lead to meaning and contentment, which further leads to well-being, as discussed in the ethics chapter (3.3). This is also the case for another reported reason to take the test, which was *for entertainment*, although this reason could seem to be one that is less reflected upon, and that derives from a more unconscious state of mind.

7.2 The Systemic Dimension

DTC genealogy tests could have many different consequences, both positive and negative, on both an individual and a global level. We have discussed some consequences in the theory and some in our portraits. We now want to tie the information together while analyzing our main thoughts around the Systemic Dimension from Mitroff's model.

7.2.1 Single vs Multiple Nationalities

Some hope for a multicultural ancestry while others will hope for a "clean" race. This could give us both positive and negative effects. This is mainly discussed by *The Globalist*, who argues for both sides, and who both ended up thinking of it as having more positive effects than negative. *The Optimistic Globalist* argues that this could strengthen global unity when you see yourself a part of a bigger context. *The Curious Globalist* also addresses that she thinks the world could become less racist and break down barriers to give people a broader mindset. *The Curious Biologist* also addresses this and ends up thinking it would give more positive than harmful effects. However, this relies on the assumption that they will get different results with ancestry from different parts of the world. This is not always the case.

There have been expressed concerns among our interviewees that some people may conduct this kind of test to confirm that they are of one particular ethnicity. If this proves to be accurate, they may deem all other ethnicities as inferior. Thus, a consequence can also be increased racism and nationalism among those who are inclined to possess these attitudes. *The Curious Biologist* thinks it could lead to an identity crisis if you figure something out that you would never have thought of. *The Optimistic Globalist* addresses that it could be an identity crisis if you are kind of racist and then get results that show that you are not 100% of what you believe you are.

This is supported by Greenwald (2002), who predicts that positive views develop when both self-positive and self-group identification exist. We believe this is also applicable to the opposite situation, that when one is not identified with a particular social group, there is a lesser chance of developing a positive view of it. If one discovers that one has a different heritage than firmer beliefs and hopes, this could lead to an imbalanced identity.

7.2.2 Discrimination

Ethnic identity could not only be a problem for the individual and the view on society but could lead to even broader consequences. None of our interviewees seemed to have been reflecting on how these DNA databases could be a target for discrimination in society. Many of them think that Norway is a stable country, and they have trust in the government. *The Optimistic Globalist* argues that discrimination would not be a problem today, but maybe 100 years ago. It does not seem like anyone sees this as a possible threat or consequence. *The Curious Biologist* argues that everything could be hacked and finds it to be other things that could have worse consequences. *The Curious Globalist* is evident in how she wants society to operate, and that does not include discrimination on genes. As we also see from the laws and regulations, insurance companies and employers are not allowed to ask for nor use any genetic information in Norway (Bioteknologirådet, 2019a), which makes us believe that this is a common belief in the Norwegian society. Our presented theory supports this in the chapter on Norwegian Society and Values (2.5).

7.2.3 Third Parties

The Curious Globalist thinks that if one pays for the test, one's data should be private. At the same time, she feels that it would be suspicious not to let law enforcement have access to her data, and *The Disinterested* supports this argument. *The Ambivalent Discoverer* also feels that the information should be private and would not feel it was suspicious, not agreeing to share her information with law enforcement, as she views it as a personal matter. This can imply that she is particularly worried about what her DNA is used for and what it could be used for in the future.

The Confident Opposer stands out because she is positive to help medical research and law enforcement by sharing her DNA, while not wanting to take a test from the commercial actors. She voices an extra concern for third parties within marketing. She worries that the data on DNA could be sold for a basis that could be used against oneself, for example, nudging one in a particular direction one does not want to go. *The Ponderer* does also worry about third parties as for future misuse. *The Concerned* emphasizes his worry that his data will be used against him, in the same way that Cambridge Analytica used data against people to influence them in the US presidential election. These findings show that there is a certain divide between people

in this issue. In general many are skeptical of sharing their genetic data, but many are positive at the same time.

7.2.4 The Surveillance Society

The Concerned thinks the security and privacy laws will be improved in the future. He sees it as a problem today but does not have particular concerns about the future. With a more technological future comes new exciting possibilities. *The Susceptible Discoverer* worries that the biological codes will become even more critical in the future. With face recognition and fingerprints being the start, you never know if you might need to use your DNA to verify yourself for a bank loan in the future. He still trusts the company to watch and control the data carefully. *The Confident Opposer* has a great worry about big data centers in the US and China becoming even more prominent. With these databases of DNA increasing in size and gaining a more significant global presence, “big brother” could soon know everything about every single person.

