PRIVACY, BIOLOGICAL RELATIVES, AND AT-HOME DNA TESTING

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Abstract

At-home DNA testing remains popular amongst individuals today. These direct-to-consumer services come with several privacy risks, that can extend far beyond the individuals taking the test. How do participants attribute risk to biological family members? How do users and non-users differ in comfort with their data being shared, and their understanding of privacy risks? How do privacy perceptions differ for ancestry and health data? To investigate these questions, we conducted a 2×2 survey, and discovered non-users were significantly more privacy conscious, and that health data was considered more beneficial overall. We then interviewed 10 biological family members of users who had not taken a test themselves; though many were unconcerned or indifferent towards privacy, privacy-conscious participants were frustrated by, and resigned to, the loss of control over their data. We discuss our findings, the implications of our research, offer recommendations to improve privacy, and identify areas for future research.

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Chapter 1

Introduction

1.1 Motivation

At-home DNA testing services, like AncestryDNA [15] and 23andMe [2], provide consumers with the ability to understand their ancestry history, connect with biological relatives, and/or provide insight into a user's health. The use of these services has seen large-scale growth since 2013, with more users having used these kits in 2018 than all previous years combined [111]. AncestryDNA, for example, has made over a trillion DNA matches amongst biological relatives, with 22 million people in its ancestry database across 60 different countries [13].

For many, at-home DNA testing services have been credited with helping users' find family [86], while for others, it may provide ethnicity estimates (and possible insight into migration patterns) [15]. Health reports provided by these tests often indicate the users' risk of certain diseases (like Type 2 Diabetes, or asthma), possible mitigations for these diseases, and general wellness reports (like what you may be allergic to, or how you metabolise certain drugs) [2]. However, the accuracy and comprehensiveness of both ancestry and health reports vary by company [16, 83]. Ancestry tests are not entirely accurate in general, and rely on the size of their database to produce results [76,132]. As a result, tests provided by different companies may present different ethnicity estimates [132]. Similarly, health-related tests also do not indicate the risk of someone developing a disease, and cannot be used to diagnose a condition or disease [8].

At-home DNA testing companies have shared their data with external parties in the past. Genetic data provided to companies through at-home DNA testing kits have been sold to pharmaceutical companies [58], and provided to law-enforcement [17], as well as academic institutions [3] (usually in aggregate form). Under some conditions, the data provided has been with users' consent [3, 10], however this has not always been the case (for example, law enforcement has been provided access to an ancestry testing company's dataset without users' explicit consent [9]). Additionally, the privacy policies of many at-home DNA testing companies are not comprehensive, and can be unclear [61, 110].

Recently, 23AndMe began research and development of clinical therapies in several different areas (for example, neurology and immunology) using their (proprietary) genetic database [4]. Sharing may be seen as beneficial by users (for example, approximately 80% of users in 23andMe's database opted to share their DNA data for research [3]). The potential for genetic databases to solve criminal cases [17], and advance the development of pharmaceutical drugs and research [3, 4], can be seen as largely positive by users [21].

Given the lack of clarity surrounding DNA-testing companies' privacy policies [61, 110], and the unique (networked) nature of DNA, there are many novel privacy risks. Every individual's DNA is unique to them and has identifiable traits [19, 120]. Even if stored de-identified, this data can be linked directly back to the individual who provided it [74, 120].

In addition to directly identifying its owner, DNA is also partially shared amongst biological relatives. Parents and off-spring share exactly 50%, while siblings share approximately 50% of their DNA [45]. Any actions that compromise the privacy of an individual consumer (for example, a data breach or data sharing by the company) would also partially compromise the privacy of their biological relatives, regardless of whether they have performed an at-home DNA test themselves.

Cases of misuse have surfaced in the past (for example, discrimination against someone with a certain health markers in their DNA [137]), and this sensitive data continues to be shared on social media [99]. Furthermore, third parties with whom the data is shared may also have incentive to misuse this data (for example, insurance companies [99]). Additionally, legislated protections for DNA data vary greatly by jurisdiction. For example, while Canadian law covers potential misuse by health and life-insurance companies [18, 133], US laws do not necessarily [32, 126]. Neither law covers potential effects to biological relatives. Moreover, DNA tests are now available all over the world. For example, AncestryDNA currently has tests available in 60 different countries and territories, spanning all habitable continents [14]. The levels of legislature vary by region, and may not provide adequate protection to consumers [87].

Given the extensive privacy concerns related to at-home DNA testing, we seek to understand more about individuals' mental models of the topic. Users have been found to have incomplete and inconsistent mental models of genetic privacy [21, 114]. Non-users' mental models may also highly vary depending on their degree of interest in the topic [60]. Literature comparing user and non-user perceptions is, however, limited. Additionally, it is unclear whether individuals perceive ancestry and health data differently. Finally, how individuals perceive their DNA to affect their biological relatives is also not well understood. This Master's thesis aims to address these gaps in existing research.

1.2 Research Question

Genetic privacy is a relatively recent area of research, given that the first company to privately offer autosomal DNA testing launched in 2006. Although there exists some literature on the benefits and risks of such testing, questions around DNA ownership, and the effects of at-home DNA testing on those who share this DNA, remain. Furthermore, it is unclear whether individuals distinguish between ancestry and health data in their mental models. We use the following questions, across two studies, to guide our research:

RQ1.1: Do privacy perceptions of at-home DNA testing differ based on whether it is for ancestry or health purposes?

RQ1.2: Do users' and non-users' privacy perceptions of at-home DNA testing differ?

RQ2: What are biological relatives' privacy perceptions of how at-home DNA testing affects them?

We address our first pair of research questions through a 15-minute survey exploring more fine-grained mental models of the topic. Our participant group consisted of both users and non-users who have explicitly chosen not to take an at-home DNA test, thereby getting opinions from individuals who had thought about the tests and taken a decision one way or the other.

Our second research question is addressed through 60-minute interviews. Our participant group consists of individuals who have not completed an at-home DNA test, but are aware of a biological relative who has.

1.3 Contribution

With the completion of this thesis, we provide the following research contributions:

1. We support and expand upon the findings of existing genetic privacy literature, and offer insights into how users and non-users (who have chosen to not take an at-home DNA test) significantly differ in this respect. We find non-users perceived many more risks, and less control over genetic data. In contrast, users perceived that the tests deliver many more benefits and positive effects on individuals in their lives.

2. We offer unique findings in the domain of networked genetic privacy, using our interviews to understand how family members of users perceive their privacy in context of the user's DNA test. We uncover three main attitudes towards privacy (concerned, indifferent, and unconcerned). Privacy conscious participants identified a loss to their personal privacy with the user's at-home DNA test. Other categories did not perceive this loss, perceiving either benefits or no effect to themselves instead.

3. We discuss the privacy and ethical implications of our research, and provide recommendations to improve the privacy of individuals and provide more opportunities for informed consent.

4. Given that related studies have mostly had participants from the United States, we add Canadian perspectives to the existing literature.

1.4 Thesis Outline

The remaining chapters of this thesis are organised as follows:

Chapter 2 We review the history of at-home DNA testing, and the current literature surrounding user and non-user attitudes towards the service. We also identify open questions in the literature that we have worked towards addressing with this thesis.

Chapter 3 We discuss our first study, a 2×2 between-subjects survey conducted with 310 participants. Our survey covers several themes, including perceived risks, benefits, and attitudes towards data sharing and usage.

Chapter 4 We present our second study, in which we conducted semi-structured interviews with 10 participants. In these interviews, we aim to understand how participants view genetic data ownership, whether (and how) biological relatives are considered during the testing process, and how participants perceive this test to affect biological family members.

Chapter 5 Finally, we identify the high-level themes and trends across our two studies, address our research questions, provide recommendations based on our findings, and highlight areas for future research.

Chapter 2

Background

We first briefly introduce at-home DNA testing technology. Next, we discuss existing literature surrounding consumer attitudes towards at-home DNA testing. We look at potential privacy and security risks, as well as the attitudes of non-users towards at-home DNA testing. We discuss attitudes surrounding data ownership, and highlight existing regulations and policy surrounding genetic testing.

2.1 What is at-home DNA testing?

At-home DNA testing services claim to provide information about either users' ancestry, health, or both. If data is available, ancestry testing provides consumers the opportunity to identify biological relatives, and claims to trace their ethnicity [15]. A large number of ancestry services also provide access to a genealogical database [93] to aid users in building and/or tracing their family tree.

Very broadly, ethnicity-estimate algorithms examine the amount, and kind, of variations in the DNA that overlap between individuals. Those in certain population groups may share more variations than others. Typically, the accuracy of such results differ based on the company used [16, 83] because the user's genetic data is compared to the genetic data of everyone else in the company's database; hence the results depend on the size and variation of this database [76, 132]. This makes the results dynamic, changing as the size of the database changes. Additionally, they provide no information on migratory patterns, and are dependent on the genetics that are passed down [113, 116]. Although a certain part of one's family may be, for example, Vietnamese, this does not guarantee the extent to which those genes are inherited by members of the family [113, 116]. As a result, even complete biological siblings may receive different results from such services [35].

Many of these services, although not claiming to offer medical advice, also provide health testing services for assessing disposition to certain diseases [2, 11, 66]. Additionally, they offer insight into traits visible in your genes (like food intolerance or the ability to curl your tongue) [2, 11, 42, 100], and “general wellness’, like fitness, or the rate at which one’s cells age [123].

2.2 History of health-related DNA testing

Prior to the existence of at-home DNA testing kits, being able to complete a DNA test was rare and only prescribed by medical professionals in particular circumstances [11]. At the time, the healthcare system was the mediator between a consumer and the information provided by such a test [72]. Prescribed through a medical professional, a test would be completed, delivered, and regulated through this system. Privacy is a high priority of the “medical model”, and is subject to the Personal Information Protection and Electronic Documents Act (PIPEDA) in Canada [72,98]. However, this model has been criticised for being inaccessible and slow. The few studies conducted to examine medical practitioners’ knowledge of genetics have found it to be lacking [20,37,67,119]. Aside from having deficiencies in their knowledge of genetics [20], some practitioners are also simply uncomfortable conducting genetic counselling with their current level of knowledge [67]. Additionally, the guidelines for prescribing these tests are often restrictive (for example, genetic testing for breast cancer can only be completed in Ontario if certain criteria are met [94]). These challenges make it comparatively difficult to obtain a genetic test through the healthcare system. However, health tests completed through at-home DNA testing services do not offer the same level of complexity, accuracy, or validity as medically prescribed genetic tests [24], since the at-home versions test only a limited number of genetic information [84]. Additionally, in a study conducted with 312 genetic counsellors practicing in the United States, at least 90% thought consumers who used at-home DNA testing would receive misinformation, and that such testing provides a false sense of security [63].

2.3 Recent trends

Growing adoption As at-home DNA testing services become more accessible, more individuals are drawn to them [72]. More than 26 million consumers purchased and used an at-home DNA testing kit by the end of 2018 [111]. Consumers can order them directly from as many companies as they like, and for as little as $59 USD in some cases [111]. From 2016 to 2018, growth in this sector has been exponential [72]. After completing a at-home genetic test, users may further upload their raw DNA data to one of many DNA-processing websites to obtain further information [49].

Regulatory scrutiny and backlash However, this has not been without controversy. In 2010, the U.S. Food and Drug Agency (FDA) launched an investigation into the at-home DNA company 23AndMe, which was marketing their Personal Genome Service (PGS) test [1] (their health-related test) at the time. Concerned about misleading marketing, the FDA queried 23AndMe about the clinical validity of the test [24, 43], and in 2013 barred the company from providing the PGS test until receiving FDA clearance [43]. This sparked a wave of backlash from individuals supportive of at-home DNA testing, gaining traction on news and social media [31]. While some argued that users have the *"right to their genomic information"* [56], others argued that given the limitations, it could not *"realistically be considered genomic information"* [24]. Social media users generally criticised this move as impeding innovation [31]; even many who sympathised with the regulations considered the regulatory body *"paternalistic"* [31]. By 2017, however, the FDA had allowed the marketing of health-related tests to provide genetic risk information of certain conditions (like late-onset Alzheimer's disease, Parkinson's disease) by 23AndMe [7].

Slight decline However, sales from private DNA testing companies started declining in mid-2019 [38], and continued to do so throughout 2020 [39, 40]. Privacy concerns have been cited as one of the main reasons for the decline. Concerns include unclear data storage and data sharing policies, the effects of such tests on others who share your DNA, and the dynamic nature of company privacy policies. For example, in a 2019 press release, the Pentagon advises against completing at-home DNA testing, considering it a security concern to military members [82]. In the midst of rising concerns, many major at-home DNA testing companies pledged to follow a list of guidelines designed by privacy advocacy groups, created with the intent of keeping the focus on transparency, security, and privacy of users [95]. Unfortunately, while comforting, these guidelines are not legally enforceable. Despite these concerns, the at-home DNA testing market is projected to exceed $10 billion USD by 2028 [112].

2.4 Benefits

Traditionally done using a saliva sample, *ancestry* tests are often used to unite adopted children with their biological relatives [22], reunite families separated over generations or as refugees [33], help form a sense of identity [22], or make progress in staggered cases of violent crimes [71] (including both identification of remains, and leads on suspects [31, 71]). There has also been discussion around whether they should be considered for, and used in, establishing minority status when possible [69, 139]; that is, supporting that the consumer belongs to an ethnic minority group.

Consumers are also especially interested in *health-related* testing to obtain information about their traits and likelihood of disease [114]. Many complete one with the intent of sharing their results with a physician [50]. This type of data can also be used by researchers to investigate the genetics of diseases [66, 120], and have been used for research in developing medication and treatments [5]. Some users complete these tests to contribute their DNA for these purposes [25, 130, 131], while others perceive a more social, recreational use for it [21, 130]. A pilot survey of college students indicate that they use ancestry tests for fun [12]. Test results may also have an educational use; genetic studies' students who chose to have their genome sequence analysed by a third-party company as an optional component of a genetics course (for example, 23andMe [121]) claimed to have a better understanding of the material, and performed better in the course overall [78, 121].

2.5 Risks

The benefits associated with at-home DNA testing are countered with several privacy risks. Furthermore, these tests could possibly be misleading [26]. The accuracy and science behind health-related at-home DNA tests is questionable [123]. There exists a moderate to high risk of false positives [127], possibly leading to unnecessary invasive and costly follow-up medical procedures or unwarranted anxiety. Such testing has also not been found to bring about behavioural changes in users [55], and may result in incorrect genetic inferences for a population [135]. DNA can also provide information about individuals' *phenotype* [66] (physical traits observable to the human eye, for example: eye, hair, and skin colour), thus increasing the chances of re-identification [66]. The information provided by DNA also extends to facial features, which can be predicted by genome data with as few as six relevant genes [107].

Additionally, the potential for privacy violations can extend far beyond the individual taking the test, possibly revealing secrets from ancestors long deceased, with varying degrees of accuracy. By sharing their own DNA, individuals are also sharing the DNA of their biological relatives (including descendants yet to be born) [28], which creates unique challenges in networked genetic privacy [44]. Researchers have used samples processed by ancestry at-home DNA testing companies to resolve paternity disputes going back approximately 150 years [102]. In solving a single cold-case, detectives used data from the database of GEDMatch to map 25 family trees, going back to the 19th century [17]. This process can be fraught with error and misinterpretation [118], and has the potential for false leads [89]. Such errors may have long-term consequences; for example, enter the name of a suspect cleared as innocent into a search engine and you may still return results linking them to the crime.

Ancestry testing has also been linked to openly discriminatory and hateful racial discourse on social networking sites like 4chan, Twitter, and Reddit [85, 101]. Mittos et al. [85] analysed 302K tweets, 77K comments on Reddit, and 7K threads from 4chan containing terms related to genetic testing. Despite Twitter having the strictest set of community guidelines, researchers were able to uncover a large amount of racist and anti-Semitic tweets. This is especially worrisome given the large number of followers some of these users have. For example, in response to a 23AndMe video, a user with more than 3000 followers at the time tweeted: *“Get this race-mixing shit off my time line!!”*. Still, a large number of positive interactions around the topic remained, occurring by enthusiasts, and at-home DNA testing companies themselves. In contrast, Reddit and 4chan consisted of much more hateful discourse, dubbed *“highly toxic”* by the researchers. This is likely due to a much more relaxed approach to community moderation by these platforms.

Mittos et al. [85] also found DNA testing to be a common, and popular, topic of discussion across 4chan’s /pol/ (politically incorrect board), as well as in subreddits with extreme, *“fringe”* political views. These views include eliminating minorities altogether, using hateful and racist imagery and slurs. This is concerning given the amount of traffic these platforms receive; Reddit, for example, was the 15th most-visited website in the world as of April 2021 [70].

Data breaches of at-home DNA testing companies’ databases have occurred in the past, exposing the data of all users in the process. The popularly used at-home DNA testing service, GEDmatch, suffered a security breach in 2020 [30]. As a result of this breach, law enforcement was temporarily provided unauthorised access to more than a million user profiles. This data breach was possibly then used to orchestrate a spear phishing attack on a different DNA testing company: My Heritage [90]. More than a hundred users accessed a website that had spoofed the main page of at-home DNA testing company MyHeritage, of which at least 16 were reported to have entered their credentials [90].

Researchers have also demonstrated how certain APIs employed by at-home DNA testing companies can be manipulated to reveal sensitive user information [92]. This could expose up to 92% of the genetic markers of users, including medically relevant ones. An attacker could then use this information to create and impersonate relatives of these users [92].

2.6 User attitudes and perceptions

User perceptions Users (i.e., individuals who have completed an at-home DNA test) perceive many benefits to at-home DNA testing [21, 53, 114], and are interested in expanding testing services [31, 51].Chow-White et al. [31] analyzed approximately

2000 tweets and found the number of positive tweets far outweighed negative tweets. Most users were supportive of at-home DNA testing services, and critical of the temporary ban incurred by the FDA [31].

User privacy concerns Users have expressed concerns about at-home DNA testing related to privacy, receiving unwanted information, and testing accuracy [21, 27, 53, 59, 73, 81]. Users are also concerned about data misuse in the future [73]. However, in a study conducted by Roberts et al., 40% of participants had not considered the negative effects of taking an at-home DNA test prior to completing one [114]. Not all users understand the sensitivity of their DNA data either, or they feel that their data is only useful to them [21, 53]. Many also trust in the privacy protections of DNA-testing companies themselves and current laws and regulations to protect them (and their data) from misuse [21, 53, 80]. This sense of trust may encourage them to conduct at-home DNA testing or share their results because they believe that risks to their privacy are low.

The literature also suggests feelings of resignation; users have indicated their desire for total genetic privacy, as well as some level of control over their data [21, 51]; however, there is cynicism on whether privacy is achievable [59]. In a 27-participant qualitative study conducted by Baig et al. [21], a small number of users discussed using protective mechanisms to help protect their DNA data (for example, using fake personally identifiable information, or deleting their accounts after a data-breach related scare). Despite these privacy concerns, very few regret their decision to take an at-home DNA test [21, 114]

Limited research exists on users' understanding of the networked nature of DNA. Grandhi et al. [53] found that users who gifted ancestry tests to their family members (and subsequently managed their kits for them) expressed respect for their privacy [53]. In contrast, other research shows that some users expressed entitlement to others' data for the greater good (for example, in the case of family-tree building) or had not considered their family members' privacy [21]. Going further, the privacy of even unrelated individuals may be compromised in unexpected ways; ancestry tests have inadvertently linked individuals to anonymous cell or organ donors [138].

2.7 Non-user attitudes and perceptions

We identified only one study exploring the specific perspectives of non-users with respect to at-home DNA tests. Using focus groups with 62 non-users in the United States, with varying degrees of interest in at-home DNA testing, Hazel et al. [60] uncovered a diverse set of beliefs. Some non-users thought of ancestry tests as quick and fun, while others perceived them to be valuable tools for health, and genealogy, especially for those who were adopted, or gaps in their family history [60]. Many participants did, however, have concerns regarding control and misuse of their data that might harm them or their families personally [60]. Specifically, participants were concerned about protecting the privacy of their family members in the face of criminal investigations. Participants were strongly divided on whether they would share their data with law enforcement – roughly a third agreed they would, especially if they knew someone who may have been involved in crime. Conversely, a third of participants would keep the data to themselves to shield their family members. The remaining third were undecided on how they would proceed. Participants were interested in this topic, and commonly asked questions about the specifics involved.

Participants in Hazel et al.'s focus groups [60] also had mixed feelings on unearthing *"skeletons in the closet"*. They discussed how information pertaining to existing family members, or even those long gone, has the potential to affect them, their sense of identity, and their familial relationships, both negatively and positively. For example, learning about new biological relatives may cause *"family drama"* with some, but be a welcome addition to the lives of those who feel isolated and alone. An ethnicity estimate could also provide uncomfortable information about previous descendants; for example, a Black individual seeing European DNA in their genetic test, *"knowing that some slave owners raped some Black women"* [60].

2.8 Studies involving both users and non-users

Our review identified two studies of at-home DNA testing that include both users and non-users as participants.

Ruhl et al. [117]'s survey sample included users and non-users but no comparisons were made between the two groups. Around half of 1000 participants surveyed by Ruhl et al. [117] had privacy concerns surrounding at-home DNA testing. These concerns including fear of data misuse, fear of inadequate data protection, and fear of data being sold without consent [117] – although less than 20% expressed that they would "Never" allow their data to be used for research. Additionally, participants perceived benefits to the scientific community and benefits for their own identity, but they also expressed concerns about potential *"familial disruptions"*. Participants were most comfortable sharing data with academic institutions, and were concerned about law enforcement having access to DNA test results. Participants especially resented the data being used to *prevent* crime, as opposed to solve it.

Grandhi et al. [53] provide the only published research study comparing users and non-users that we came across in our literature review; we summarize their methods and main findings since this is the closest research to our work. While respondents were regionally diverse, 80% of participants were residents of the United States.

Grandhi et al. [53] conducted a survey with 510 respondents comparing the privacy concerns of (i) users, (ii) non-users who were willing to take an at-home DNA test, and (iii) non-users who were unwilling to complete an at-home DNA test. Their survey consisted of 5 questions: 2 were quantitative, and 3 were qualitative. Using an additive score of two survey items, they found significant differences between all 3 groups. Those unwilling to take a DNA test had the highest average level of concern, while existing users had the lowest level of concern. All groups of participants were concerned about unethical or unauthorised usage of their data, such as misuse by insurance companies. Concerns about law enforcement accessing DNA data without explicit consent were echoed across both users and non-users, as well as worry about the government using such data to discriminate. Some respondents worried that their limited knowledge of the topic may work against them, and worried about potential future risks. Overall, however, a major concern amongst all non-users was that of control: who owns the DNA data, who gets to decide where the data goes, and who chooses the longevity of the data.

The majority of users had few privacy concerns, perceived privacy to be an illusion, thought the benefits outweighed the risks, and demonstrated incomplete mental models of DNA data (how it can be used, by whom, and what for) [53]. Furthermore, many users trusted existing regulations to protect them. The few users who were concerned about privacy were sceptical of testing companies' terms and conditions, and concerned about fraud, though this apparently did not stop them from taking the test. Some did express concern for their biological family members, and acknowledged how risks may extend to them as well.In comparison, many more non-users expressed privacy concerns about data misuse, storage, and sharing. Furthermore, non-users were concerned that *individuals* (as opposed to third-parties organizations) would judge them based on their test results (for example, if certain health risks exist, or if someone turns out to be related to a criminal). Potential future consumers were especially concerned about the possibility of a data breach.

2.9 Policy

Laws addressing genetic discrimination have existed as early as the 1970s in the United States [41]. These laws are not consistent across different countries, with some countries having stronger privacy laws than others. However, even in countries with stronger privacy laws, limitations exist. The Genetic Information Nondiscrimination Act [32] of the United States protects against increased health insurance or employment bias, but not bias from other insurers. Similarly, the Disability Discrimination Act of Australia [52] prohibits life insurers from using genetic test data to influence premiums; however, violation have been documented in the past [128]. Canadian laws also prohibit use of genetic data by insurers, but this does not extend to pharmaceutical companies or healthcare [18].

In addition, most of these laws also do not extend to, or regulate, the at-home DNA testing companies themselves. Further compounding the problem, the terms and conditions provided by at-home DNA testing companies have low readability [103, 104], and users desire further transparency [21]. Consumers are unsure of how their data is being handled, and are generally unaware of privacy risks [21, 73]. Moreover, privacy policies are subject to change at any time [77, 115], and it is unclear whether users can request removal of their data if they dislike an upcoming change [77].

Even when companies have extensive privacy policies, few companies reveal how long data is kept for [75], and they do not discuss associated risks [75]. In a 2018 analysis and examination of 90 at-home DNA testing companies [61], 35 companies (39%) either provided no information on data usage and tracking, or did so but only for web-based information (like cookies), and not genetic information.

2.10 Summary

Both users and non-users perceive a diverse set of benefits to at-home DNA testing. Based on the literature, users of at-home DNA testing companies and trusting non-users have incomplete mental models of the risks associated with at-home DNA testing services. They have faith in existing regulations to protect them from potential adverse effects. Non-users have higher levels of concerns about data privacy (sharing, storage, and misuse of data), and of security concerns (data breaches, impersonation, fraud).

Understanding of how participants attribute risk to biological family members is not, however, well documented. Although some concern have been recorded on a higher level, the nuances have not been well explored. Questions remain relating to how comfortable users and non-users are with their data being shared and with whom, and their understanding of concerns and privacy risks. Furthermore, no research has compared whether these privacy perceptions differ for ancestry and health data, despite the different information derived from each type of test.

To answer these questions, conducted two studies. First, we developed and deployed a questionnaire to both users and non-users of at-home DNA testing. This 2×2 study compared responses of users versus non-users and health versus ancestry data. Secondly, we conducted interviews with biological family members of at-home DNA test users to further understand how the tests conducted by their family member have affected them personally. We analyse and discuss family members' perception of privacy in these circumstances, and examine the degree to which they were involved in the decision-making process.

Chapter 3

Study 1: Online survey

To obtain a deeper understanding of the perceptions of at-home DNA testing amongst both users and non-users, we conducted a quantitative, 2×2, between-subjects survey (users vs non-users, health vs ancestry DNA testing). Participants discussed their perceptions of what happens to DNA data after completing a test, as well as their personal preferences for data sharing and control. Additionally, we collect data on participants' attitudes towards genetic privacy, and their perceptions of how this data might affect themselves and others.

In this chapter, we address the following research questions:

RQ1.1: Do the privacy perceptions of at-home DNA testing differ based on whether it is for ancestry or health purposes?

RQ1.2: Do users' and non-users' privacy perceptions of at-home DNA testing differ?

3.1 Methodology

Our survey study was reviewed and cleared by Carleton's Research Ethics Board.

3.1.1 Recruitment

We recruited participants using the online crowdsourcing platform Prolific [106], which is dedicated specifically to research studies. The surveys themselves were hosted on Qualtrics Survey Software [108]. Participants completed a 1-minute pre-screener to assess eligibility for the main survey. To be eligible to complete the pre-screener, participants were required to reside in Canada and be over 18. Participants were paid 0.13 GBP ($0.20 CAD) for the pre-screener, and 1.88 GBP ($2.90 CAD) for the main survey.

Table 3.1: Number of participants who completed each version of the survey (after cleaning of the data).

	Ancestry	**Health**	**Total**
Users	76	64	140
Non-users	85	85	170
Total	140	170	310

In total, 998 participants were pre-screened. After cleaning the pre-screening data, 190 participants had previously used at-home DNA testing and all were invited to complete the appropriate version of our survey (health users completed the health version, ancestry users completed the ancestry version). A random selection of 200 non-users were also invited to complete the survey. Non-users were pseudo-randomly assigned to either survey condition to ensure 100 participants per condition. From the 390 (i.e., 190 + 200) invitees, a total of 328 participants completed the main survey.

We excluded data from participants who failed any of the attention checks and from participants where there were other indicators of unreliable data. For example, we excluded participants who appeared, to the researcher's best judgement, to have blatantly conflicting answers. While this process was subjective, the resulting number of surveys to be removed was small enough that we were able to err on the side of caution.

After cleaning, our data set consisted of 310 participants who completed the main survey. The number of participants per condition is provided in Table 3.1.

3.1.2 Participants

A detailed breakdown of participant demographics (age, gender, highest level of education, current employment) can be seen in Table 3.2. The majority of our participants (51%) resided in Ontario, followed by British Columbia, Alberta, and Quebec. 56% were men, 42% were women and 1.3% comprised of other genders.

Demographic	# of participants	% of participants
Area of residence		
Ontario	157	50.6%
British Columbia	45	14.5%
Alberta	36	11.6%
Quebec	31	10.0%
Nova Scotia	13	4.2%
Manitoba	12	3.9%
Saskatchewan	6	1.9%
Newfoundland and Labrador	4	1.3%
New Brunswick	4	1.3%
Prince Edward Island	1	0.3%
Northwest Territories	1	0.3%
Gender		
Men	173	55.8%
Women	131	42.2%
Non-binary	3	1.0%
Genderfluid	1	0.3%
Prefer not to answer	2	0.6%
Age		
18 – 24	78	25.2%
25 – 34	152	49.0%
35 - 44	55	17.7%
45 - 54	14	4.5%
55 - 64	8	2.6%
65 - 74	1	0.3%
Prefer not to answer	2	0.6%
Highest/current level of education		
Elementary school	1	0.3%
High school	34	11.0%
College	27	8.7%
Technical, trade school, or apprenticeship	17	5.5%
Undergraduate degree (Bachelor's)	154	49.7%
Graduate degree (Master's, PhD) or professional degree	68	21.9%
Post-graduate certificate or diploma	7	2.3%
Prefer not to answer	2	0.6%
Occupation		
Administrative Support	19	6.1%
Art, Writing, Journalism	5	1.6%
Business, Management, and Financial	39	12.6%
Education	16	5.2%
Legal	8	2.6%
Medical	6	1.9%
Science, Engineering, and IT Professional	61	19.7%
Service	20	6.5%
Skilled Labour	7	2.3%
Student	58	18.7%
Unemployed	21	6.8%
Retired	5	1.6%
Other	38	11.3%
Prefer not to answer	10	3.2%

Table 3.2: Study 1 participant demographics.

3.1.3 Study Procedure

Through Prolific, we made our recruitment notice for the pre-screening questionnaire available to anyone within Canada. After this, qualifying participants were invited to complete the main survey. Our main survey was divided into four different versions, aligning with our four study conditions as follows:

1. **User, Ancestry (UA)**: participants have used at-home DNA testing services for ancestry purposes + completed the ancestry version of the questionnaire ($n = 76$).
2. **Non-user, Ancestry (NUA)**: participants have never used at-home DNA testing services + completed the ancestry version of the questionnaire ($n = 85$).
3. **User, Health (UH)**: participants have used at-home DNA testing services for health purposes + completed the health version of the questionnaire ($n = 64$).
4. **Non-user, Health (NUH)**: participants have never used at-home DNA testing services + completed the health version of the questionnaire ($n = 85$).

Users who had completed only ancestry at-home DNA testing were assigned to the ancestry version of the questionnaire (UA). Users who had completed health testing alone or both ancestry and health-related at-home DNA testing were assigned the health version of the questionnaire (UH) because fewer individuals had completed health testing.

3.1.4 Survey Design

The survey design underwent several iterations, followed by pilot testing of both ancestry and health versions of the survey by 2 participants each. Pilot participants were knowledgeable in computer security and privacy. As a result of pilot testing, only minor changes in wording were done to increase clarity.

Each survey began with a consent form, and all questions contained a “prefer not to answer” option. Participants could withdraw from the study at any point by exiting our survey. At the end of each survey, participants were once again provided the opportunity to withdraw their data. As is the norm on Prolific, only participants who completed the surveys were paid. All of our survey materials are available in Appendices B to F.

Pre-screener: The pre-screener asked participants about their province of residence, and whether they had completed and received the results of an at-home DNA test. If so, they were asked whether this was done for ancestry or health purposes, and to select which companies they had use from a provided list. If not, they were asked how comfortable they were with completing an at-home DNA test. Those who indicated some level of discomfort were asked whether they had explicitly chosen not to complete a DNA test. The pre-screener questionnaire took approximately 1 minute to complete.

Main survey: Participants who qualified for one of the four study conditions were invited to complete the associated version of the survey.

Our survey consisted of 145 questions (excluding attention checks), and draws from existing literature [21]. The questions were organised into themed blocks, which we describe below along with the number of questions in each block:

1. **Demographic information [6 questions]:** for example, age, gender, province of residence.
2. **Control [8 questions]:** who do participants think controls or manages their DNA data?
3. **Access [13 questions]:** who do participants believe has access to their DNA data?
4. **Deletion [7 questions]:** what are participants' mental models surrounding deletion of their data?
5. **Concerns [9 questions]:** how concerned are participants about certain risks surrounding at-home DNA testing?
6. **Data sharing [13 questions]:** with whom do participants feel comfortable, or uncomfortable, sharing their ancestry/health data?

7. **Data usage [7 questions]:** for which reasons are participants comfortable, or uncomfortable, with their ancestry/health data being used?
8. **Contributions [7 questions]:** under which circumstances do participants feel that *other* users of at-home DNA tests should share their DNA data?
9. **General attitudes [11 questions]:** what are participants' general perceptions of genetic privacy (including DNA ownership)?
10. **Effects [10 questions]:** who do participants think their at-home DNA test affects?
11. **Scenarios [21 scenarios, 3 questions each]:** how plausible and likely do participants find certain scenarios involving at-home DNA testing?

Non-demographic questions were 4-point Likert-scale questions, with the exception of the Effects (3-point scale) and Scenarios (binary scale) blocks. Likert scale questions were presented in blocks; the order of questions within each block was randomised. At the end of the survey, participants had the opportunity to explain (using a text-entry box) why they did or did not choose to complete an at-home DNA test. Additionally, many of the scenarios were constructed based on actual incidents that have occurred in Canada or elsewhere (e.g., [23, 29, 89, 105, 137]). The main survey took approximately 15 minutes to complete.

3.2 Analysis

To answer our research questions, we use inferential statistics to compare across study conditions as appropriate. We conducted *Mann-Whitney U tests* on the individual questions in each block (with the exception of Scenarios). For the Scenario block, we performed *Fisher's exact test* . We also performed the *Holm-Bonferroni family-wise adjustment* [64] per block (family) of questions. We report means, standard deviations, and medians as measures of central tendency and support our findings with additional descriptive statistics.

We look for significant differences between users and non-users (*UA versus NUA*, *UH versus NUH*). We also compare our data based on ancestry or health-related

DNA data (*UA versus UH*, *NUA versus NUH*). Figures summarising the results of the Holm-Bonferroni adjusted Mann-Whitney U tests ($p < 0.05$, two-tailed), and graphs summarising the descriptive statistics accompany each section of the results.

3.3 Results

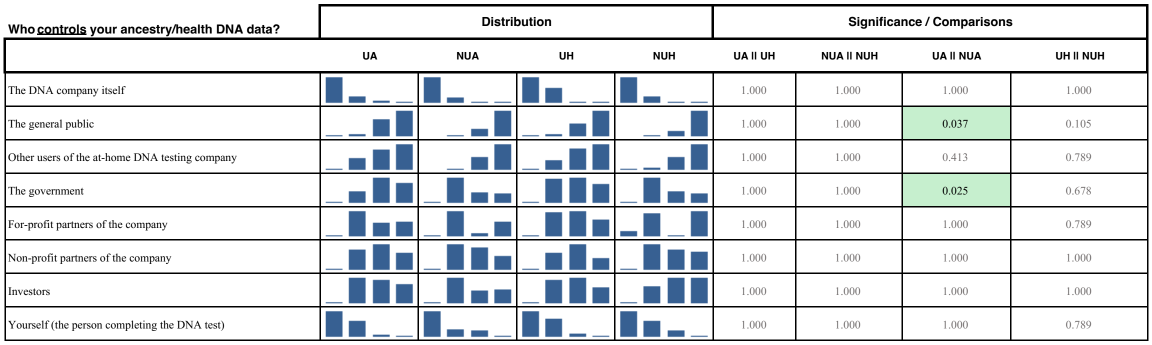
We discuss each block of questions separately in the context of our research questions. All mentions of *significance* refer to *statistically significant* results. The Likert scale options provided to participants were 4-point (e.g.: *strongly agree*, *agree*, *disagree*, *strongly disagree*) unless otherwise indicated. For readability, we generally discuss the two positive responses together and the two negative responses together (for example, instead of writing *strongly agree* and *agree*, we simply write *agree*), although our statistical tests maintained the four distinct responses. Appendix A provides descriptive statistics about each condition, while Tables 3.1 to 3.9 include column sparklines illustrating each data distribution, and results of the inferential tests comparing (i) UA vs UH, (ii) UA vs NUA, and (iii) UH vs NUH condition pairings. We briefly discuss the results for each block of questions. Appendix A provides further descriptive statistics relating to each block of questions.