The Disinterested and *The Science Advocate* do not follow news and finds the future to be intimidating. They do not want to think of these kinds of consequences as they frighten them.

7.3 The Scientific/Technical Dimension

We see from our empirical study that many of our portraits have some problems with trusting the companies. It either relates to the accuracy/validity of the tests, or the commercial aspect and that it could seem like this only exists because someone has figured out a way to earn money. In this chapter, we will take a deeper look into the Scientific and Technical Dimension presented in Mitroff's model.

7.3.1 Validity and Reliability

How accurately do the results need to be for being allowed to market and sell? As discussed in theory there are no particular regulations or laws regarding this issue today. In 2022 the companies will have some regulations conferring to the need to label the test to show how accurate they are (Bioteknologirådet, 2019b). Today we only know that the results may vary among the different companies according to their reference groups (Via et al. 2009).

NAME	ATTITUDE	ACCURACY
The Optimistic Globalist	Yes	90%
The Curious Globalist	Yes	90%
The Susceptible Discoverer	Yes	70%
The Ambivalent Discoverer	Yes	60%
The Disinterested	Maybe/Yes	80%
The Pending	Maybe/Yes	60%
The Concerned	Maybe/No	85%
The Ponderer	Maybe/No	80%
The Confident Opposer	No	80%
The Science Advocate	No	70%

Figure 8: An overview of beliefs about the accuracy of the tests results.

From our study, we found that people generally have some mistrust in the results, but that it varies from 60% to 90% perceived accuracy. What we find especially interesting is that our negative people, The Confident Resistor and The Science Advocate, thinks the test accuracy is higher (80-70%) than The Ambivalent Discoverer (60%), who has taken the test.

Our findings show that the two people who have conducted the test places the lowest trust in the accuracy of these tests. *The Ambivalent Discoverer*, as mentioned, felt it at 60%, as The Susceptible Discoverer felt the results were too shallow, and perceived the accuracy to be only 70%. This makes us believe that they may not find the validity of the result to be an essential factor for her taking the test. They also address this through the interviews; they are only out for fun. It could also mean that *The Ambivalent Discoverer* distrusted the accuracy of the test more after getting her results, as they were surprising to her and left her more confused than she was before. Both experienced a mismatch between their initial beliefs and their results. If they already see their identity as a part of a particular social group and find this knowledge to be incorrect, it could lead to an imbalance in their identity. However, the person with the new-found identity felt more satisfied with her results as she was pleasantly surprised, whereas the person who got results that contradicted his initial beliefs of heritage in other countries was disappointed by the results. We assume that this could be explained by the fact that his results contradicted his ideal self.

For our negative people, the accuracy of the test seems to be a more important aspect, even though it does not seem like this is their primary motivation for their anti-testing attitude. One other exciting element, in this case, is that both of The Globalists believe the accuracy of the test is 90% correct. They seem to be the most positive towards the results. That could make sense in the way that these people are the ones that are ready to take the test but have not done it yet. If we compare them with the ones that have done the test, we see that they have a significantly lower reliance on the accuracy of the results. This could give us an indication that you may lower your thoughts on the validity once you get results you were not expecting.

The Curious Globalist claims that she would not want to take the test if she knew for a fact that the accuracy was low. This could indicate that she places a firmer belief in the accuracy of the tests because she wants them to be accurate. At the same time, she would think there was

something wrong with the validity of the results had it shown that she was something she could never have imagined.

The Science Advocate even compares her belief of the accuracy of the test with alternative medicine, which is a negative thing to her.

7.3.2 Consent – Terms and Conditions

When asking our people what they think of consenting, the typical answer is that it is crucial to read through the terms and conditions. Even the people who have taken the test think it is essential to know what you are consenting to. However, they did not read through the terms and conditions before conducting the test, thus, they do not know precisely what they have consented to. The prevailing view is that it is hard to care. You accept everything because you trust that the government or the media would punish companies working with unfair terms and conditions in some way. We are used to living in a society that needs you to accept terms and conditions to be a part of it. Norwegian peoples' nature of an unusually high level of trust could explain our findings. It is possible that people in other countries would, in general, express more concerns around this issue.

When informed about the length of these terms and conditions, all of our interviewees agreed that they not would bother to read all of it. Some of them said that they would look for keywords or find some other website that explains it before consenting. *The Ambivalent Discoverer* consented to everything because she felt blinded by curiosity. *The Susceptible Discoverer* felt it was so little they could figure out that he did not see it as a threat. Epicurus' thoughts may explain their actions that one aims to achieve happiness through fulfilling desires, like satisfying one's curiosity. They also seem to aim to avoid bad feelings, such as being anxious about consequences.