In this section, we focus on reporting direct findings from our data. The implications of our results and how our results align with previous literature relating to user and non-user privacy perceptions and attitudes towards familial privacy are discussed in Section 5.1. We also discuss common misconceptions regarding the risks (Section 5.2), and how unclear privacy policies factor into risks (Section 5.3).

3.3.1 Control

Participants were presented with eight entities, and rated how involved they believed each entity to be in deciding how their DNA data is managed. That is, how much control does each of these entities have? Table 3.1 summarises the results for the *Control of data* question block.

Ancestry Users (UA) vs Health Users (UH). No statistically significant differences were found between ancestry users (UA) and health users (UH).



Who controls your ancestry/health DNA data?	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ll UH	NUA ll NUH	UA ll NUA	UH ll NUH
The DNA company itself					1.000	1.000	1.000	1.000
The general public					1.000	1.000	0.037	0.105
Other users of the at-home DNA testing company					1.000	1.000	0.413	0.789
The government					1.000	1.000	0.025	0.678
For-profit partners of the company					1.000	1.000	1.000	0.789
Non-profit partners of the company					1.000	1.000	1.000	1.000
Investors					1.000	1.000	1.000	1.000
Yourself (the person completing the DNA test)					1.000	1.000	1.000	0.789

Figure 3.1: *Control of data* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

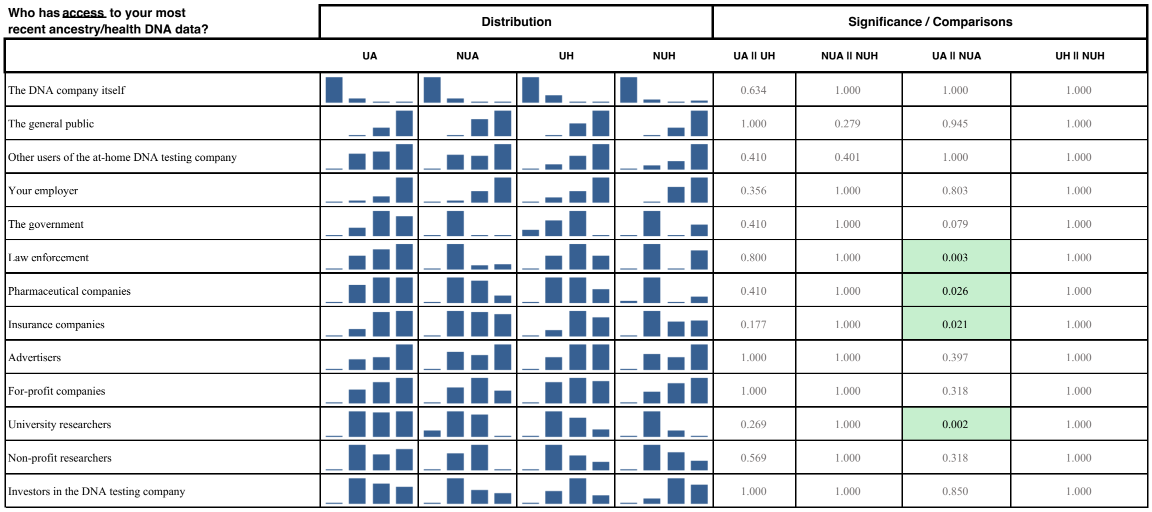
Ancestry Users (UA) vs Non-users (NUA). Visual inspection suggests no obvious pattern across entities. Two questions showed statistically significant results. Significantly more ancestry non-users (NUA) thought the *government* was involved in how their data is managed but that the *general public* has no involvement.

Health Users (UH) vs Health Non-users (NUH). No statistically significant differences were found between health users (UH) and health non-users (NUH).

3.3.2 Access

Participants were presented a list of thirteen entities, and rated whether each had access to their ancestry and/or health data. Table 3.2 summarises results for the *Access* question block.

Ancestry Users (UA) vs Health Users (UH) There were no significant differences between ancestry users (UA) and health users (NUH).



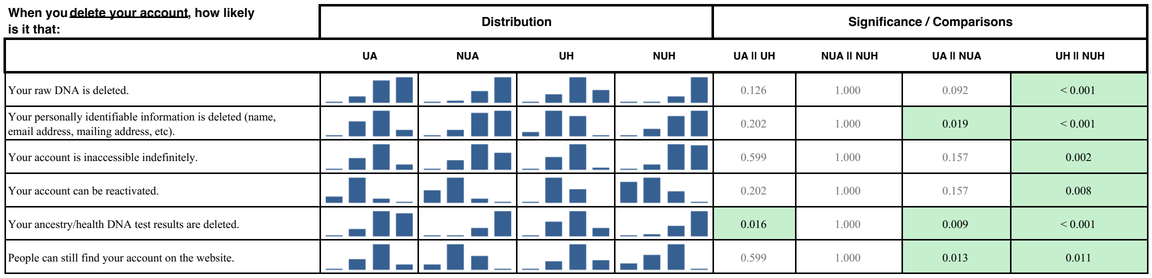
Who has access to your most recent ancestry/health DNA data?	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ll UH	NUA ll NUH	UA ll NUA	UH ll NUH
The DNA company itself					0.634	1.000	1.000	1.000
The general public					1.000	0.279	0.945	1.000
Other users of the at-home DNA testing company					0.410	0.401	1.000	1.000
Your employer					0.356	1.000	0.803	1.000
The government					0.410	1.000	0.079	1.000
Law enforcement					0.800	1.000	0.003	1.000
Pharmaceutical companies					0.410	1.000	0.026	1.000
Insurance companies					0.177	1.000	0.021	1.000
Advertisers					1.000	1.000	0.397	1.000
For-profit companies					1.000	1.000	0.318	1.000
University researchers					0.269	1.000	0.002	1.000
Non-profit researchers					0.569	1.000	0.318	1.000
Investors in the DNA testing company					1.000	1.000	0.850	1.000

Figure 3.2: *Access to data* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA). Overall, visual trends suggest that ancestry non-users (NUA) were more likely think that the various entities had access to their data. We found significant differences for four entities. Ancestry non-users (NUA) were significantly more likely to think that *law enforcement, pharmaceutical companies, insurance companies, and university researchers* had access to their data than ancestry users (UA).

Health Users (UH) vs Health Non-users (NUH). No statistically significant differences were found between health users (UH) and health non-users (NUH).



When you <u>delete your account</u>, how likely is it that:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA II UH	NUA II NUH	UA II NUA	UH II NUH
Your raw DNA is deleted.					0.126	1.000	0.092	< 0.001
Your personally identifiable information is deleted (name, email address, mailing address, etc).					0.202	1.000	0.019	< 0.001
Your account is inaccessible indefinitely.					0.599	1.000	0.157	0.002
Your account can be reactivated.					0.202	1.000	0.157	0.008
Your ancestry/health DNA test results are deleted.					0.016	1.000	0.009	< 0.001
People can still find your account on the website.					0.599	1.000	0.013	0.011

Figure 3.3: *Deletion of data* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

3.3.3 Data deletion

To assess participants' understanding of data permanence, we asked them to assume that they have deleted an account affiliated with at-home DNA testing. We then asked six questions related to their expectations of what happens to their data in these circumstances. Table 3.3 summarises the results for the *Data Deletion* question block. Overall, trends suggest that most participants thought at least some of their data was likely to stay on the platform despite user actions to delete an account.

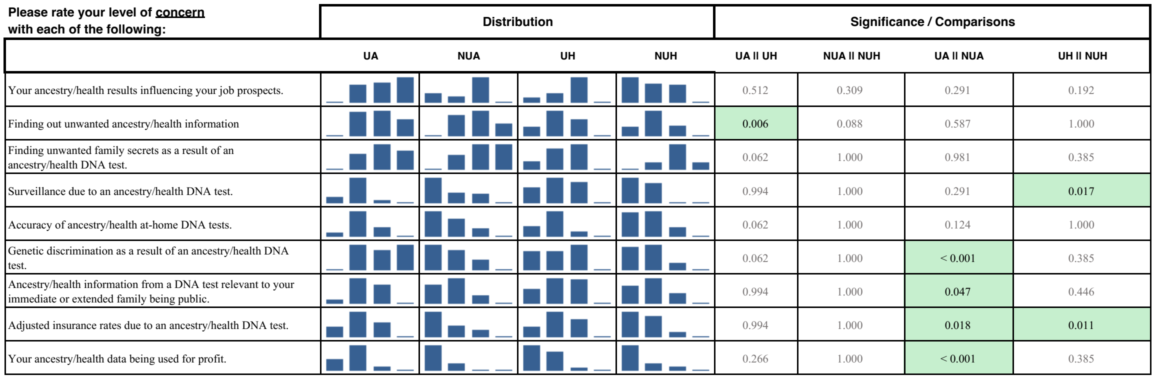
Ancestry Users (UA) vs Health Users (UH) Across all questions, trends suggest that ancestry users (UA) were more skeptical than health users (UH) about their data being deleted, but only one question showed a statistically significant difference. Specifically, health users were more likely to believe that their DNA *test results* are deleted with their account.

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA) Similar trends between users and non-users were apparent in the distributions for ancestry data; we found three statistically significant differences between the UA and NUA conditions.

Health Users (UH) vs Non-users (NUH) We found significant differences between users (UH) and non-users (NUH) for *every question* in this block. In all cases, health users (UH) were more likely to trust the platform to permanently remove all their data while health non-users (NUH) were more skeptical.

3.3.4 Concerns



Please rate your level of concern with each of the following:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA II UH	NUA II NUH	UA II NUA	UH II NUH
Your ancestry/health results influencing your job prospects.					0.512	0.309	0.291	0.192
Finding out unwanted ancestry/health information					0.006	0.088	0.587	1.000
Finding unwanted family secrets as a result of an ancestry/health DNA test.					0.062	1.000	0.981	0.385
Surveillance due to an ancestry/health DNA test.					0.994	1.000	0.291	0.017
Accuracy of ancestry/health at-home DNA tests.					0.062	1.000	0.124	1.000
Genetic discrimination as a result of an ancestry/health DNA test.					0.062	1.000	< 0.001	0.385
Ancestry/health information from a DNA test relevant to your immediate or extended family being public.					0.994	1.000	0.047	0.446
Adjusted insurance rates due to an ancestry/health DNA test.					0.994	1.000	0.018	0.011
Your ancestry/health data being used for profit.					0.266	1.000	< 0.001	0.385

Figure 3.4: *Concerns* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

We presented to participants nine potential at-home DNA testing related concerns identified from previous research, and asked them how they felt about each one. Table 3.4 summarises results for the *Concerns* question block. Many participants expressed apprehension, with more than half of participants choosing *concerned* or *very concerned* on nearly all questions. Visual inspection of the distributions suggests overall trends where users (UA/UH) are less concerned than non-users (NUH/NUA), and where health participants (UH/NUH) are mildly more concerned than ancestry participants (UA/NUA).

Ancestry Users (UA) vs Health Users (UH) Despite the visual trend, statistical tests were significant for only one comparison. Health users (UH) were significantly more concerned about *learning unwanted information* compared to ancestry users (UA).

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

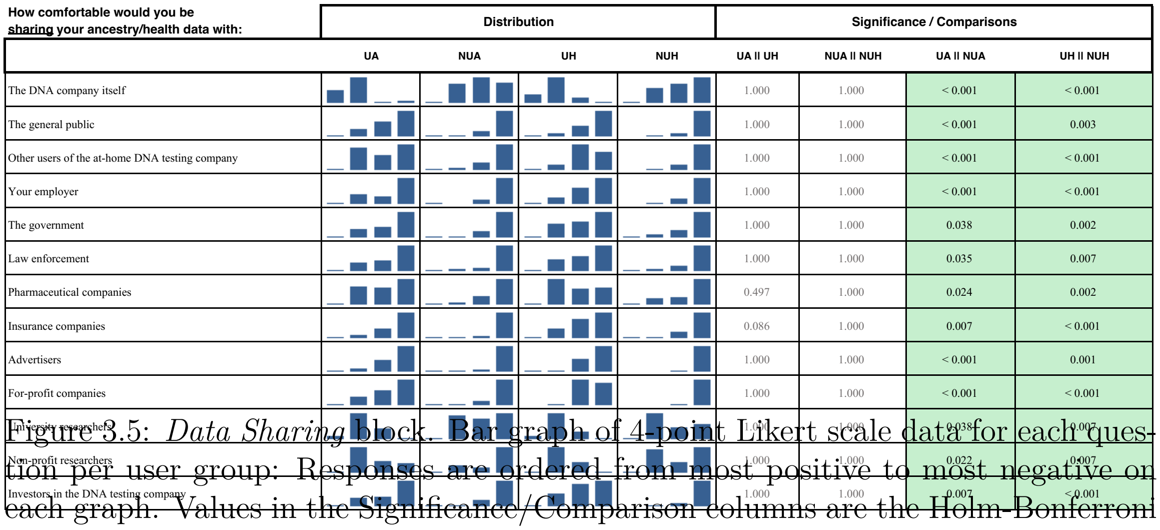
Ancestry Users (UA) vs Non-users (NUA) Similar visual trends are apparent and there are statistically significant differences on four questions. Ancestry non-users (NUA) were significantly more concerned about *surveillance*, their *family data being public*, the adjustment of *insurance rates*, and the use of their data for *profit* than ancestry users (UA).

Health Users (UH) vs Non-users (NUH) The overall visual trend indicates that health non-users (NUH) are more concerned than health users (UH), and the statistical analysis reveals significant results for two questions. Health non-users (NUH) are significantly more concerned about potential *surveillance* and *adjusted insurance rates* than health users (UH).

3.3.5 Data sharing

We asked participants to rate how comfortable they felt sharing their data with thirteen different entities. Table 3.5 summarises the results for the *Data Sharing* question block. High-level trends generally suggest discomfort amongst participants in sharing their data with all entities except *university researchers*, and *non-profit researchers*, but that users appear somewhat more comfortable than non-users overall.

Ancestry Users (UA) vs Health Users (UH). No statistically significant differences were found between ancestry users (UA) and health users (UH).



How comfortable would you be sharing your ancestry/health data with:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ll UH	NUA ll NUH	UA ll NUA	UH ll NUH
The DNA company itself					1.000	1.000	< 0.001	< 0.001
The general public					1.000	1.000	< 0.001	0.003
Other users of the at-home DNA testing company					1.000	1.000	< 0.001	< 0.001
Your employer					1.000	1.000	< 0.001	< 0.001
The government					1.000	1.000	0.038	0.002
Law enforcement					1.000	1.000	0.035	0.007
Pharmaceutical companies					0.497	1.000	0.024	0.002
Insurance companies					0.086	1.000	0.007	< 0.001
Advertisers					1.000	1.000	< 0.001	0.001
For-profit companies					1.000	1.000	< 0.001	< 0.001
University researchers					1.000	1.000	0.038	0.007
Non-profit researchers					1.000	1.000	0.022	0.007
Investors in the DNA testing company					1.000	1.000	0.007	< 0.001

Figure 3.5: *Data Sharing* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result. U = Users, N = Non-users; A = Ancestry, H = Health.

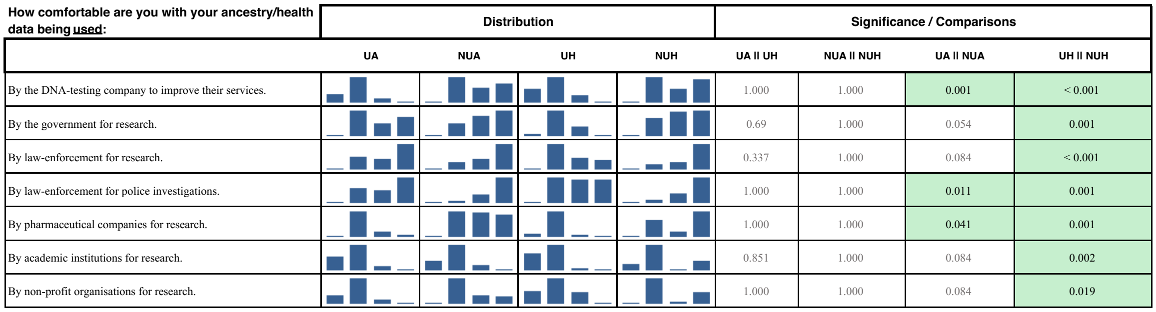
Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA). Significant differences exist for every question. With every entity, ancestry users (UA) were significantly more comfortable sharing their data than ancestry non-users (NUA).

Health Users (UH) vs Non-users (NUH). Similarly, health users (UH) were significantly more comfortable sharing data with all entities than health non-users (UH).

3.3.6 Data usage

We provided participants a list of seven different usages for their data, and asked how comfortable they were with their data being used for each one. Table 3.6 summarises results for the *Usage of Data* question block. Visual inspection suggests that users are generally more comfortable than non-users.



How comfortable are you with your ancestry/health data being used:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ∥ UH	NUA ∥ NUH	UA ∥ NUA	UH ∥ NUH
By the DNA-testing company to improve their services.					1.000	1.000	0.001	< 0.001
By the government for research.					0.69	1.000	0.054	0.001
By law-enforcement for research.					0.337	1.000	0.084	< 0.001
By law-enforcement for police investigations.					1.000	1.000	0.011	0.001
By pharmaceutical companies for research.					1.000	1.000	0.041	0.001
By academic institutions for research.					0.851	1.000	0.084	0.002
By non-profit organisations for research.					1.000	1.000	0.084	0.019

Figure 3.6: *Usage of data* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

Ancestry Users (UA) vs Health Users (UH). There were no significant differences in the Data Usage block between ancestry users (UA) and health users (UH).

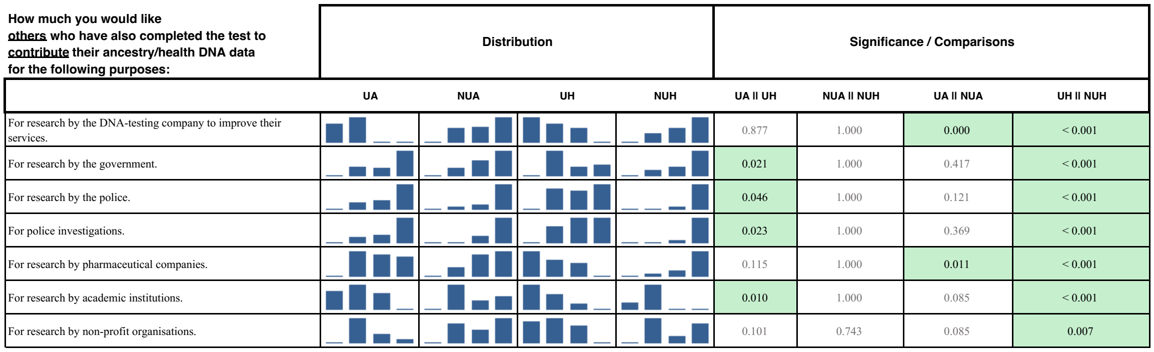
Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA). Ancestry users (UA) were statistically more comfortable than ancestry non-users (NUA) with three different uses: *by the DNA-testing company for research*, *by law enforcement for police investigations*, and by *pharmaceutical companies for research.*

Health Users (UH) vs Health Non-users (NUH). Significant differences were found for every question in this block. For every listed usage, health users (UH) were more comfortable with their data being used than health non-users (NUH).

3.3.7 Contribution of others

We asked participants how much they would like *others* to volunteer their data for seven different purposes. Table 3.7 summarises results for the *Contributions of Others* question block. Visual inspection reveals no obvious general trends.



How much you would like others who have also completed the test to contribute their ancestry/health DNA data for the following purposes:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ∥ UH	NUA ∥ NUH	UA ∥ NUA	UH ∥ NUH
For research by the DNA-testing company to improve their services.					0.877	1.000	0.000	< 0.001
For research by the government.					0.021	1.000	0.417	< 0.001
For research by the police.					0.046	1.000	0.121	< 0.001
For police investigations.					0.023	1.000	0.369	< 0.001
For research by pharmaceutical companies.					0.115	1.000	0.011	< 0.001
For research by academic institutions.					0.010	1.000	0.085	< 0.001
For research by non-profit organisations.					0.101	0.743	0.085	0.007

Figure 3.7: *Contribution of others* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

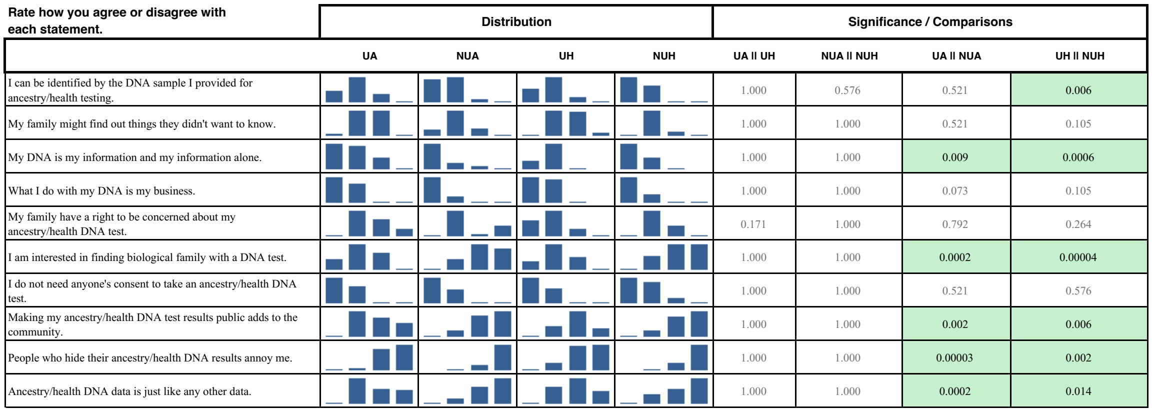
Ancestry Users (UA) vs Health Users (UH). Health users (UH) generally had a greater desire for communal contribution of data than ancestry users (UA). Statistical analysis revealed significant differences with four questions. Significantly more health users (UH) thought that DNA data should be contributed by others for research by the *government*, *police*, and *academics*, and for *police investigations*.

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA). Visual inspection suggests that users (UA) had a greater desire for others to volunteer their data than non-users (NUA). However, this was only statistically significant in two cases: research done by *the DNA-testing company to improve their services*, and research done by *pharmaceutical companies*.

Health Users (UH) vs Non-users (NUH). For every listed purpose, health users (UH) were significantly more likely to want others to contribute their data than health non-users (NUH).

3.3.8 General Attitudes



Rate how you agree or disagree with each statement.	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA II UH	NUA II NUH	UA II NUA	UH II NUH
I can be identified by the DNA sample I provided for ancestry/health testing.					1.000	0.576	0.521	0.006
My family might find out things they didn't want to know.					1.000	1.000	0.521	0.105
My DNA is my information and my information alone.					1.000	1.000	0.009	0.0006
What I do with my DNA is my business.					1.000	1.000	0.073	0.105
My family have a right to be concerned about my ancestry/health DNA test.					0.171	1.000	0.792	0.264
I am interested in finding biological family with a DNA test.					1.000	1.000	0.0002	0.00004
I do not need anyone's consent to take an ancestry/health DNA test.					1.000	1.000	0.521	0.576
Making my ancestry/health DNA test results public adds to the community.					1.000	1.000	0.002	0.006
People who hide their ancestry/health DNA results annoy me.					1.000	1.000	0.00003	0.002
Ancestry/health DNA data is just like any other data.					1.000	1.000	0.0002	0.014

Figure 3.8: *General attitudes* block. Bar graph of 4-point Likert scale data for each question per user group: Responses are ordered from most positive to most negative on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

Ten statements that touched on a variety of DNA-related topics were provided to participants, who then rated how much they agreed or disagreed with each one. Topics discussed include DNA ownership, DNA sensitivity, and privacy risks. Table 3.8 summarises results for the *General Attitudes* question block. In general, participants perceived high individual ownership over their data, were unconcerned with how others chose to share their data, and seemed to perceive high sensitivity of their data.

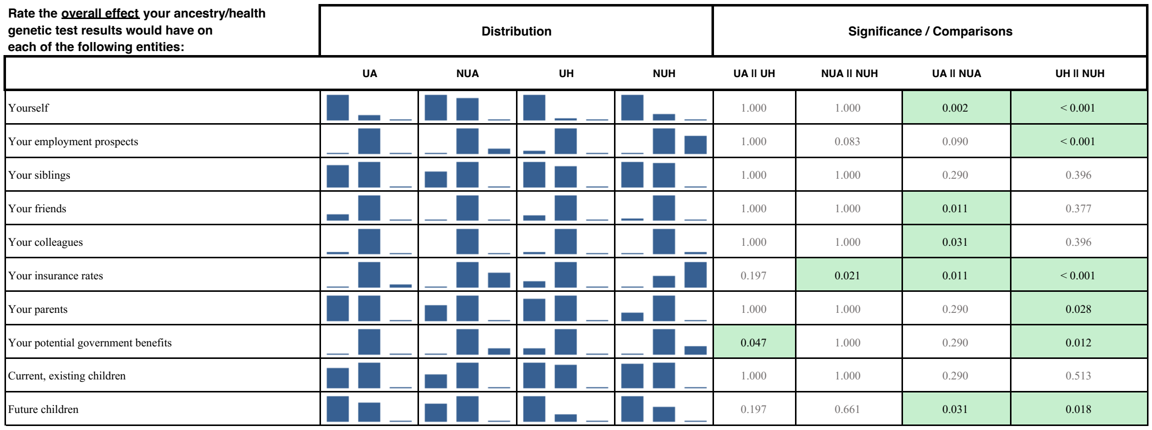
Ancestry Users (UA) vs Health Users (UH). There were no significant differences between ancestry users (UA) and health users (UH) for this block.

Ancestry Non-users (NUA) vs Health Non-users (NUH). No statistically significant differences were found between ancestry non-users (NUA) and health non-users (NUH).

Ancestry Users (UA) vs Non-users (NUA). Of the ten questions, five had significant differences between ancestry users (UA) and non-users (NUA), with non-users (NUA) generally displaying a more privacy-conscious attitude. Significantly more non-users (NUA) strongly agreed that their DNA was *their information, and their information alone.* Non-users (NUA) were also significantly less interested in *finding biological family with a DNA test.* Users (UA) were more likely to agree that *ancestry data is just like any other data*, that *those who hide their DNA test results are annoying*, and that *making their ancestry DNA test results public adds to the community.*

Health Users (UH) vs Non-users (NUH). The same trends and significant differences were found for health as for ancestry. In addition, significantly more health non-users (NUH) believed that they could be *identified by the DNA sample they provided for health testing*, compared to health users (UH).

3.3.9 Effects



Rate the overall effect your ancestry/health genetic test results would have on each of the following entities:	Distribution				Significance / Comparisons			
	UA	NUA	UH	NUH	UA ll UH	NUA ll NUH	UA ll NUA	UH ll NUH
Yourself					1.000	1.000	0.002	< 0.001
Your employment prospects					1.000	0.083	0.090	< 0.001
Your siblings					1.000	1.000	0.290	0.396
Your friends					1.000	1.000	0.011	0.377
Your colleagues					1.000	1.000	0.031	0.396
Your insurance rates					0.197	0.021	0.011	< 0.001
Your parents					1.000	1.000	0.290	0.028
Your potential government benefits					0.047	1.000	0.290	0.012
Current, existing children					1.000	1.000	0.290	0.513
Future children					0.197	0.661	0.031	0.018

Figure 3.9: *Effects* block. Bar graph of 3-point Likert scale data for each question per user group: Responses are ordered as “Positive”, “No effect”, and “Negative” on each graph. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green indicate a statistically significant test result. U = Users, N = Non-users; A = Ancestry, H = Health.

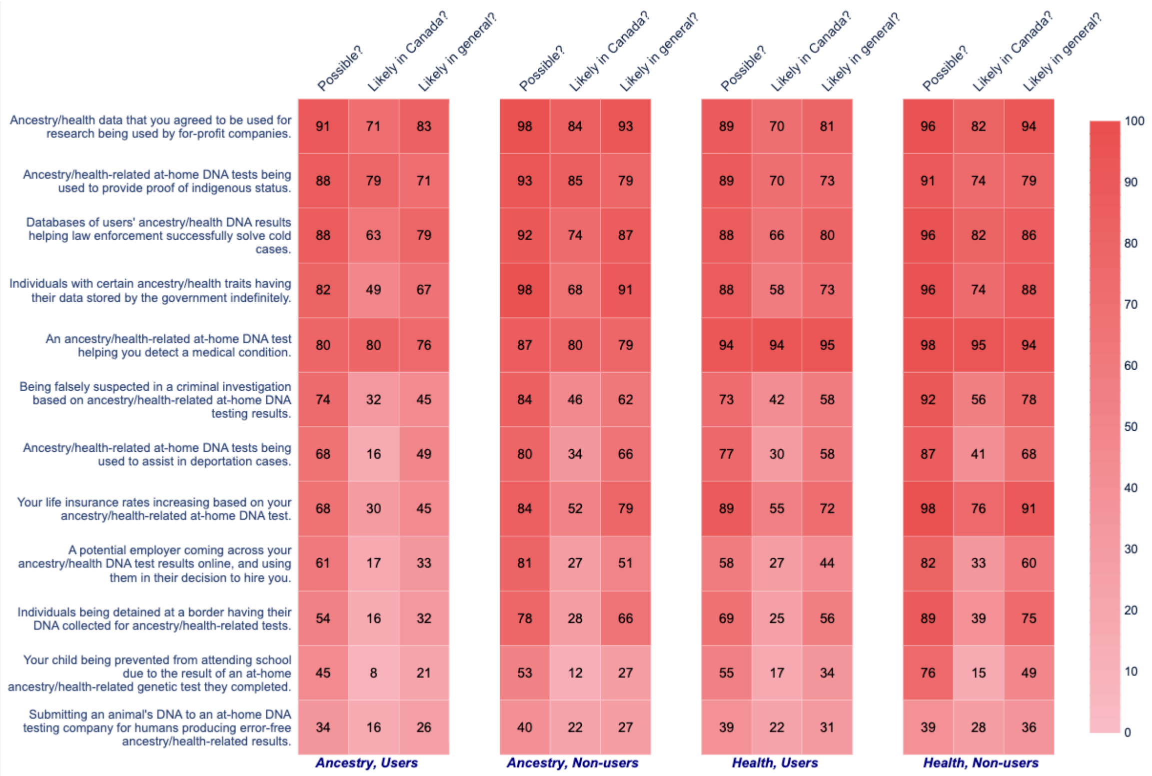
Participants rated how their own DNA test would affect each of ten entities. Table 3.9 summarises results for the *Effects* question block. Visual inspection suggests participants generally perceive very little effect of their DNA test on other entities, or they perceive the occasional positive effects.

Ancestry Users (UA) vs Health Users (UH). Visually, trends appear similar between ancestry and health users. Statistically, only one statistically significant difference exists: health users (UH) are more likely to believe that their DNA test would *positively* affect their potential government benefits.

Ancestry Non-users (NUA) vs Health Non-users (NUH). Trends between the two non-user groups appear mostly similar on visual inspection. However, significantly more health non-users (NUH) thought their DNA test result would have a *negative* effect on their insurance rates compared to ancestry non-users (NUA)).

Ancestry Users (UA) vs Non-users (NUA). Visually, users (UA) were observed to be slightly more positive than non-users (NUA). Statistical analysis uncovered five significant differences to this effect. Ancestry users (UA) perceived significantly more positive effects on *themselves*, their *future children*, *friends*, *colleagues*, and *insurance rates*. In contrast, non-users (NUA) perceived either no or negative effects on these entities.

Health Users (UH) vs Non-users (NUH). Visual inspection of the data indicates health users (UH) to perceive more positive effects than health non-users (NUH). Statistical analysis shows that users (UH) had a significantly more *positive* perception of how their DNA test would affect *themselves*, their *parents*, *future children*, *employment prospects*, *insurance rates*, and *potential government benefits*.



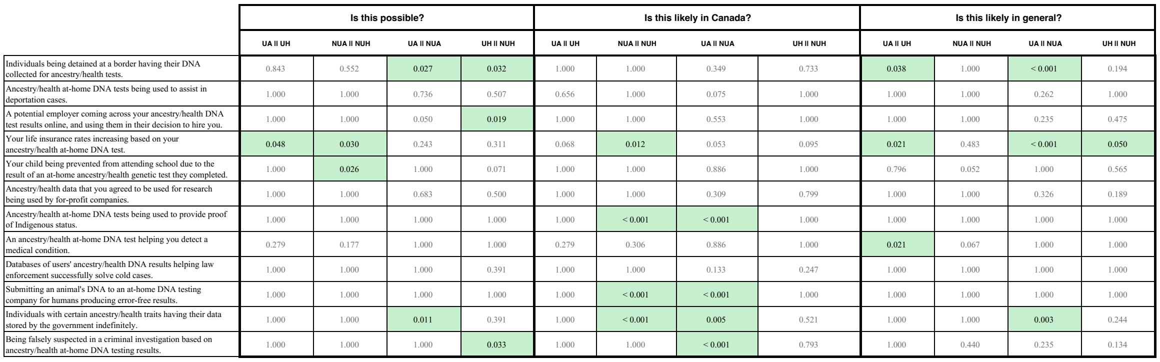
	Ancestry, Users			Ancestry, Non-users			Health, Users			Health, Non-users		
	Possible?	Likely in Canada?	Likely in general?	Possible?	Likely in Canada?	Likely in general?	Possible?	Likely in Canada?	Likely in general?	Possible?	Likely in Canada?	Likely in general?
Ancestry/health data that you agreed to be used for research being used by for-profit companies.	91	71	83	98	84	93	89	70	81	96	82	94
Ancestry/health-related at-home DNA tests being used to provide proof of indigenous status.	88	79	71	93	85	79	89	70	73	91	74	79
Databases of users' ancestry/health DNA results helping law enforcement successfully solve cold cases.	88	63	79	92	74	87	88	66	80	96	82	86
Individuals with certain ancestry/health traits having their data stored by the government indefinitely.	82	49	67	98	68	91	88	58	73	96	74	88
An ancestry/health-related at-home DNA test helping you detect a medical condition.	80	80	76	87	80	79	94	94	95	98	95	94
Being falsely suspected in a criminal investigation based on ancestry/health-related at-home DNA testing results.	74	32	45	84	46	62	73	42	58	92	56	78
Ancestry/health-related at-home DNA tests being used to assist in deportation cases.	68	16	49	80	34	66	77	30	58	87	41	68
Your life insurance rates increasing based on your ancestry/health-related at-home DNA test.	68	30	45	84	52	79	89	55	72	98	76	91
A potential employer coming across your ancestry/health DNA test results online, and using them in their decision to hire you.	61	17	33	81	27	51	58	27	44	82	33	60
Individuals being detained at a border having their DNA collected for ancestry/health-related tests.	54	16	32	78	28	66	69	25	56	89	39	75
Your child being prevented from attending school due to the result of an at-home ancestry/health-related genetic test they completed.	45	8	21	53	12	27	55	17	34	76	15	49
Submitting an animal's DNA to an at-home DNA testing company for humans producing error-free ancestry/health-related results.	34	16	26	40	22	27	39	22	31	39	28	36

Figure 3.10: A heatmap with the percentages of participants who responded “yes” to whether each scenario was (a) possible, (b) likely in Canada, and (c) likely in general. Darker cells represent higher agreement.

3.3.10 Scenarios

Participants were presented twelve different scenarios that were either based on a real situation that had occurred within Canada, or based on existing concerns. A discussion of the privacy risks used to inform these scenarios can be found in Section 2.5. A breakdown of how existing policies factor into these risks can also be found in Section 2.9. Additionally, we discuss instances where situations presented in some of these scenarios have impacted users in real-life. This is done in Section 5.2, under the *Data misuse* paragraph).