7.3.3 Commercialization

One big issue that emerges is the intentions of the companies selling these tests. They seem quite unclear on that point, and we have seen several stories of third-party sales.

Our research did not initially focus on this aspect. It became clear to us that it is something that worries many of our interviewees. Almost everyone we interviewed mention commercialization to be one of the problems they had with these types of tests. They wonder what kind of motives the companies have, and who is the end-game winner.

The Ambivalent Discoverer supports her argument with a personal view. She does not understand why she has to pay more money for getting all the information they have when she already has paid for the DNA-test and given them personal information. Why do they not give her the full picture of her heritage?

Many of the others argue for commercial aspects and agree to this being a big problem. *The Ponderer* talks about trust being a problem. She feels that the companies have no incentive to keep the data safe when they are profiting from the data. Many of them see how this could be a smart way of achieving profits and assume someone is making much money at the top. They feel that this is exploiting the weak by taking advantage of people's curiosity and need to know. *The Confident Opposer* calls this unethical. *The Curious Globalist* believes it is wrong to profit on others' DNA and thinks it would be more legitimate if the World Bank or a governmental organization were the ones handling this sort of information. Our findings show that negative attitudes are formed because they view companies as exploiting, which can be considered a negative attribute.

The Concerned seems to be more positive towards privately held companies like these. Firstly, he believes that the growing supply of these tests by different companies will lead to more competition and, therefore, will be beneficial to consumers in the form of lower prices and better services. He also believes privacy and other issues tied to these companies will improve, as it will be even more critical for the companies to hold a good reputation in the future to keep their customer base.

7.3.4 Cultural differences

In our study, we seem to find quite a few cultural differences. Many seem to trust a Norwegian company more than one from other countries like the USA, especially after all the media attention from the Facebook scandal and Cambridge Analytica. They feel the trust for American companies is lower today than it was a few years ago. Another reason is that they feel that American companies are more interested in profits than Scandinavian companies. They seem to trust the Norwegian or any other Scandinavian government for being there to protect us and claim that they would have felt safer if it was a Scandinavian company they were able to buy these tests from. Even though this is a common perception among our interviewees, most of them would still want to buy a test form the US.

The Science Advocate and *The Curious Globalists* feel that we live in a strictly regulated and civilized society, and therefore, it is easier for us to have a positive attitude. This could be one of the reasons why Norwegians are high consumers of DNA tests.

Norwegian society is based on values of equality and trust. From our findings, we have seen that our interviewees seem to base their attitudes on this fact. All of them report that they instead would have taken a DTC genealogy test from a Norwegian company if that was possible. Several claim they would preferably conduct a test in a Norwegian hospital, as they place high trust in Norwegian institutions. We believe this could be generalized to a larger population of Norwegian society, as trusting governmental institutions is a common trait among Norwegians. This is supported by the theory of a balanced identity, which predicts that one develops a positive view of the social group one belongs to.

Some of the interviewees, on the other hand, trust American companies more because they think that technology in the US is better and that they have more funds to have updated new technologies, as well as a more significant genetic database that provides a better foundation for the test results.

7.4 The Existential Dimension

Lastly, we will analyze our findings in light of the existential dimension. As we see from the different other dimensions there is a sense of existentialism in them as well. We will give this dimension extra attention because we believe it is the dimension that best can explain the attitudes and meanings of our respondents, as it is oriented towards the person's self. Further, this is the dimension we believe to be the most essential for answering our research question.

7.4.1 Identity

How people view their identity and what they feel like their identity is based on seems to be an essential factor in the decision behind conducting a DTC genealogy test. The need to find out the results of these tests seems to depend on how confident or content someone is in their identity. Some people view their ancestry as a part of their identity, while others do not. *The Science Advocate* exemplifies this as she does not need to explore anything of her ancestry, although it is partly unknown to her. This could be because she is a confident person who is sure of her identity and does not need further self-realization.

People who view their ancestry as a part of their identity might feel like something is missing in their lives if there are parts of their ancestry they do not know about. This need for self-realization seems like a significant motivation for people wanting to conduct a test. Hence, the product they are buying helps them find not only their roots but also themselves. This is in line with Aristotle's views on happiness, which is finding meaning through self-realization.

Another interesting finding is that the two people that had already conducted a test had the former beliefs of their ancestor history disproved after getting their results and reported that they became less confident about their knowledge about their family as they had discovered conflicting facts. They are sure about their identity, but getting a different result than expected could also lead to conflicts regarding their identity. *The Ambivalent Discoverer* seems to find it was some life-changing moment for her getting the results, and that she has a newfound identity. However, *The Susceptible Discoverer* did not feel like he had a newfound identity, although he did not get the results he expected. This could be because he does not accept the fact that his ancestor history is not as 'exotic' as he thought. His meanings show us that getting new findings could affect one's view of one's identity. We can look at this in two different ways; one positive boost and no effect. It could either increase the confidence in one's identity

or one may distrust and discard the results. We assume that a third effect could be that one feels less appealing as a person, although we did not have any people in our sample expressing this thought.