After being presented with scenarios, participants then answered whether the scenario was: (1) possible, (2) likely in Canada, (3) likely in general. A heatmap of the percentage of participants who responded “yes” to the scenario questions can be seen in Figure 3.10. Table 3.11 summarises the results of inferential statistics tests



	Is this possible?				Is this likely in Canada?				Is this likely in general?			
	UA ‖ UH	NUA ‖ NUH	UA ‖ NUA	UH ‖ NUH	UA ‖ UH	NUA ‖ NUH	UA ‖ NUA	UH ‖ NUH	UA ‖ UH	NUA ‖ NUH	UA ‖ NUA	UH ‖ NUH
Individuals being detained at a border having their DNA collected for ancestry/health tests.	0.843	0.552	0.027	0.032	1.000	1.000	0.349	0.733	0.038	1.000	< 0.001	0.194
Ancestry/health at-home DNA tests being used to assist in deportation cases.	1.000	1.000	0.736	0.507	0.656	1.000	0.075	1.000	1.000	1.000	0.262	1.000
A potential employer coming across your ancestry/health DNA test results online, and using them in their decision to hire you.	1.000	1.000	0.050	0.019	1.000	1.000	0.553	1.000	1.000	1.000	0.235	0.475
Your life insurance rates increasing based on your ancestry/health at-home DNA test.	0.048	0.030	0.243	0.311	0.068	0.012	0.053	0.095	0.021	0.483	< 0.001	0.050
Your child being prevented from attending school due to the result of an at-home ancestry/health genetic test they completed.	1.000	0.026	1.000	0.071	1.000	1.000	0.886	1.000	0.796	0.052	1.000	0.565
Ancestry/health data that you agreed to be used for research being used by for-profit companies.	1.000	1.000	0.683	0.500	1.000	1.000	0.309	0.799	1.000	1.000	0.326	0.189
Ancestry/health at-home DNA tests being used to provide proof of Indigenous status.	1.000	1.000	1.000	1.000	1.000	< 0.001	< 0.001	1.000	1.000	1.000	1.000	1.000
An ancestry/health at-home DNA test helping you detect a medical condition.	0.279	0.177	1.000	1.000	0.279	0.306	0.886	1.000	0.021	0.067	1.000	1.000
Databases of users' ancestry/health DNA results helping law enforcement successfully solve cold cases.	1.000	1.000	1.000	0.391	1.000	1.000	0.133	0.247	1.000	1.000	1.000	1.000
Submitting an animal's DNA to an at-home DNA testing company for humans producing error-free results.	1.000	1.000	1.000	1.000	1.000	< 0.001	< 0.001	1.000	1.000	1.000	1.000	1.000
Individuals with certain ancestry/health traits having their data stored by the government indefinitely.	1.000	1.000	0.011	0.391	1.000	< 0.001	0.005	0.521	1.000	1.000	0.003	0.244
Being falsely suspected in a criminal investigation based on ancestry/health at-home DNA testing results.	1.000	1.000	1.000	0.033	1.000	1.000	< 0.001	0.793	1.000	0.440	0.235	0.134

Figure 3.11: *Scenarios* block. Values in the Significance/Comparison columns are the Holm-Bonferroni adjusted p-values from Mann-Whitney U tests. Green cells indicate a statistically significant test result.
U = Users, N = Non-users; A = Ancestry, H = Health.

comparing study conditions.

Is the scenario possible?

Participants believed most of the provided scenarios to be plausible.

Ancestry Users (UA) vs Health Users (UH) Both ancestry (UA) and health (UH) users generally believe that almost all scenarios are possible. However, statistical analysis shows that significantly more health users (UH) believe that *life insurance rates would increase based on their at-home DNA test.*

Ancestry Non-users (NUA) vs Health Non-users (NUH) Ancestry (NUA) and health (NUH) non-users thought that almost all scenarios are possible. Statistical analysis shows two significant differences: significantly more health non-users (NUH) believe that *life insurance rates would increase based on their at-home DNA test*, and that *their child could be prevented from attending school due to the result of an at-home genetic test they completed.*

Ancestry Users (UA) vs Non-users (NUA) Statistical analysis shows that significantly more non-users (NUA) believed that *individuals being detained at a border could have their DNA collected* for ancestry tests. Similarly, non-users (NUA) were significantly more likely to believe that *individuals with certain ancestry traits could have their data stored by the government indefinitely.*

Health Users (UH) vs Non-users (NUH) Although visual inspection indicates that participants believe most scenarios to be plausible, there are three significant differences between the two groups.

Health non-users (NUH) are significantly more likely to believe that *individuals being detained at a border could have their DNA collected* for health-related tests, that *a potential employer could come across a candidate's health DNA test results online, and use them in their hiring decision*, and that it was possible to be *falsely suspected in a criminal investigation* based on health at-home DNA testing results.

Is the scenario likely in Canada?

Ancestry Users (UA) vs Health Users (UH). There were no significant differences between ancestry users (UA) and health users (UH) for this block.

Ancestry Non-users (NUA) vs Health Non-users (NUH). On visual inspection, a larger percentage of non-users believed the listed scenarios were likely to happen within Canada (compared to users). There are statistically significant differences on four scenarios between ancestry (NUA) and health non-users (NUH).

Significantly more health non-users (NUH) believed it likely that *those with certain health traits would have their data stored by the government indefinitely*, and that *at-home DNA tests can be used to provide proof of Indigenous status* or to *increase life insurance rates* within Canada.

Conversely significantly more health users (UH) believed that *submitting animal DNA to an at-home DNA testing company for humans would produce error-free results* within Canada.

Ancestry Users (UA) vs Non-users (NUA) Visual inspection indicates both groups of participants (UA, NUA) believe slightly fewer than half of the scenarios likely within Canada. Four statistically significant differences exist between ancestry users (UA) and non-users (NUA).

Significantly more non-users (NUA) believed that at-home ancestry DNA tests could be used to *provide proof of Indigenous status*, and that *those with certain ancestry traits could have their data stored by the government indefinitely.* Significantly more non-users (NUA) also believed that one could be *falsely suspected in a criminal investigation* based on these test results, and that *submitting an animal's DNA to an at-home DNA testing company for humans would produce error-free ancestry results.*

Health Users (UH) vs Health Non-users (NUH). There were no significant differences between health users (UH) and health non-users (NUH) for this block.

Is the scenario likely in general?

On visual inspection, it appears that participants generally believed negative scenarios to be less likely to occur in Canada compared to being generally likely.

Ancestry Users (UA) vs Health Users (UH). Visual inspection of the data indicates that more health users (UH) believe the scenarios to be likely in general, compared to ancestry users (UA). Despite this observation, only three differences between the two groups were statistically significant.

Significantly more health users believe that it is generally likely for *individuals being detained at a border to have their DNA collected for health tests*, that their DNA test could *help them detect a medical condition*, and that the results of a health DNA test could be used to *increase life insurance rates.*

Ancestry Non-Users (NUA) vs Health Non-users (NUH). There were no significant differences between ancestry non-users (NUA) and health non-users (NUH) for this block.

Ancestry Users (UA) vs Non-users (NUA) Visual trends suggest that non-users (NUA) are more likely to think that a scenario is likely to happen in general compared to users. However, only three scenarios have statistically significant differences. Ancestry non-users (NUA) are significantly more likely to believe that *individuals being detained at a border have their DNA collected for ancestry tests*, that an ancestry test would *increase their life insurance rates*, and that *individuals with certain ancestry traits could have their data stored by the government indefinitely.*

Health Users (UH) vs Non-users (NUH) On visual inspection of the data, both groups of participants find most of the provided scenarios to be likely in general. However, one significant difference exists: health non-users (NUH) are significantly more likely to think that life insurance rates increase based on your health DNA test results.

3.4 Discussion

Our research questions focus on the differences between participants' privacy perceptions of ancestry and health DNA data, as well as those between users and non-users of at-home DNA testing. In this section, we discuss how our research answers these questions.

3.4.1 Addressing RQ1.1

> **RQ1.1:** Do privacy perceptions of at-home DNA testing differ based on whether it is for ancestry or health purposes?

For most of our survey questions, there were no statistically significant differences between participant perceptions of ancestry and health-related DNA data.

We note three areas where differences occurred. Users in the *health* data condition were significantly more concerned about discovering unpleasant information than ancestry users. Unpleasant news related to health can be perceived as a risk to one's life and has potential for serious medical implications to the user or their biological family members. In comparison, such severe consequences are less with ancestry tests.

Health data was also seen as providing value for the greater good; significantly more participants believed health data should be contributed by others for research by the government and police, to academic institutions, and for police investigations. Similarly, significantly more users believed health testing would positively affect users' potential government benefits.

Finally, significantly more health users (and health non-users) believed a series of privacy-compromising scenarios to be likely within Canada or in general. Such scenarios include being tracked by the government, or receiving an increase in life insurance rates. Interestingly, however, we found no significant differences between ancestry and health data for general questions in other survey blocks that discuss concerns (including those of surveillance, or an increase in insurance rates).

3.4.2 Addressing RQ1.2

> **RQ1.2:** Do users' and non-users' privacy perceptions of at-home DNA testing differ?

Broadly, non-user participants were more privacy conscious, more protective of their personal data, and distrustful of third parties (like the government). Non-users perceived fewer benefits from DNA-testing to themselves than users. Significantly more non-users perceived risks associated with at-home DNA testing (like an increase in insurance rates, or negative consequences from an employer accessing results online). Significantly more non-users agreed their DNA to be their business alone, and disagreed that it was similar to other forms of data.

Users, on the other hand, were significantly more likely to perceive benefits associated with DNA testing (including finding family members, and having a positive effect on their insurance rates, their government benefits, and employment). Users were also significantly more likely to believe DNA tests would have positive effects on their family members.

3.4.3 Limitations

First, we identify a few limitations to our participant sample. Given that participants who completed the study were interested in the topic, there may be self-selection bias.

We recruited through Prolific, so our participant pool was limited to those enrolled in this service. Finally, these results should be generalized with caution given that we did not control for a representative sample of the Canadian population, or other demographic factors.

Secondly, we identify potential biases introduced by the survey. While completing our survey, participants likely became aware that we were interested in the topic of privacy, and this may have primed them to be more privacy-conscious than in their everyday life. On a related note, participants may have been subject to the social desirability effect, and provided answers that they believed would be more socially acceptable.

Chapter 4

Study 2: Interviews

Our second research question concerns the perspectives of individuals with a family member who has taken an at-home DNA test. We employ an interview as our primary data collection instrument, along with the use of a short pre-screening survey for context. Particularly, we discuss how familial privacy is considered in users' choices: the degree to which biological family members were involved in the decision to take an at-home DNA test, and how the news of such a test is disseminated amongst families. We also discuss participant preferences regarding testing, their perceptions of privacy risks, and how they perceive their users' test to affect them and other family members (if at all). Through these interviews, we address our the second research question:

> **RQ2** What are biological relatives' privacy perceptions of how at-home DNA testing affects them?

In this section, we report direct findings from our data. Links to the existing literature on non-users' perceptions of familial privacy, as well as implications of these findings for users' and their biological relatives' privacy, are discussed in Section 5.1. Misconceptions regarding privacy risks are discussed in Section 5.2. We provide recommendations on privacy policies, the user experience (UX) of such services, and possible technological solutions to address some of these concerns in Section 5.4.

4.1 Methodology

This study was cleared by Carleton's Research Ethics Board. We used an iterative design process for the study instruments. Both the survey and the interview were piloted by 2 graduate students with reasonable knowledge of security and privacy. As a result of the pilot study, small changes in wording were made in the survey to increased readability. No changes were made to the interview.

Demographic	**Number of participants**
Area of residence	
Ontario	4
Alberta	2
British Columbia	1
Nova Scotia	1
Manitoba	1
Saskatchewan	1
Gender	
Men (cisgender)	5
Women (cisgender)	5
Age	
18 – 24	2
25 – 34	3
35 - 44	3
55 - 64	2
Highest/current level of education	
High school	4
Undergraduate degree (Bachelor’s)	2
Graduate degree (Master’s, PhD) or professional degree	4
Occupation	
Administrative Support	1
Business, Management, and Financial	1
Education	1
Science, Engineering, and IT Professional	1
Skilled Labour	1
Student (Law)	1
Student (Speech Language Pathology)	1
Unemployed	3

Table 4.1: Study 2 participant demographics.

4.1.1 Recruitment

Participants were recruited via the online research crowd-sourcing platform Prolific [106]. We recruited participants who had not completed an at-home DNA test themselves, but knew someone in their biological family who had. This eligibility criteria includes both immediate and extended family. Aside from these criteria, we only recruited participants who were above 18 years of age, resided in Canada, were fluent in English, and consented to be audio-recorded.

We pre-screened a total of 250 participants, of which 10 participants were interviewed. Excluding those who failed our attention check, or did not meet our eligibility criteria, we had 149 eligible participants. We extended invitations at random, in sets of 20, until a sufficient number of participants had booked interviews.

4.1.2 Participants

Most participants resided in Ontario (n = 4), and half were aged between 18 – 34 (n = 5). Exactly half of our participants (n = 5) were cisgender men, and half (n = 5) were cisgender women.

All participants had at least a high school education, and represented a wide variety of occupational backgrounds, including Administrative Support, Education, Skilled Labour, Business/Management/Financial, and Science/Engineering/Information Technology professionals. Table 4.1 provides further detail of these demographics.

4.1.3 Study procedure

The study consisted of two steps: a pre-screening survey and an interview.

1. Interested participants completed pre-screening survey advertised on Prolific. Participants selected the survey via Prolific, and were compensated 1.5 GBP ($2.34 CAD) upon completion. The survey, hosted on Qualtrics Survey Software [108], took approximately ten minutes to complete. Survey answers were later discussed in the main interview. All questions contained a “Prefer not to answer” option, and participants could withdraw at any point during the survey by simply closing their browser tab.

2. Eligible participants were invited through Prolific to schedule an interview. After completing the interview, participants were compensated 10.00 GBP ($16.42 CAD) through Prolific. Each interview was semi-structured and lasted approximately 60 minutes. All interviews were conducted through Zoom [140], and were audio-recorded. In addition to answering themed interview questions, participants also expanded on their survey answers. Participants could skip any questions, or withdraw by informing the researcher.

Participants completed consent forms as part of the pre-screener and scheduling surveys. Personally identifiable information was limited to participants' voice; any emails or Prolific IDs collected for scheduling the interview sessions was deleted immediately after completion of the interviews. We further assigned pseudonyms to our participants that were divorced from their identity (e.g., NP1–NP10). These pseudonyms were used for transcription and the subsequent data analysis.

4.1.4 Pre-screener survey

The pre-screener questionnaire is available in Appendix G . Aside from demographics, questions used 4-point Likert scale, unless otherwise stated. Categories with an asterisk overlap, either partially or fully, with the Study 1 main survey questions. These are included because they are relevant to Study 2's main research question. The survey was divided into the following categories:

1. Demographics: This includes participants' age, gender, province of residence, occupation, and level of education.

2. DNA-testing history: We asked whether participants or their biological family members had completed an at-home DNA test, and whether they had (or would) consent to their DNA data being used for research purposes.

3. Origins of perceptions: Participants rated how each of 5 different entities have influenced their perceptions of at-home DNA testing (*"Not at all"*, *"A little bit"*, *"Somewhat"*, *"Very much"*).

4. *Data sharing (self): Participants rated their comfort with contributing their data for various purposes (*“Not at all”*, *“A little bit”*, *“Somewhat”*, *“Very much”*).
5. *Data sharing (others): Participants rated the degree to which they would like others to contribute their data for various purposes (*“Not at all”*, *“A little bit”*, *“Somewhat”*, *“Very much”*).
6. *General perceptions: Participants were presented a series of statements focused on data ownership and general perceptions of at-home DNA testing. They rated how strongly they agreed with each statement (*“Strongly agree*, *“Agree”*, *“Disagree”*, *“Strongly disagree”*).
7. *Effects: Participants were provided a list of different entities, and asked whether the effect of an at-home DNA test would be *“Positive”*, *“No effect”*, or *“Negative”* on each entity.
8. Involvement in testing: Participants were presented a list of entities, and rated whether each entity should be involved in the decision to take an at-home DNA test (*“Yes”*, *“Maybe”*, *“No”*). A text box was provided to list any additional entities that they believe should be involved.
9. Reasons: Using a text box, participants discussed the reasons why they have chosen not to take an at-home DNA test.

4.1.5 Interview guide

The semi-structured interview included themes similar to the Study 1 survey. A copy of the interview script is available in Appendix H.We covered the following topics:

1. Introductory questions: Relationship to the user(s) in the participants’ lives, how often the user had completed at-home DNA testing, when, and why (ancestry, health, or both).
2. Motivation: The reason why the participant hasn’t completed at-home DNA testing.

3. Understanding of the process: The technical details related to at-home DNA testing (including perceptions of accuracy).
4. Family discussions: The circumstances surrounding how the user communicated the news of their at-home DNA test.
5. Family opinions: The biological family's initial and current thoughts on the decision.
6. Benefits and risks: Perceived benefits and risks to the participant and to the user from the user's at-home DNA test.
7. Ownership: The degree of involvement various entities should have in the decision to take an at-home DNA test.
8. Effects: The effects on the participant and their biological family if certain entities had access to the user's test results.
9. Questionnaire answers: Clarification, and explanation, of the choices made by participants in the pre-screening survey.
10. Closing questions: Any advice the participant may have for those considering an at-home DNA test, what stood out to them in the interview, and any final comments.

4.2 Analysis

Over the course of the interviews, we collected 9 hours of audio, transcribed using an online transcription software (Trint [*]). The interview data was analysed with inductive thematic analysis [34], using the qualitative data analysis software NVivo [†].

All transcripts were then manually compared with the audio files, and edited to ensure accuracy. During the editing process, the researcher took note of any high-level themes present in the data. These 20 high-level themes were used to form the very first codebook. After this, the main researcher completed coding 2 very different

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[*] `https://www.trint.com/`

[†] `https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home`

Themes	**Description**
Accuracy	How accurate participants perceived at-home DNA tests, and why
Advice	Any advice participants had for family members, future users, and current users of at-home DNA testing
Anecdote	Anecdotes shared by participants; e.g.: personal experiences, a news article they came across
Attitudes towards at-home DNA testing	High-level attitudes towards at-home DNA testing (positive, negative, or otherwise)
Participant Background	Participants' educational background
Benefits	Benefits participants perceived to themselves, others, or in general
Desires, recommendations	Participant needs relating to the privacy of at-home DNA testing
How information was shared	The circumstances under which the news of the at-home DNA test was shared (e.g.: when, how)
DNA testing process	Participants' understanding of the various processes involved in at-home DNA testing (e.g.: the science behind it, the handling of data)
Effects on self, others	How participants perceive something to affect either themselves or others, and the extent of this effect
Entities	A list of the various entities discussed by participants (e.g.: immediate and extended family, friends and colleagues, and external organisations)
Involvement in testing process	Participants' opinion on who should be involved in the decision to take a DNA test, and why
Laws, regulations	Mentions of laws and regulations, and whether these were protective, or concerning
Level of concern	The degree to which participants expressed concerns about a topic
Mental models	Indications of incomplete or inconsistent mental models
Motivation (or lack thereof)	Reasons why participants have not taken a DNA test, and whether they would choose to do so
Nature of DNA	Participants' perceptions of DNA (e.g.: complexity, uniqueness, sensitivity)
Origins of perceptions	Mentions of articles or events that influenced or change participants' perceptions of at-home DNA testing
Other	Niche, miscellaneous codings
Protective measures	Privacy-protective measures that may help mitigate loss of privacy once a user has completed a test
Reactions to DNA test	Participants initial reactions to the users' DNA tests, and current feelings on the topic
Region comparison	Any mentions of how benefits, risks, privacy laws, etc differ amongst different regions (Canada, USA, Europe)
Risks	Risks perceived by participants to themselves, others, or in general
Shared nature of DNA	Mention of amounts of DNA overlap between users, the participants, and/or other family members.
Sharing of results	The degree to which results were shared with participants
Trust, Distrust	Participants' levels of trust, and distrust, towards different entities, and why
Type & goal of test	Participant opinions differed based on the purpose of DNA test being discussed; this code indicates the type of test being discussed by participants

Table 4.2: The 27 high-level themes (present as codes) in the final version of the codebook. Many codes implicitly refer to aspects of privacy.

Participant quote	Themes
P1: It's not something substantive that I can be like, "Oh, here's my DNA", because nobody runs around like that. But, you need to… It's like any part of your your data profile. You just need protections around it, so that it's not misused.	• Risks • Laws, regulations • Desires, recommendation
P6: [Health DNA tests are] probably also fairly accurate depending on the disease that you're asking for... I used to work in a genomics lab, and I think that certain diseases have fairly well known genomic markers.	• Accuracy • Background • DNA testing process
P3: My very, very basic knowledge of DNA is that if I provide a DNA sample, they can figure out who I am, just from my knowledge of police investigations and stuff like that.	• Risks • Nature of DNA • Entities

Table 4.3: Examples of the coding process: three participant quotes and associated themes.

transcripts to refine the codes. 46 fine-grained codes were added as a result, resulting in a second, more holistic codebook. In the first pass, all transcripts were then coded with the second codebook. Coding for all transcripts was revised and refined multiple times throughout the analysis process. The third, and final codebook was created consisting of 27 high-level themes/codes, with 236 codes in total. A list of these final themes can be seen in Table 4.2. All 10 transcripts underwent one final revision using this third codebook. Examples of the coding process are provided in Table 4.3.

The analysis was conducted by the main researcher, who conducted the interviews and was most familiar with the data. Discussions with the researcher's supervisor helped to refine the analysis.

4.3 Results

Participants referred to both ancestry and health-related DNA testing throughout the interview. Where necessary, the researcher asked for clarification, or asked specifically about both forms of at-home DNA testing. We identify participants' biological family members who have completed at-home DNA testing as *users*. When referring to the

Descriptor	**Number of participants**
Relationship to users	
Immediate family (parent, full-sibling, half-sibling, child)	6
Extended family (grandparent, aunt/uncle, niece/nephew, cousin)	3
Both immediate, extended family members	1
Number of users in family (that were discussed during interviews)	
Single user	9
Multiple users (2)	1
Type of DNA test completed by users	
Ancestry	9
Health	2

Table 4.4: Details of the DNA tests completed by users in the participants' families.

interviewee specifically, we use the term *participant.* Finally, when addressing the users' or participants' family in general, we refer to them as *family members.* We frame our results around privacy to address our research questions.

4.3.1 Learning about the DNA test

We asked participants about the details surrounding the users' at-home DNA tests (how many family members have completed a DNA test, how they are related, their purpose for the test, how the information was disseminated to participants, and to which degree). A summary of this information is available in Table 4.4.

Most participants only had a single family member who completed at-home DNA testing. Two participants knew more than one user in their families; one of them focused on the user who was an immediate family member, while the other discussed both the users that they knew. All participants were informed about their family members' test by means of casual conversation: over a phone call, because the topic came up amongst friends, or in a family gathering. In most cases, participants were informed *after* the test had been completed (usually in context of the results).

Almost all participants had some knowledge of their family members' DNA test results. Most participants received highlights or detailed *ancestry* DNA results from the user(s). P10 described how their entire family has a keen interest in genealogy and family-tree building. As a result, they have access to detailed information that pertains to the uncovered portions of the users' family tree: *'One of them was like, "we'll make this family history kind of document where we go through the individuals in this lineage that we can find, and we go over what research we've uncovered about them". And they had it printed [...]. So like one [sibling] has one and the other [sibling] has one and their families can look at it whenever. It's just at their house(s)."* (P10). According to P10, a copy of this journal has been distributed to various households in the user's family. On the opposite end of this spectrum, however, is P6 who has no knowledge of their family member's results because they *"never asked"* (P6).

Only two participants knew family members who had completed testing for *health* purposes; one was quite young when it happened, and also felt that *"it wasn't really my business,"* (P3) to know the results, while the other (P1) was informed in detail.

4.3.2 Reasons for not having completed a test

We categorized the reasons why participants had not completed at-home DNA testing. We indicate whether ancestry or health testing was being discussed, and summarise the overall attitudes towards privacy displayed by participants. Roughly a third of participants fit into each privacy category.

(i) Privacy-protective, risk-averse (Ancestry, Health): Participants who were strongly averse to completing an at-home DNA test were concerned about the flow of their data (e.g., where it's stored, for how long, where it is shared). Additionally, they worried about the potential consequences of completing a test, either as a result of privacy violations or risk of receiving upsetting information.

P1 explained that while they would *like* to *"know the genetic consequences of my familial inputs into my genetic makeup... [and] understand where my health is going"*, they *"don't trust where the data goes"* and *"wish there was a secure way to do it"*. Their reservations arise, in part, from their knowledge of previous incidents; for example, how *"one of the at-home services just had their company repurchased, and they're planning to use the data anonymised – however well that works – in other things that people didn't sign up for"*. P2 describes a *"general distrust of what that information might be used for"*, and P6 doesn't think it's *"necessary to supply my*

DNA for any sort of databasing... if the government wanted to do large scale data analysis in order to track certain things, they could.”.

Some participants were indifferent to ancestry testing but were skeptical and uneasy at the thought of completing an at-home DNA test for health purposes. Doing one directly with a medical physician was perceived as more accurate and safer: *“to send DNA is kind of weird to me... like if you need to do any sort of medical tests, you just get your doctor to order some tests for you.”* (P8). P8 also echoed a sentiment shared by many participants who were averse to at-home DNA testing for health purposes: *“Like if a doctor said you should do this... (only) then I would think about it more,”* (P8).

Additionally, some participants simply did not want to deal with potentially life-altering information they might uncover. P6, for example, thought that *“there's some things better left unknown,”* (P6).

In discussing their privacy concerns, participants mentioned perceived risks and their distrust of third parties and the DNA testing company itself, which are described separately (Sections 4.3.5 and 4.3.7).

(ii) Privacy indifferent, disinterested (Ancestry): Several participants were disinterested in at-home DNA testing as a whole. These participants felt they already knew what there was to know about their health and family, or did not find such testing relevant to their lives.

Participants may, for example, lack *“that itch to kind of deep dive into it”* (P5) because they already perceived to have an adequate knowledge of their background from talking to family members: *“It's always been kind of mystery solved in that regard,”* (P5). These participants did not expect anything *“shocking or new to learn”* (P9), the test results would have *“no bearing on [participants'] day-to-day”* (P9), and were not *“relevant”* (P9) to them.

Alternatively, participants may have simply gleaned all the information they could from the user's DNA test. P8 *“got the information that was most interesting”* out of their extended family member's DNA test: *“the composition of ethnicities wasn't really surprising, like 5% Slavic or whatever... it's such a small percentage that... you don't really think about it or wanna research it [yourself]. Like, I'll probably get* *very similar results so I wouldn't need to do it myself," (P8).*

Interestingly, participants referenced their family member's DNA results to make assumptions or guesses about their own results. There is the awareness that DNA is shared, but this raised no privacy concerns.

(iii) Privacy unconcerned, future consumers (Ancestry, Health): Participants who felt most positively about at-home DNA testing in general expressed the intent to eventually complete one. For the duration of this subsection, we will refer to them as "future consumers". Only one participant intended to conduct research into the potential consequences of at-home DNA testing; privacy was not mentioned otherwise.

All future consumers were constrained either by monetary reasons or time. The majority expressed financial concerns, with three participants (P3, P9, P10) being students: *"Yeah, I would do one, I think. Another thing though, is the cost... I'm a graduate student, so if it's costly, I'm obviously not going to do it,"* (P3). P10, while concerned about finances, is also unsure of which company to test with: *"There's so many options. So I was kind of balancing or reading the pros and cons between multiple ones"*. Although P9's major concerns were about the cost of such a test, they also expressed how they did not feel *"knowledgeable enough"* to comfortably do it : *"I think I'd want to know a little bit more about what it means and what comes with that"* (P9). Finally, although future consumer P4 simply hasn't *"gotten around to doing it"*, they did express interest in the service, indicating that: *"if [user] would have asked me to do it (with them), I would have done it, too"*.

Some participants were dismissive of ancestry testing, but were supportive of at-home DNA testing for health purposes. Participants encouraged those who were concerned about their health or about passing on *"some less than desirable genetic condition to their offspring"* to get tested to uncover potential medical implications.

4.3.3 Reactions to the DNA test

Participants' general attitudes towards their family member's DNA tests often set the tone for the rest of the interview. Roughly a third of participants each reacted either positively, negatively, or with indifference. We discuss participants' reactions to the news and whether their feelings have evolved over time.

First thoughts

We categorise participants' initial reactions based on the privacy implications associated with each response. Roughly a third of participants belonged to each category.

(i) Personal privacy lost: shock, resignation P1 and P2 perceived a personal loss of privacy at hearing the news' of their family members' DNA tests. The users, however, were oblivious to this consequence as they shared the news of the test: *" they were fairly nonchalant about it... not sort of understanding the whole issue of DNA and security and data... privacy,"* (P1). This news did *"cause some issues"* (P1) for P1, who perceives part of their privacy as completely lost: *"We share DNA, so it's out there. I haven't done anything illegal in my life where DNA is required, but at the same time... there's a partial, or part, of the DNA profile out there. It belongs to me. It's out there."* (P1).

P2 also felt *"a bit of a shock"* when first learning about their immediate family member's DNA test, explaining that it was unexpected due to the user's general distrust of such services. They discuss having some *"mild paranoia"* because *"it may be enough data to just connect back to me in some way".* P2 would have *"still felt pretty shocked if they decided to go through with it"* even if they had discussed the test with the user beforehand.

Initial discomfort aside, both participants expressed feelings of resignation: *"...it was sort of a bell rung that couldn't be un-rung at that point,"* (P1). P2 shared a similar *"it is what it is"* (P2) attitude, feeling that *"what's done is done"* (P2). P1 thought that limiting the amount of personally identifiable information (PII) provided with the DNA test could have made them feel slightly more comfortable, but these were not taken by their family member. For example, the use of a pseudonym instead of the user's real name, or a P.O. box for delivery of the DNA testing kit.

P2 felt pessimistic about the dissemination of this data. Resigned, they did not believe any protective measures could have been taken *"that would affect anything"*

(P2). Once their privacy was gone, it was gone.

(ii) Privacy indifferent: total neutral, gentle support For those who were completely indifferent to the news, the conversation surrounding the topic was minimal: *"it was a quick little part of the conversation. I was just like "oh, cool, let me know how that goes", essentially. That was about it."* (P5). P7 could not recall their initial reaction: *"Whatever my reaction was, it probably wasn't strong enough to make a real impact, because I don't remember it now,"* (P7). P6, while having a very privacy conscious attitude towards their own data, was *"ambivalent"* towards the news of the user's DNA test: *"I don't really care if other people... what they do with their body or their DNA. It's up to them."* (P6). P9 indicated that *"there was nothing that was relevant to me"*.

Had they been informed of their family member's intentions beforehand, participants who had expressed indifference would be supportive, or attempt to remain neutral. P7, for example, states: *"just on the basis of curiosity, I think I would have encouraged them to go ahead with it... I think just because it's interesting to know where you come from,"* (P7). More neutrally, P9 mentioned that they *"wouldn't discourage"* their family members, but *"wouldn't necessarily encourage them"* either.

(iii) Privacy unconcerned: excitement, intrigue Future consumers of at-home DNA testing were strongly in favour of their family member's test. All three participants discussed how DNA is networked between family members but did not draw connections to risks, only benefits.

P4, for example, found it to be *"very exciting"*, recognising that *"whatever [user] is related to, I'm related to"*. These participants were intrigued by the amount of personal information that could be gleaned from a sample of DNA: *"I thought it was kind of neat, the way they could get a certain amount of information on extended relatives from* ***themselves****,"* (P10). If these participants had learned of their family members' DNA tests beforehand, they would have actively encouraged them to complete one.

Current thoughts

Our participants were informed about their family members' DNA tests anywhere from a few months to a few years ago. Participants' opinions towards the users' DNA tests have remained consistent over time, with the exception of P1 who is now more worried. They note the dynamic nature of at-home DNA testing companies: *"(with) time, companies have disappeared, and other companies have sprung up in their place, and the people running some of the companies are not as honourable as the people that started them,"* (P1). Given these changes, P1 now feels more frustrated that *"I don't have control over the elements of my DNA that's out there"*.

4.3.4 Perceived benefits

Participants discussed the positive impacts of at-home DNA testing on the user themselves and on their biological family members (including the participant themselves). In addition, benefits to the "greater good" were referenced by participants throughout our interviews.

(i) Necessity, not luxury

In cases of building identity or serious health concerns, testing can be seen necessary to the physical, mental, and/or emotional well-being of certain individuals. As such, even privacy conscious users may put their privacy concerns aside to attain data that is personally invaluable to them.

Identity, family Participants understood the importance of ancestry and health DNA testing for those with *"dysfunctional or broken connections in relationships"* (P7). P2 discussed how the user's DNA test helped them feel connected to their background: *"[user] was an orphan... so [they] didn't really know their background, [their] family. So by extent, I didn't either from [their] side,"* (P2). For those with limited information about their family and identity, an at-home DNA test may be the only way to find other family members, or gain any insight into their ethnic background. This may even be a compromise privacy conscious individuals choose to make. For example, the user in P2's family was indicated to be more distrustful of third-parties than P2 themselves (who was already quite privacy protective). Due to their life circumstances, they set aside their reservations about privacy to gain something considered more valuable in return.

DNA testing was also identified as a way for multi-generational immigrants to build identity: *"it's hard to recognise [your heritage] when your extended family, or a couple generations back, they're born somewhere else. But now you're just living in Canada and you see Canada. Maybe knowing heritage in that way might be positive as a descendant of immigrants"* (P10).

Health precautions Many participants considered health-related DNA tests as a precaution individuals could, or should, take for their (and possibly their family's) health. Individuals can ascertain whether they have any "predispositions" (P2, P6, P10) to serious diseases: *"that would be good to know in advance, especially if there were certain conditions in old age that aren't necessarily apparent when you're younger,"* (P10). Aside from general interest in one's health, P3 notes that their family member is *"on the side of family where there's a little bit of cancer in the genetics"*, and was supportive of their at-home DNA test. Similarly, P5 mentions *"one of my friends... their parents passed away really young. So I think it'd be beneficial to... see if there's any underlying cause to that"* (P5). P1 also outlined how having *"a rather large family"* with many half siblings could be a *"small, slight concern"* for similar reasons.

The resulting information could either be used to make lifestyle changes or be taken to a medical physician for further testing: *"I could get one done, and then take it to a doctor... they could look at it and go, "There are further tests we can do to ascertain whether you've got a problem coming up,""* (P1). Many also commented on the use of health-testing to inform decisions involving future children. In some cases, participants noted *"benefits in knowing earlier than later on"* (P10). In cases where a child may need extra support, early awareness through a health or ancestry DNA test may result in *"intervention skills (coming) out faster"* (P4): *"the [intervention] will be sooner in life, because I'll be more aware of the traits I'm looking for"* (P4). It was noted, however, that although *"impactful"* (P9), the results could still be *"discouraging"* (P9). Results indicating that future children may have serious medical issues would raise *“pretty difficult ethical questions... it would be an ethical question of whether or not to have children”* (P9).

(ii) Scientific benefit to society

Most participants supported the storage and usage of DNA data for *“any research initiative”* (P3), especially if they were not for profit, nor for *“any personal gain”* (P3). Most commonly referenced was the use of this data to help *“advance medical science”* (P3): *“with the health DNA, I feel like they can kind of get down to any sort of root causes with it and then hopefully proactively work on a solution based on the results that they get,”* (P5). Aside from health purposes, one participant who works with vulnerable populations discussed how both ancestry or health data could be helpful: *“If I were to look at my ancestry and I see that I have autism in my family, then that means that I would be aware a lot faster... Like, I think there’s benefits to having that out there and available.”* (P4).

(iii) Light-hearted benefits

Aside from more pressing reasons to complete at-home DNA testing, participants identified a few more light-hearted benefits to at-home DNA testing.

Fun, general curiosity Ancestry DNA testing was seen by many simply as a fun thing to do. Knowing what *“your true ethnic background [is]... the cool different things going on in your DNA”* (P3) was considered a benefit, *“[regardless of] whether that’s 1% or 5%”* (P3). Participants who perceived the *“entertainment factor”* (P3) also considered ancestry DNA tests to be highly accurate. They considered the information gleaned from such tests as *“intriguing”* (P3) or *“cool”* (P2, P3, P4, P8) to know. *“I think it was just general curiosity”*, states P9 to this effect, about the reason behind their user family member taking a test.