We find that most of our interviewees felt a desire be more exotic and unique, rather than entirely of one ethnicity. They feel that being 100% Norwegian is dull and that to be a part of a new ethnicity would boost their feeling of being unique.

7.4.2 Privacy

Most people claim that they care moderately to significantly about privacy, but when we dig deeper into this issue, they often admit that they do not reflect on this in their everyday lives, and they often degrade themselves by claiming that their privacy is not critical to keep safe. Several of our interviewees admitted that they should increase their efforts in this area after reflecting upon it during the interview.

Although this could seem surprising, we believe this could be explained by the ways of Norwegian society, as described in chapter XX. The fact that Norwegians are unusually trusting people could result in a lesser concern for privacy issues than it would for consumers in other countries. However, it is essential to distinguish between their beliefs in Norwegian companies and government, versus companies and governments in other countries. Several of our interviewees express concern for their privacy, especially in the hands of foreign companies.

The Susceptible Discoverer feels that privacy is not a big problem for him because he feels that he is such a small individual in a big world. Therefore, his information would be of no interest to others. He feels that people with a more critical role in society would need to be more concerned than him. *The Optimistic Globalist* also expresses this view. We find this to be interesting because we believe the real power of misuse lies in both big groups of data and individuals. *The Science Advocate* does not care much for privacy either as she evaluates openness rather than privacy.

Another finding from our interviews shows that concerns about privacy tend to correlate with the amount of previous information our interviewees have about DTC genealogy testing. *The Concerned* sets a prominent example here, as his motivation to conduct a test in terms of the

desire for curiosity and entertainment is there. However, his significant barrier towards taking the test is the privacy concern relating to sending away his DNA. During our interview with him, we learned that he had read several news articles that had illuminated the negative aspects of these kinds of tests. He was the most informed in the DTC genealogy testing area, and also the most concerned. He refrains from fulfilling his desire of curiosity and knowledge as his privacy concerns are too prominent. As Ims (1992) says, “*the threat of possible use or abuse can affect our self-perception and our self in the most profound sense,*” meaning that this could affect his perceived self. His perceived self could explain why he refrains from taking a test, as it would possibly increase anxiety about the future and therefore evoke bad feelings, in line with Epicurus’ thinking.

The Ponderer also had some background knowledge of these firms and the industry as she had written a paper on them earlier this year. She also turned out to be one of the more concerned people in our study. On the other side of the scale is *The Optimistic Globalist*, who is the least worried about the privacy issues of these tests. Our conversation conveyed that she is one of the people with the least knowledge about the companies and the industry. These findings could point in the direction that the more information one has on DTC genealogy testing, the more one is concerned about privacy.

One essential finding is that the two people that are negative towards taking a test does not explain privacy concerns to be a significant reason. We could assume that concerns for privacy may not count as much for people with high confidence because they trust themselves and that they have nothing to worry about.

7.4.3 Happiness

As described in the literature chapter, there are several ways of achieving happiness. We will look at the actions and attitudes of our respondents in the light of the hedonic and eudaimonic view, as we believe it could bring further understanding of their lifeworlds.

We see examples of people trying to attain happiness by avoiding bad feelings. *The Science Advocate* says that she does not watch the news because she does not feel like it adds anything positive to her life. *The Disinterested* tells us she does not want to reflect on what the future could look like because she thinks it is scary. This can imply that these two people are seeking

happiness in their lives through the avoidance of “pain” or negative feelings. As previously explained, anxiety about the future is seen as one of the greatest destroyers of happiness in the hedonic view.

According to the hedonic view, human beings can also be seen as seeking pleasure through satisfying desires to attain a state of happiness. This can explain why some people put their desire for curiosity and entertainment first when deciding on conducting a DTC genealogy test. As some of them explain, like *The Ambivalent Discoverer*, you can become blinded by curiosity, to the extent that you do not consider the consequences further down the road. This is supported by the fact that 9 out of 10 people we interviewed said they would do the test ‘for fun’ – or as a ‘fun Sunday activity,’ as *The Susceptible Discoverer* explained.

Others seem to be seeking happiness through meaning, as in the eudaimonic view. One way of achieving meaning can be through self-realization, which is something the respondents can attain through getting the results of these tests. As previously explained, the eudaimonic view emphasizes that one achieves happiness through meaning and self-realization. To understand oneself by being sure of one’s identity and heritage can, therefore, be an essential motivation for conducting a DTC genealogy test.