Personal projects Ancestry-based DNA testing was also recognised for its potential to aid in genealogy-based endeavours like building a family tree. They were sometimes completed as part of a *“larger project”* (P2), sometimes as a hobby: *“so* *my [family member] did it for ancestry. [They're] very into that whole family tree thing. [They've] gone to those in-person places that have all the ancestry tree documents and stuff,"* (P3). For this reason, completing ancestry DNA tests could help directly in *"hobby-meeting"* (P10) and being something the user enjoys: *"Knowing how interested [family members] are in genealogy... I'd be like 'Yeah, that sounds like up your alley or something you'd really enjoy doing. So go ahead.',"* (P10). Although this would satisfy curiosity, some participants did not consider this to have a major positive effect: *"the only benefit would be niche... other than that, I don't think there was huge benefits to it"* (P4).

(iv) Benefits to family members

Those with limited knowledge of their family tree found benefit in their immediate family members' DNA tests: *"[we have] a lot of half-sisters and half-brothers... it's a bit more information about who and what we are," (P1).* P2 thought that *"just knowing the background for my [user's] side,"* was a benefit despite privacy concerns.

Others saw little to no benefit to themselves. P1 was generally dismayed about the partial loss of privacy resulting from their family member's DNA test but used the opportunity to review their own privacy habits: *"it just made me a little more conscious of trying to lock up some of my data and keep things as safe as I can" (P1).* P3 did not feel their extended family member's health-related DNA test was beneficial to them because *"they're pretty distant to me in that genetic line" (P3).* P7 also considered their family member's ancestry DNA test irrelevant: *"What my ancestry was doesn't affect my day in and day out... I don't really see that there are any [benefits to me],"* (P7).

4.3.5 Perceived risks

Participants identified several privacy risks to both the user and their family (including the participant themselves).

(i) Disseminating information without consent (risk to family) With an at-home DNA test, the user may discover information affecting other family members.

For example, the ethnicity estimate of ancestry testing may differ from a consumer's verbal family history. If shared nonchalantly with other affected family members (for example, a sibling or parent), this could directly violate their personal consent to receive such information. P9's grandmother knew the family to be part-Italian on their grandfather's side (who had died when his children were very young). P9 recalls how *"growing up, my [parent] was always making Italian dishes"* and seemed connected to that part of their identity. After taking an at-home DNA test, their parent's sibling received an ancestry result indicating that they were only 2% Italian. The conversation surrounding it was generally lighthearted, but P9 was unsure how their parent perceived it: *"I think my [parent] might have been more disappointed... because it's [their] birth father too. I personally didn't think it was a bad way to share the info, but [user] may have wanted to ask them first,"* (P9).

(ii) Revealing family secrets (risk to family) A concern mentioned by most participants was of the user, and their family, finding out something unexpected *"in the timeline of genealogy"* (P5), especially something that could *"insinuate maybe an affair"* (P5) or *"stem some existential crisis"* (P10). While such secrets did not affect the user's privacy personally, they could be violating the confidentiality of other family members. To many of our participants, this possibility was the only tangible risk of completing an at-home DNA test: *"(the at-home DNA test) doesn't affect anyone, because... we didn't have any extra siblings we didn't know about, or extra uncles, or anything like that,"* (P4). In all cases, the users' ancestry test results did not cause any *"messy family drama"* (P9), with no added *"mental strain"* (P5) to their biological family members.

Although viewed as unlikely by participants, it was still advised for potential users to be *"open-minded"* (P9) because they may find out that *"you know, you have [extra] siblings, or that you were adopted"* (P4), and so it's important for a potential user to *"make sure it's something you want to do"* (P5). Additionally, given that this knowledge might affect family members, a few participants suggested to *"ask for permission"* (P9) before sharing the results with them.

(iii) Discrimination, bias (risk to user, family) Another privacy concern voiced by participants was the potential for sensitive DNA data to be misused to discriminate against individuals with certain traits. Consumer data could possibly be shared with third-parties without the users' informed consent. Participants perceived access to this sensitive information could potentially reduce academic and employment opportunities, be used to charge more for services (or cut them altogether), or could result in racial profiling.

Employment opportunities: *"Sometimes there is a certain bias towards certain genealogy backgrounds that could impact how things go based on their experiences"*, P5 explains, *"I just feel like, depending on the boss you have, sometimes it could impact your employment"*. Participants also noted a risk with health-related data; an employer may not want to hire an individual because *"they don't want to take on that burden of having to cover medical costs"* (P2). This may also affect biological family members of a user: *"Let's say for my children, if they're looking to get employed with Company X... and the DNA pops up that "oh, the [family member] had 85% positive for cancer. This person is not a good fit, because they could become ill consistently over time, and cost the company money"*. There's nothing that person can do," (P1).

Insurance companies: Many participants were concerned that life, health, and even auto insurance companies could use this data to increase insurance rates or deny access. P2's concerns stem from their time living in the United States: *"Before, I was from the States. So I have kind of a fear that they would use it as a way to determine the rates,"* (P2). P5 also has as an insider's understanding of how such personal information can, and will, be used to determine insurance rates: *"When I did work for a bit as an insurance underwriter, insurance rates were based on a huge [number] of things, like the background that you have or the name you have from your background... that would impact your insurance rates. So I have seen it become a negative thing,"* (P5). A disease that affects your ability to drive may also be used while calculating auto insurance rates: *"I have [disease]. I lose my vision, my feeling, and my strength in my body... I'm assuming that can be found in my genetics. I would only assume my insurance would go up because I'm at a higher risk of getting in an accident because I can't control [disease],"* (P4). Effects on insurance rates were commonly recognised to ripple throughout biological family, and family members run the risk of being *"categorised with [the users]"* (P2): *"we're obviously [immediate family members], or more than likely going to have the same kind of results. So they could adjust premiums based on the results, so that could impact me for sure,"* (P5).

Government immigration: Government access to DNA results were perceived by some to affect the status of immigrants to the country under some circumstances. These risks were perceived to affect both the user and their biological family members.

The political inclinations of the party in power could be cause for concern: *"There's definitely very right-wing politics that feel a certain way about what Canada should and shouldn't be and where immigration stands. There are definitely people out there who are purists,"* (P10). In a similar vein, P9 discusses how DNA data could potentially be used against those who aren't legal citizens, citing the USA as an example: *"It's a bigger problem in the States, with people getting deported. I know it happens here too, I'm sure. And it's not right, especially for children of immigrants who were born here... their DNA should not affect their status as citizens,"* (P10). P2 recalls their own immigration process, and expresses concerns around medical inadmissibility: *"If your parent has a condition that might make them inadmissible due to medical concerns, but you didn't inherit it... I feel like based off just the data that your parent has, that would be enough for them to consider making a decision,"* (P2). Other participants felt much more secure in their status as legal citizens: *"I'm already a citizen. So, like, what are you going to do?"* (P4).

Law enforcement: Most participants were wary of DNA-related data being shared with, and accessed by, law enforcement. Participants saw potential for misuse, even if uncertain of specifics, and believed withholding that information would protect the overall well-being of users. Part of participants' unease stems from being unsure *"why (law enforcement) would need (DNA data), unless it's for an investigation... it doesn't seem like something they would need"* (P5). Law enforcement having access to databases of DNA data seemed *"unethical"* (P5) to many of our participants.

P6 believes at-home DNA testing companies *"corroborate with law-enforcement"* for *"monetary incentives"*. They likened keeping your DNA private to staying silent when questioned by law-enforcement, implying that once you provide your DNA to a testing company, there's no going back: *"With the police, anything that you say can and will be used against you, but not for you. It's like when you read your Miranda rights, you have the right to remain silent, and that is for a reason. You can always choose to remain silent,"* (P6). P9 also touched on *"systemic racism in a lot of government areas and (the police)"*, although they were somewhat uncertain of the specifics due to their perception of racism being *"visual. Not necessarily someone's DNA, you know?"* (P9).

Some participants felt they were not personally at risk of harm from law-enforcement, but others felt that *"it wouldn't end well for some reason,"* (P5). There also exists the potential for *"false positives"* (P2): *"You could end up in trouble, even though you didn't do anything,"* (P1). This could be further amplified if multiple family members had completed an at-home DNA test, making it a more *"profound issue, [that] causes more implications"* (P1); each DNA test by a family member contributes to revealing more about the non-user since each user shares different DNA and cumulatively these could provide a more complete profile of the non-user.

(iv) General privacy concerns (risk to user, family) Participants were generally concerned about the limited informed consent process, and about the storage, sharing, and misuse of DNA data.

Data free-for-all: With the *"nebulous"* (P1) terms and conditions associated with at-home DNA testing, it is unclear *"where that information is, and who's got access to it"* (P1). Individuals are encouraged to *"read the fine print"* (P3), or *"maybe do some additional research if you're very adamant about it"* (P10). P2 thought that given the digital state of *"current society"* (P2), DNA could be *"the only information we have that big companies don't yet know"* (P2). Even if not currently impacting anyone, the data is *"just free-floating out there"* (P1), and could *"easily (be) tracked back"* (P1) to the participants, even if they themselves are not users.

Permanency of digital data: Once a DNA test is completed and analysed, the resulting DNA data is subsequently *"out there"* (P1). It becomes exceedingly difficult to keep track of and control: *"It's personal information, just like any other personal information, and you don't know what people are going to do with it. And once it's out, it's out. It's no longer just yours. So, yeah... be careful with it,"* (P5).

Large-scale data analysis: The potential for large-scale data analysis also worried participants because *"there's some people that do some weird stuff with your data"* (P1). P6 foresees this data being used by governments or law enforcement to track certain traits or create profiles on individuals *"the same way that Facebook does"* (P6): *"Life expectancy, your probability of committing crimes, buying certain things... just the probability that you do the things that anyone does,"* (P6). P2 expressed the following privacy concerns: *"The community starts to become jaded about the privacy aspects, kind of like we have about advertisements. Now there's just this giant pull of data... the more people doing it, the better the accuracy of the company's [DNA] test. But I feel like it just makes it worse for everyone overall,"* (P2). Interestingly, the sentiment involving cynicism towards privacy was noted by the researcher across interviews: some participants laughed about how they are now *"probably going to see some Facebook ads (for DNA testing), but I guess that's just the way it goes"* (P5).

Future risks: Some participants perceived no immediate risk: *"Unless we sort of project an increasingly dystopian future where DNA data is used to affect the way I live somehow... I don't really think there's a risk. Not at present,"* (P7). Others thought the current terms and conditions of such services could also leave you at risk of future privacy violations: *"Nobody reads those documents at all. It leaves you quite vulnerable to things that may or may not even have been developed yet,"* (P1).

(v) Health-related distress The discomfort, fear, and anxiety associated with learning something negative about your health is also a risk associated with health-related at-home DNA testing. Some participants perceived negative impacts even if done by choice: *"Because there's a chance you're not going to ever develop that [disease], but knowing that might weigh on you"* (P9). P1 discusses how their immediate family member received *"scary, but not accurate"* health-related results: *"It turns out the (DNA test-results) were wrong. There was no sign of any of the diseases that they had said... and that's one of the things that I find difficult with the way that a lot of these testing procedures are done, because it's often not described really well for the people getting it. I would imagine you would get a multitude of different sort of (reactions) from "Oh, yeah, that's not bad" to "I'm planning the end of my life now". I don't know if that's helpful to people,"* (P1).

4.3.6 Biological family members' role in decision making

Participants also discussed the degree to which family members should be involved in the decision to take an at-home DNA test. The factors involved in this include (1) emotional closeness, (2) biological closeness, and (3) participants' understanding of how users' results would impact the other. Ultimately, however, all participants believe that the final decision belongs to the individual wanting to take a DNA test. Overall, while participants acknowledged that *"everyone can kind of do what they want"* (P2), the importance of *"(doing) your own research* (P2), *"never sharing your data with anyone"* (P6), and *"discerning quality information (from) disinformation"* (P1) while conducting research online, were highlighted during our interviews.

(i) The right to discuss Some participants believed *"family members definitely have the right to be concerned if they have any distrust"* (P2). They may not necessarily be making the decision, but *"maybe they should have some say, right?"* (P3). Most commonly, participants mentioned the potential users' parents, siblings, partners, and children when discussing who should be involved. These entities were deemed to be important to the individuals' lives, and could also be affected by an at-home DNA test's results: *"these are the people closest to you. I feel like they should, you know, get to say their piece,"* (P3).

Participants who perceived a loss of their personal privacy from users' DNA tests also echoed this sentiment: *"it would have been a conversation if [user] had called me beforehand,"* (P2). While ultimately believing they could not interfere in the users' choices, both participants would have *"walked them through the pros and cons of it"* (P1), helping them *"weigh all (their) options"* (P2), so that *"at least they would have been informed"* (P1). P6 further advised to *"only do it if you're truly curious"*, while P2 stressed how *"maybe there's another way"* for individuals to conduct their familial and/or health research, considering DNA testing a last resort. Given the sensitivity of DNA, participants thought this was particularly important: *"When people are trying to figure out whether they should do a DNA test, it's akin to... I don't know, would I open up my banking information to just anybody?"* (P1).

(ii) The right (not) to know Due to the shared nature of DNA, the results may apply to family members (especially parents, siblings, or children): *"If there was something that you found out that was maybe shocking for your siblings, they'd want a say in that,"* (P9). These participants felt that family members had a right to opt out of hearing the results, but the choice to test remained with the individual: *"If they don't want to hear the results, then I just wouldn't share it. But it doesn't mean that I can't know,"* (P4).

(iii) Complete user agency Some participants perceive DNA to be highly personal and unique to them, something *"that can only be related to me"* (P4). Participants who shared this view did not think their personal DNA test would concern anyone else, and believed that *"others' concerns should not have any impact on my actions,"* (P6). P5, for example, does not perceive the DNA test to be *"asking for anything extreme"*: *"It doesn't seem overly invasive or anything that would impact anybody else,"* (P5). The only exception was if minor children were involved; participants believed that parents should decide whether a child takes a test.

4.3.7 Trust, Distrust

The way participants viewed the *"trust factor"* (P8) of various corporate entities played a role in how they perceived the privacy of at-home DNA testing. Notably, many participants looked unfavourably upon, and were distrustful of, for-profit entities. For at-home DNA testing companies, distrust was compounded by the illegibility of their user terms and conditions.

(i) For-profit DNA-testing companies: Participant attitudes towards at-home DNA testing overall were linked to how much they trusted the companies offering the service. Many participants acknowledged that data needs to be stored and used by the DNA testing company, sometimes begrudgingly: *"I know at the bare minimum they need some of (the data) to widen the pool, but it doesn't necessarily mean I like it,"* (P2).

Those who perceived the service more positively, or with indifference, agreed with the storage of data for some purposes. *"Maybe for their own way of ensuring accuracy... or for [demographics]..."* (P3). These participants generally trust that, even if *"someone's looked at (the data) on its way through"* (P9), the data would be fully anonymised, and so *"that wouldn't be a big deal"* (P9). These participants, even if unsure of how data travels beyond and within the DNA-testing company, seemed generally unconcerned about the implications. P3 only briefly touches upon the topic: *"I don't know why the company would need that data. I would feel like it would benefit the medical profession, doctors at large, a bit more,"* (P3).

Privacy conscious participants, however, *"don't trust them to have that data at all"* (P2). P1, for example, discussed how *"companies are bad at security"* overall: *"You keep seeing things on the news... like Company X has leaked five million people, their information. So yeah, it's quite possible that I could, you know, if I did a search on the dark web I could find [my family member's] DNA results,"* (P1). The *"flowery"* (P1) terms and conditions of such companies were also looked at with distrust, failing to convince P1 of the company's competence in handling data: *"how they describe what they do... (it's like) when I was in the university doing lab work and studying DNA. If I can do this, somebody making fifteen dollars an hour could do this. And is it being done well, being done securely? Probably not,"*(P1). Aside from selling data, privacy conscious participants were also concerned that the company could potentially *"develop a DNA database"* (P6) and provide access to various third parties.

(ii) For-profit pharmaceutical companies: while begrudgingly acknowledging that *"we need pharmaceuticals in a lot of settings"* (P9), participants were still generally distrustful of pharmaceutical companies, largely due to their for-profit nature. While *"it's somewhat important they have the data"* (P2), participants *"still just have a strong distrust of what they would do with the data, even if they're trying to do something good out of it"* (P2). Most participants did not have complete mental models of the risks, but all distrust focused on privacy: how the data is used, who has access to it, and how long it is used for. P1, for example, discusses the dynamic nature of private companies: *"a private platform could go bankrupt, and suddenly some company in the United States is buying your DNA results to use for profit"* (P1). It's unclear when the data get destroyed, if it does at all: *"I don't think there's any way they* *don't keep a copy of (your data) on that end unless the government says you have to destroy all the results and only the user can keep those results. But otherwise, I don't see a way where the private companies don't keep your data as well,"* (P8). Finally, it's unclear how altruistic pharmaceutical companies really are: *"they probably benefit from people having chronic issues or things where they need medication. So I think my fear there... is that they benefit their selves first, and their pockets and then they take care of the people,"* (sic) (P4). If provided access to genetic data, the resulting insights may cause them to *"spike their prices and make more profit"* (P4). P9 also notes how there's *"systemic racism" (P9)* in pharmaceutical companies. In summary: *"if you give them more data, they'll use it for their own gain, but not for your gain, probably,"* (P6).

(iii) Government The government was generally viewed as untrustworthy by participants; however, some viewed it to be an uncaring entity, while self-identified future consumers placed a large amount of trust in them. Based on this trust, they were accepting of having to surrender their privacy to them for the greater good: *"I do support any research initiative, even if it's by the government or by police. Like they're obviously not using it for any personal gain. It's obviously to advance whatever initiative they're taking on"*, (P3).

Those on the other end of the spectrum, however, considered them to be manipulative and, quite simply, bad with data. They either *"just don't have a good grasp on what's happening with that data"* (P1) or they have *"just enough of a grasp"* (P1) to be able to use the data for their own gain, *"not really looking out for the population"* (P1). Likely, this data would be used to *"disqualify"* (P2) users from receiving healthcare or retirement benefits.

Additionally, future consumers, and some other participants, trust that federal and provincial standards exist to help regulate at-home DNA testing services both for accuracy, and privacy. For example, participants likened health-related DNA tests to medical devices, and *"we take the security of medical information very seriously here in North America"* (P7). However, privacy conscious participants are frustrated with the limited regulation on data privacy: *"There's no regulations out there for me to say "You can't use (my data) for that", because they'll just say "Yes, we can", and* *that's the argument. If I go to my Privacy Commissioner, they'll just go "Well, we don't have any regulations", you know, and then it's like, do I need to run for office?"* (P1).