7.5 THE HERMENEUTIC CIRCLE

Throughout this process, we have examined the attitudes for DTC genealogy tests. Since this is a topic many of our interviewees do not have in-depth knowledge about, we want to look at it through a hermeneutic circle. This is a learning process where the attitudes could change over time after more information is given on the subject with a holistic view to understand the parts to comprehend the whole, by looking at the parts. We are interested in their initial thoughts and, at the same time, how these thoughts evolve throughout the interview process. We want to take the portraits on a journey inside themselves to look at different values and thought processes behind a given statement. Therefore, one of our contributions is how their meaning changed after discussing the topic. We have seen some meanings changing regarding specific topics when given the time to think and reflect. The aspects we have pointed out throughout this analysis are based on their final standings.

In general, none of the interviewees changed their initial standing on whether they would take the test or not. Some of the participants feel they have become more enlightened and reflected, while some felt they have become more precautional concerning privacy. The people who were initially against DTC genealogy testing proved to be even more confident in their opinions after some reflection - they are now even more sure they would never do it.

The main change we noticed is within the 'Maybe' category. These are still relatively undecided, but some started more positive and ended up being more negative, while some ended up more positive than their first stand. All over, we would argue that they mainly became more skeptical since there were many subjects they had never thought about earlier. Hence, knowledge brings power.

8. CONCLUSION AND RECOMMENDATIONS

Throughout this master thesis, we have discussed several different aspects of DTC genealogy testing. We have presented the market and the most prominent actors within the industry, taken a deep dive into current laws and regulations to understand the big picture and implications this kind of fast-developing industry may have. With this, we aim to provide information for society and possible consumers. It is hard to keep pace when there is so much happening at the same time. We have an understanding of why the laws and regulations do not manage to keep up. The problems deal with significant societal issues, while at the same time dealing with issues related to the existential dimension within oneself. The portraits give a feeling of what kind of people we have met along our journey, to provide a greater understanding of the problem. Through analyzing the attitudes of our interviewees, we have aimed to give an answer to our research question: “What are the attitudes of consumers regarding DTC genealogy tests?”.

To understand these different dimensions of the phenomenon, we have presented ethical theories and applied them to our research, to dig deep into the mindset of our interviewees. By taking this approach towards a greater understanding, we make it possible to address all the different problems and implications this kind of tests could have.

Our most significant finding is that we need to look at this problem in the big picture, all parts included. Our research emphasizes that most of the interviewees have a desire to be special and finding their true unique selves. It seems like they feel the DTC genealogy test could enhance their feeling of self to another level, one that contains a mix of spiritual and scientific understanding of oneself. We also see that people actively against it often look at DTC genealogy tests as exploitation of people and an unethical way of making money.

Another finding is that some people feel the DTC genealogy test could bring the world together to a significant global unity. Most people see the positive effects it could have on science and society. They place high trust in the government and have a belief that they can regulate this right. This entails ensuring that individuals wanting to conduct these sorts of tests can do it safely, and that possible misuse of data and personal information has no negative consequences for the individual.

What the real implications and consequences of the commercialization of our DNA are going to be, is unclear. However, our empiricism shows that most interviewees trust society and the government to handle the problems related to these issues. Nevertheless, we believe the most critical finding of our research is that consumers need to be informed of the consequences of taking a DTC genealogy test. Only then can they make a reflected decision they can stand for.

We have hope that we have shown you our journey through this jungle of aspects relating to this highly relevant issue.

8.1 RECOMMENDATIONS

After studying this issue for half a year, we find it sensible to give a few recommendations for consumers based on our understanding of the issue. Whether one is interested in taking a DTC genealogy test or is unsure of what to do, we would like to stress that we fully respect either decision. New, emerging technologies will always create fascination and make people intrigued. This list is created based on our understanding, and from what we learned through conducting our interviews. We experienced several aspects that our interviewees did not know about or had never thought of. We find it essential to reflect upon what reasons one has for taking the test, to be sure of what one is doing, and to be able to make an informed decision. Therefore, we provide a list of aspects you should know in advance.

8.1.1 Commandments for DTC genealogy testing

1. You do not know that the test would not be 100% accurate.
2. You do not know that the test would be accurate
3. You could end up feeling different about yourself
4. You could end up feeling deceived
5. You could end up feeling unique and more interesting
6. You could end up feeling nothing
7. You have the right to get your data deleted
8. Although you delete your data, it may still exist in other forums if it has already been used in research or sold to third parties
9. You should look into the terms and conditions, so you know the essence
 - a. To know if they are sharing data with third parties
 - b. To know what your data is used to
10. You should know that the company may know more about you than you get information about
11. You should keep in mind that this technology and research is only in its early stages and can, therefore, have many faults
12. You should keep in mind that this technology evolves quickly and that your DNA can be used and misused in new ways in the future
13. You should keep in mind that law enforcement can access your information in these databases if they have a warrant

8.2 CRITICAL REFLECTION

A weakness in this study is the low amount of people. We assume that a more significant sample would reflect more meanings. Due to time and resources, this was not possible in this study but would be a great asset in future research. We find great value in being two people during the interviews as it is hard to interpret all non-verbal communication at the same time as conducting an interview. Being two people makes it is easier to fulfill each other by intervening with additional questions during the semi-structured interviews. We often got the most exciting answers and conversations when we both added in questions.

We wanted to get a good overview of different people and their meanings. If we were to do this again, we would have focused more on the extremes. A weakness in this study may be some of people in the ‘maybe’ category, who had many exciting thoughts but were challenging to separate from each other, as they often were unsure about certain aspects. Some found it unnecessary to reflect on several issues. However, something that could justify the choice of including the ‘maybe’ category is that we believe this is a category where many people in society could fit into, as knowledge about these tests and their implications, in general, seem to be weak.

Another constraint is that it is hard to be sure whether we have interpreted the right meaning of the interview. Issues concerning Identity, Attitude, Self-Esteem, and the Self do not have a right or wrong answer. Thus, we need to use all the guidelines that could help us understand the whole. We see it as an advantage that we already know our interviewees because it possibly makes it easier for us to understand their lifeworld’s and their true meaning. As we are of the same age and possess a thorough contextual knowledge, it could be easier for us to interpret their attitudes. This is an essential strength of our study. We interpret a higher degree of honesty in the people we know well, compared to acquaintances.

We also find it important to emphasize that we have touched upon fields of studies that we do not have particular knowledge in from before, such as law, biology, medicine, psychology, philosophy and ethics. This has been challenging, as we have had to immerse ourselves in new knowledge and new ways of thinking about the world. However, we are thankful for being able to get insights into all these new disciplines – and wish that maybe the field of economics and

business would include more on the new perspectives we have learned about, such as holism, ethics, happiness and meaning.

8.3 FUTURE RESEARCH

Since the nature of this study is an exploratory approach, this study paves the way for others to study this phenomenon even deeper. It would be interesting to study more people with the same variation. A bigger sample could provide more information and details around meanings and could make it easier to portray essential similarities among the different categories.

The nature of this master thesis entails a time limit; it makes it appropriate to study it with a cross-sectional method. One thing that could give us an even more in-depth look into the hermeneutic circle is if we were to look at the same people over a more extended period, as in a longitudinal study. With this method, we could achieve a greater understanding of the reactions and attitudes from before they have conducted a test on how reactions develop over time. It would be interesting to understand what kind of impact it has on the self and one's identity - whether it would only have an immediate effect or if it could become a life-changing event for one's lifeworld.

It would also be interesting to study more people who have conducted a genetic test and received surprising results. In our view, the two people we have interviewed had different reactions. If you get results you do not like, is it more likely that you throw away the results and think they must be wrong? Or could it be that you make life changes based on your newfound identity?

Future research could look more into the implications of DTC tests with a focus on personal traits. We see that there could be several implications if this were to be a standard for people to do. Would people only do the sport they are genetically good at? Could these tests create an A and B society that indirectly discriminates on genes?

One interesting issue to study could be whether age has something to do with attitude. Are older people more confident in themselves, and subsequently feel less need to take these kinds of tests? Are older people more concerned about consequences and, therefore, more reluctant? It

would also be interesting to study whether younger people feel more insecurities in their self and their identity and therefore find it more interesting to conduct a DTC genealogy test.

From many of these tests, you can receive your raw data. This means that you could do further research yourself on your genes. This could have many consequences. Are consumers ready to become their own doctors? Could the DTC test be the start of a revolution within health care? We find it interesting to look deeper into how people would feel about having the possibility to find out more about themselves. Could DNA genealogy testing be the gateway towards conducting even more tests?

It could be interesting to study whether the trust in governmental institutions has a correspondence with the willingness to take a test. Some of our interviewees talked about them not having any particular concerns because they place great trust in the Norwegian government. Is this an essential factor for more people?

One interviewee told us that she would instead share her DNA and contribute to research solely for science and the public good. Could it be that many people are feeling this way? Would the willingness to contribute be higher without the commercial aspect? Furthermore, in that case, is this a possibility either governmental institutions or private companies should act on?

As mentioned, there will be various new regulations in 2022, and we predict there will probably be even more in the future, as consumers and authorities put more pressure on companies. How would this affect the attitudes? We had two persons implying that they would have done it if there were safe, open, and regulated. Could regulations lead to more DTC genealogy testing?

The technology is evolving at a high pace. Right now technology exists that could alter and change specific parts of your DNA, CRISPR. Could DTC genealogy test lead to people doing further research on their genes to get more knowledge, and possibly encourage people to alter their DNA to become smarter or more athletic?

In general, we are looking forward to reading new studies within this topic. We believe it is extremely relevant and interesting, and that it has the possibility to change the future of our society for good.

Thank you

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APPENDIX

APPENDIX 1 - Overview of interviewees

Nr. (chron.)	New Name	Attitude	Age	Gender	Nationality	Interview
1	<i>The Science Advocate</i>	No	25's	F	Norwegian	In person
2	<i>The Ponderer</i>	Maybe/No	25's	F	Norwegian	Phone
3	<i>The Disinterested</i>	Maybe/Yes	20's	F	Norwegian	In person
4	<i>The Susceptible Discoverer</i>	Yes	25's	M	Norwegian	Skype
5	<i>The Optimistic Globalist</i>	Yes	20's	F	Norwegian	Skype
6	<i>The Curious Globalist</i>	Yes	25's	F	Norwegian	In person
7	<i>The Concerned</i>	Maybe/No	25's	M	Norwegian	In person
8	<i>The Confident Opposer</i>	No	25's	F	Norwegian	In person
9	<i>The Ambivalent Discoverer</i>	Yes	25's	F	Norwegian	In person
10	<i>The Pending</i>	Maybe/Yes	25's	F	Norwegian	In person

APPENDIX 2 - INTERVIEW GUIDE

SUBJECT	POTENTIAL INTERVIEW QUESTION
Introduction	<p>Introduce ourselves and our study. Explain the purpose of the interview. Inform about the length of the interview. Ask if we can audio record the interview.</p> <p>Express that we only want to know their attitudes. There are no wrong answers.</p>
DTC genealogy testing	<p>How is your stand towards DTC genetic testing today? What is the reason for why you have taken/want to take/do not want to take a test? What answers do you expect to get from an ancestry DNA test? Why do you think others want to take an ancestry DNA test? Do you know anybody who has taken a test? Would you take a test if it was for free? Could you give a test away as a present to somebody? Do you think there is a difference between conducting a test at home or in a hospital?</p>
Reaction	<p>How did you think you would react to the result? How did you react?</p>
Marketing and influence	<p>What companies within the industry have you heard of? How do you perceive these companies? Does your trust have anything to do with the country the company is from? Did you see anybody promoting these tests? Do you think you have been influenced? Do you think people your age are influenced?</p>
Family and relations	<p>Have anybody in your family taken a test? Have you shared your results with anybody? Have you discussed with anybody about taking an ancestry test?</p>
Identity and self-realization	<p>Do you feel like you know yourself? How do you identify yourself? How sure are you about your heritage? Do you care where you could have relatives or heritage? On a scale from 1-10, where 1 is ordinary and 10 is special/unique, where do you place yourself ancestry wise? Are you related to anybody in another country? Would it matter to you if this was not correct?</p>
Accuracy	<p>What do you think about the accuracy of the tests?</p>

	Do you think the accuracy varies between companies and types of tests?
Privacy	<p>How important is it for you that your data information is safely stored?</p> <p>What information do you consider to be important that is safe?</p> <p>Do you view DNA for ancestry tests as sensitive information?</p> <p>Do you have any concerns about giving away your DNA and the future?</p> <p>What does privacy mean to you?</p> <p>Do you think you data could be used to something other than what you had planned?</p> <p>Do you trust that your DNA is safely stored?</p> <p>Do you know who data is shared with?</p> <p>What do you think about sharing data with medical research?</p> <p>Have you thought about the fact that the company may know more about you than what you have ordered?</p> <p>Have you deleted/did you know you could delete your data from the database?</p> <p>Ethical dilemma: What would you think was worse if was spread: your DNA or a naked photo of yourself?</p>
Consequences	<p>What implications do you think it can have/has had for yourself?</p> <p>What do you think the benefits of ancestry tests are?</p> <p>What do you think the disadvantages of ancestry tests are?</p> <p>Would you share your data if it could help cure illnesses?</p> <p>Would you share your data if it could help solve crimes?</p> <p>Do you see any positive or negative consequences with having such a large genetic database?</p> <p>Do you think these genetic databases can lead to discrimination?</p> <p>Discussion around Norway today and Norway in the future, and insecurities tied to this.</p>
Reflections and termination	<p>Do you have any thoughts regarding genetic tests we have not talked about?</p> <p>Is there anything you wish to add?</p> <p>We inform our interviewees that we will send their results to them to be able to verify citations and content.</p> <p>Thank them for their help.</p>

Vil du delta i forskningsprosjektet «Holdninger til gentester i Norge?»

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke holdninger, brukeropplevelsen og personvern knyttet til gentesting. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Denne studien er en del av masterutredningen innen Strategi og Ledelse ved Norges Handelshøyskole (NHH). Formålet med prosjektet er å få innsikt i brukeropplevelsen, holdninger og opplevd personvern for brukere av gentester. Dette prosjektet vil spesifikt fokusere på holdningene til gentester som handler om å avdekke slekt og genetisk opphav. Problemstillingen som skal analyseres er: «hvordan er brukeropplevelsen og opplevd personvern knyttet til gentester?». Vi skal ikke bruke dataene videre, men vi vil informere om at utredningen publiseres som forskning der all data vil være anonymisert.

Hvorfor får du spørsmål om å delta?

Deltakere er valgt ut gjennom et bekvemmelighetsutvalg via vårt nettverk. Antall deltakere vil være mellom 9 og 15 personer. Vi setter stor pris på ditt bidrag til vår studie!

Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du deltar på et *intervju*. Det vil ta deg *ca. 60 minutter*. Intervjuet inneholder spørsmål om personlige opplevelser og refleksjon knyttet til gentesting.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke

samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Dine svar fra intervjuet blir tatt opp på lydopptak, samt at det blir notert underveis. For å oppnå anonymitet vil vi slette opptaket i etterkant av at vi har anonymisert og transkribert intervjuet.

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Kun masterstudentene som skriver oppgaven (Anniken og Marie) vil ha tilgang til opplysningene. Navn og kontaktopplysninger vil som lagres på en egen navneliste adskilt fra øvrige data samt bli gitt en kode slik at ingen uvedkommende kan få tilgang til personopplysningene.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Dataene anonymiseres innen prosjektslutt: 20.12.2019.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Norges Handelshøyskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

Anniken Brauti, tlf: 47808222, anniken.brauti@student.nhh.no

Marie Løvteit, tlf: 97464373, marie.lotveit@student.nhh.no

Veileder og professor ved NHH, Knut J. Ims, knut.ims@nhh.no.

NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller [telefon: 55 58 21 17](tel:55582117).

Med vennlig hilsen

Anniken Brauti og Marie Løvteit

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Holdninger til gentester i Norge», og har fått anledning til å stille spørsmål. Jeg samtykker til:

å delta i intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 20.12.2019.

(Signert av prosjektdeltaker, dato)

APPENDIX 4 – NSD Approval

20.12.2019

Meldeskjema for behandling av personopplysninger



NSD sin vurdering

Prosjekttittel

Masteroppgave: "Hvordan er brukeropplevelsen og personvernet knyttet til gentester?"

Referansenummer

713537

Registrert

19.11.2019 av Marie Løtveit - Marie.Lotveit@student.nhh.no

Behandlingsansvarlig institusjon

Norges Handelshøyskole / Institutt for strategi og ledelse

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Knut J. Ims, Knut.Ims@nhh.no, tlf: 55959239

Type prosjekt

Studentprosjekt, masterstudium

Kontaktinformasjon, student

Marie Løtveit, marielotveit@hotmail.com, tlf: 97464373

Prosjektperiode

19.08.2019 - 20.12.2019

Status

22.11.2019 - Vurdert

Vurdering (1)

22.11.2019 - Vurdert

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg 22.11.2019, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

UNNGÅ HELSEOPPLYSNINGER

Enkelte av spørsmålene i intervjuguiden åpner for at det kan deles en begrenset mengde helseopplysninger. NSD forutsetter at studentene gjør treffende tiltak for å unngå dette, ved å be utvalget om å ikke dele helseopplysninger under intervjuet.

MELD VESENTLIGE ENDRINGER

<https://meldeskjema.nsd.no/vurdering/5d9f1ce8-7968-478e-8eae-5d9c797fe0ac>

1/3

Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:

https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html

Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle alminnelige kategorier av personopplysninger frem til 20.12.2019.

LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

PERSONVERNPRINSIPPER

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke behandles til nye, uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingssansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Dersom du benytter en databehandler i prosjektet må behandlingen oppfylle kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og/eller rådføre dere med behandlingssansvarlig institusjon.

OPPFØLGING AV PROSJEKTET

NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!