(iv) Academic institutions Universities and similar bodies were viewed the most favourably by participants due to their *"pure science"* (P1) nature. Given that they come from a *"less money motivated position"* (P2) than for-profit institutions (like pharmaceutical companies), academic institutions are perceived as wanting *"data for data's sake"* (P7). Academic institutions were perceived to have more altruistic purpose, like for finding *"solutions to diseases"* (P8), medical *"treatments and prevention"* (P9), or simply *"benefit academia"* (P7) as a whole. Participants' personal experiences with academic research, either taking part in studies or *"being in a university setting"* (P9) themselves, has shaped the idea that such institutions have stronger set of controls, *"caveats"* (P1), that they must adhere to when conducting studies. These controls include transparency, honesty, and an overall *"better chance of the data being destroyed at a certain point,"* (P1). In addition, they have a reputation of ‘‘*(keeping) their information really private"* (P5), and *"probably wouldn't have any identifying info"* (P9). In short, academic institutions *"keep the data in a sort of different way than other entities do"* (P7), with less of a *"power imbalance"* (P7).

4.3.8 Factors influencing perceived accuracy

Participants mentioned several factors contributing to their perceptions of accuracy/inaccuracy of DNA test results. Perceived accuracy is linked to their motivations to complete one. Where relevant, participants mentioned how their background has affected their perceptions. In some cases, perceptions differed between ancestry and health-related DNA testing services.

(i) Database size (Ancestry) A few participants identified that the accuracy of an ancestry DNA test *"depends on the size of the data pool"* (P10). While *"initially inaccurate" (P2)*, over time, they *"get more accurate as they get more data from different people"* (P2). Participants with this knowledge had come across it during self-conducted research. P10, for example, had been *"reading the pros and cons"* of multiple DNA testing companies to help choose one for themselves. In addition to a DNA database, the availability of genealogical records was also considered a factor for some: *"if it's somebody in North America... they can dig down [in the] records, but if it's somebody from Europe or somewhere else, it would be a lot tougher, I think,"* (P8).

(ii) Anecdotal evidence (Ancestry) Some participants with limited knowledge of the inner workings of ancestry DNA testing relied on others' experiences to help shape their perceptions. P5, for example, knows approximately 5 people who have completed such a test, all of whom had good experiences: *"They all seem to say that it was fairly accurate. So like nine times out of ten, I'd say it seems to be pretty bang on,"* (P5). P10, while aware of the role of database size in determining ethnicity compositions, also referenced their family members' DNA tests when discussing accuracy: *"from the results that I've heard about individuals tracking family links in genealogy... it seems accurate in some way"* (P10).

One participant, however, expressed extreme distrust for ancestry DNA test (*"I would guess about 20% of the information is going to be accurate"* (P1)). P1's view was based on what they've *"read"*, citing *"questionable results for a number of companies"*: *"I think it might have been Vice, but someone basically sent DNA to four different places. It got four different genetic results. They were sort of similar, but not identical,"* (P1).

(iii) Precision (Health) Many participants did not consider health-related at-home DNA testing services to be as precise or specific as medical tests conducted through a doctor. Some participants considered health-related tests to be "a starting point" (P1) though not wholly reliable. They would much rather have testing done "in a professional setting" (P7), and would possibly be more confident if these tests were publicly endorsed by licensed medical bodies: *"(If) promoted by the College of Physicians or something like that, I would say that [the test's accuracy] is more closer to 90% – 100%,"* (P8).Other participants leaned further towards inaccuracy when describing their concerns: *"I'd say [they're] probably pretty inaccurate, currently. I just feel like private companies wouldn't have access to the same information that health companies have"* (P2).

(iv) Scientific knowledge (Health) One participant's opinions were shaped by their knowledge of how genes express themselves in humans: *"I think [health tests are] less accurate than sort of lineage, just because there's a lot of gene environment interactions when it comes to health. So yes, you might have the gene for something, but I don't think that is a prediction. 50%, maybe,"* (P9).

(v) Regulations (Ancestry, Health) One participant, P3, considered ancestry tests accurate, given that *"they're used all over the world"*. Similarly, P3, considered the health-related tests to be *"medical device(s) at large"*, and was *"sure they're regulated federally or provincially, just to set standards and ensure accuracy,"* (P3).

(vi) Trust (Ancestry, Health) Other participants placed their trust in the integrity of at-home DNA testing companies themselves or the science involved. P8, for example, believes that *"they would use some sort of scientists or scientific tools"* (P8). Similarly, P9 also assumes, and hopes, that *"the people in the labs who are doing these... that they have degrees in this area,"* (P9). P4 placed their trust entirely in the testing company itself, as opposed to the related science: *" I believe that the company would fulfill their due diligence and do what they've promised to do"*.

(vii) Scientific knowledge (Ancestry, Health) One participant in particular, P6, believed both ancestry and health DNA tests to be accurate based on their specific knowledge of how the process works. P6 *"used to work in a genomics lab"*, and believed certain diseases to have *"fairly well-known genomic markers"*, hence making the tests accurate. P6's mental model of ancestry DNA testing involved the use of phenotypes to determine ethnicity. Given this, they believe ancestry DNA testing to be *"fairly accurate"*: *"Those genomic markers should be quite prevalent... for certain phenotypes, like for certain hair colours, skin tones/colours,"* (P6).

4.4 Discussion

In our study, little importance seemed to have been placed on such DNA tests by users; in most cases, the news of a DNA test, and consequently the results, were shared informally with family members. Users were *“fairly nonchalant about it, not... understanding the whole issue of DNA and security and data usage and privacy”* (P1). In all cases, participants were not consulted for consent prior to the revealing and discussing the users’ test results.

Ultimately, while all our participants considered DNA to be personal to an individual, there were varying degrees of sensitivity present. For example, while privacy conscious participants considered DNA to be as sensitive as *“banking information”* (P1), those who were indifferent or unconcerned about privacy didn’t consider it to be *“anything extreme”* (P5).

4.4.1 Attitudes towards privacy

Three levels of conscientiousness towards privacy were apparent in our interviews.

Privacy conscious Those who were privacy conscious identified several privacy risks for at-home DNA testing. Notably, risks revolve around the loss of their own personal privacy as a family member – the fact that things could be traced back to them (even erroneously), and that once data is out there, it’s out there. They felt a loss of autonomy: their data has been given away without their consent. These participants had greater knowledge of the privacy risks involved, and a greater distrust overall of the process.

Due to this, privacy conscious participants perceive significant privacy risk to themselves, despite not having completed an at-home DNA test. The benefits, in comparison, were minuscule. Privacy conscious participants expressed the desire to be involved in the discussion for whether a family member should take an at-home DNA test. While not responsible for the final decision, they would like the chance to properly inform the potential user, and help them find alternate solutions or problem solve if possible. Additionally, at the government level, they would like regulations that make it very clear where the data goes, and that provide total control and protection to the user, and protections for relatives of the users as well. All privacy conscious participants expressed needs that were privacy protective to themselves as family members, as well as the users of at-home DNA testing services.

Privacy indifferent Those who who did not give privacy much thought, but weren't planning on taking actions to negatively affect their genetic privacy, had limited privacy concerns. Participants in this category perceived no risk to slight risks. The main privacy risk highlighted was family members finding out information without their consent, or the unveiling of unpleasant, previously hidden information. Some participants mentioned being slightly wary and uncertain about the terms and condition surrounding at-home DNA testing. Participants in this category recognized benefits to family members, but they did not transfer risks the same way. Due to the lower severity of privacy risks perceived, participants either believed that (i) the opinions of immediate family members should be heard prior to a DNA test but ultimately the decision to test is personal, or that (ii) family members only need to be consulted before *sharing* results.

Privacy unconcerned Those who self-identified as future consumers perceived great benefits and virtually no privacy risks to themselves from the users' DNA tests. These participants perceived the only privacy risk to be hypothetical unwanted information but did not consider this to be a risk in their own family. Participants' strong curiosity of their ethnic or ancestry background, along with no perception of risk, made them more dismissive of family members' concerns. They had a limited understanding of what concerns might exist, and did not think anyone else should have be involved in the decision to take an at-home DNA test. As such, they exhibited no privacy protective behaviours or attitudes.

4.4.2 Privacy mental models

A large number of our participants had incomplete, and sometimes contradictory, mental models of the risks associated with at-home DNA testing. During interviews, a commonly asked question was *"Why?"* Why would any third parties need their data? What would they do with it? They could not perceive any reasons for which a third party (like law enforcement) would need their DNA, especially if they were a law-abiding citizen. They were also unsure how this data could be accessed by, or sold to, third parties without their consent.

A few participants also displayed contradictions in their mental models. For example, although identifying several shared benefits with the user, P3 was unsure of how they might be at risk themselves: *" I'm a little confused because wouldn't they need like a sample from [me]... I don't know exactly how they could identify myself... unless they were to get a sample from me,"* (P3). These contradictions were also seen in privacy conscious participants. For example, P6 believed the results of an at-home DNA test would affect different generations of the user's family equally. However, they did not think their extended family member's DNA test affected them because *"they share what, like... at most, an eighth of chromosomes with me?"* (P6).

4.4.3 Effects on others

Overall, participants perceived the most impact to the users' immediate children (both current and future). This may be due to the perceived nature of health-related DNA testing in helping users make decisions regarding conceiving children, or being prepared in case future children are at-risk. Next, participants' other immediate family members (and partners) were believed to be directly affected by users' at-home DNA tests. This is not only due to biological reasons, but also due to a culture of trust associated with immediate family. Extended family members were perceived as the least affected amongst biological family members. Depending on their position in the family tree, this was either due to the reduced biological overlap with the user, or simply the age of family members involved. Those seen to be quite young or elderly were perceived to have no interest in the topic.

4.4.4 Limitations

We recruited through Prolific and participants who were interested in the topic signed up for our interviews so there may be some degree of self-selection bias. In addition, our pre-screening survey may have primed participants to respond in a manner that is geared towards privacy. Finally, given the limited number of participants, generalising these findings to the general community should be done with caution.

Chapter 5

Discussion and Conclusion

Our research addresses a prominent gap in the at-home DNA research regarding privacy perceptions, preferences, and attitudes towards users' biological family members. Additionally, we identify (on a larger scale) differences between how users and non-users perceive at-home DNA testing, and how ancestry data is perceived in comparison to health data. To augment our quantitative research, our qualitative study provided more insight into how non-users (family members) made some of these decisions, and the factors influencing their perceptions.

Our survey indicates contrasting privacy attitudes between users and non-users, with non-users being (1) more distrustful, (2) more likely to believe that data is being shared with, and used by, various external parties, (3) less comfortable with sharing their data with external parties, and (4) more likely to believe the plausibility, or likelihood, of negative scenarios involving at-home DNA testing services. Our interview expands on the aspects of the survey related to familial privacy. We find three main attitudes towards privacy: (1) concerned, (2) indifferent, and (3) unconcerned. The degree to which participants believed family members should be involved in the decision to take a DNA test hinged on their understanding of risks to them as family members. We discuss how our interviews link to our survey (where appropriate), the unique findings of our interviews regarding familial privacy, potential implications of at-home DNA testing for the consumer and their family members, as well as recommendations going forwards.

5.1 Attitudes towards familial privacy

5.1.1 Limited perceptions of risks

Interviews Participants who identified benefits and risks to the user often extended these benefits to themselves and the user's immediate family members. This, however, was mediated by their understanding of how much DNA is shared between them and the user; for example, those who perceived less DNA overlap did not perceive much effect on themselves. Additionally, the more supportive a participant was of at-home DNA testing, the fewer the risks they perceived. These participants perceived more control over genetic data, either through trust in the testing company or through government regulations. This emphasis on benefits and minimal perception of risk was extended to family members.

Survey The survey results align with those of the interviews; compared to non-users, significantly more users perceived benefits to a variety of entities, even beyond their immediate families (like colleagues, and friends). Significantly more users believed the government to not be involved in the management of DNA data, and were less concerned than non-users about a variety of risks (including their comfort with sharing their data with external entities). This may be due to the increased perception of control: more users believed they were able to delete their data.

Existing literature Our study results fit in well with the existing literature; several studies have shown that users perceive benefits much more strongly than non-users, and perceived more control over their data [53, 117]. Many had incomplete mental models of privacy and risk [53], or had not considered risks in their decision [114]. Non-users, conversely, had concerns about control, and perceived several more privacy risks [53,60], even though some considered the process fun [60]. Additionally, concerns over protecting family members' privacy in the case of a criminal investigation or previously hidden information were also expressed [60].

Our study results are largely in line with this existing research. Many of our interviewees' main concern was uncovering unpleasant information involving their family through the users' DNA tests, while non-users in our survey expressed significantly more privacy conscious attitudes towards genetic testing. In contrast, users perceived more benefits, to both themselves and others in their lives (through their own genetic test).

5.1.2 Dual view of DNA

Interviews Some participants identified DNA to be extremely personal to the user, and, as such, reserved the right to unilaterally take a DNA test. They voiced this right despite also identifying the connection to biological family members in the context of certain benefits and risks. Conversely, privacy conscious participants took this aspect of DNA negatively: because it was so personal and identifying, it deserved to remain private, or – at the very least – the prospect of taking a test should be discussed with those who share the DNA. With such polarised attitudes towards the personal, unique nature of DNA, the handling of this data is consequently also equally polarising as a result.

Survey These views are alluded to in our survey results as well: non-users were significantly more likely to believe that their provided DNA sample could identify them, that DNA data is not like other data, and is their information alone.

Existing literature Research examining how participants' understanding of the nature of DNA affects their privacy attitudes is limited. We add to the literature by bringing attention to it, given its apparent important implications in shaping participants' attitudes towards privacy.

5.1.3 Shared consent

Interviews Ultimately, most participants believed that there should be minimal involvement of biological family members in the decision to take an at-home DNA test. This was because many did not perceive risks to family members beyond accidentally finding out unpleasant information. As such, many indicated involvement be limited to consenting to *receive* such information after the fact. Choosing DNA testing was considered to be the decision of the individual, and the individual alone, for many of our participants. Those who viewed their data as tied to the users' data, however, felt otherwise. Given that they perceived a personal loss of privacy, they preferred having the opportunity to discuss their concerns, and possibly change the users' mind.

Existing literature To the best of our knowledge, our interviews are the first study to examine the attitudes of users' biological family members towards their privacy, in context of the completed DNA test.

5.1.4 Implications

When a user completes an at-home DNA test, they are not only providing a complete DNA sample of their own, but also partially the DNA of biological family members. All risks to users could also extend to their family members as well. Trends in our data indicate that significantly more users underestimated the implications of providing their DNA data to at-home DNA testing companies. In addition, many did not perceive the implications to biological family members.

This presents serious concerns for privacy. Users end up being the main decision makers when it comes to exposing their family members' DNA data. An individual deciding to complete an at-home DNA test has complete control over when they inform their family members, if they do at all. Given this, family members may go months or years without knowing that parts of their DNA have been provided to at-home DNA testing companies. One of our interviewees, for example, was informed of the user's DNA test two years after they had taken such a test. There is also a chance that they may never know, unless unexpectedly faced with consequences as a result. For example, in a major deportation case, two distant relatives of the individual being deported were contacted by the Canadian Border Services Agency (CBSA) using links made through at-home DNA testing [29]. This was confirmed to have happened multiple times in the past, with different individuals [29].

Once an at-home DNA test is completed, the users' family members no longer hold autonomy over that portion of their data. They cannot control where it goes, who has access to it, or for what it is used. This data is at the whim of privacy policies, and becomes very difficult to track.

These implications are, unfortunately, in direct contradiction to what many in our interviews perceived to be their individual right to their DNA. Several interviewees believed involvement of family members should be minimal, and that the choice to take a DNA test belonged to the user alone. Given these attitudes, it could even be considered invasive for family members to enquire what users consented their data be used for (even though this data could potentially identify the family member). Complicating matters further, even privacy conscious individuals may feel like they must give up their data in exchange for what they perceived to be invaluable information [21]. For example, P2 discusses how the user, despite being generally distrustful of at-home DNA testing companies, completed a test due to large gaps in their family history. It is unclear how these conflicting attitudes/notions, and, in some cases, the necessity of such tests, can be reconciled with the severe privacy implications to biological family members.

5.2 Misconceptions

Also hinted at by our survey results (especially in the two user groups: UA and UH), our interviews revealed incomplete, and sometimes contradictory, perceptions of risk amongst many participants. In the following paragraphs, we highlight participant misconceptions of risk, discuss the actual degree of said risk, and explain any resulting implications. An in-depth discussion of the risks associated with at-home DNA testing is presented in Chapter 2. This includes privacy risks (Section 2.5), and the risks from current laws and regulations surrounding at-home DNA testing (Section 2.9).

Re-identification In our survey, users were significantly less likely to believe that it was possible to be traced back through their DNA sample. However, not only can DNA be used to trace the individuals themselves [65, 74, 120], but it can also be used to identify their relatives (even those who have not taken a DNA test) [36, 120]. This has serious implications for privacy: relatives have lost enough of their own data that they can be traced, possibly without having any say. As of 2018, more than half of individuals with Northern European heritage in the United States can be identified using user uploaded DNA [120].

Data misuse As part of our survey, we aimed to understand the degree to which participants perceived the plausibility and likelihood of their data being misused in various circumstances. To this end, we investigated these perceptions using scenarios based on either real life events, concerns, or benefits of genetic testing. While most participants considered all scenarios plausible, significant differences were found between users' and non-users' perceptions.

Non-users were significantly more likely to believe a variety of negative scenarios to be plausible, and likely to happen in Canada and in general. This presents several concerns: while several negative scenarios were considered comparatively unlikely by users, some of them have already happened [23,29,137], or have had their implementation discussed [105]. Such instances have been presented in the media over the years. In one case, discrimination based on health-related data occurred [137] on the basis of markers for a disease that had not manifested in the user. In this incident, the DNA information was also shared with unauthorised individuals by the organisation who had received the information in confidence. This demonstrates that health-related DNA data, even with its perceived sensitivity, may not always be treated with the expected confidentiality.

It is also plausible that such information may inadvertently be revealed to unintended parties. Several entities, for example, use social media to conduct research on individuals, whether it's web-scraping to investigate suspects in criminal investigations, or Facebook searches by hiring managers to research a potential future employee [122, 129]. Having this information public may publicise it beyond the user's intended network, and could present further negative consequences (for example, negatively affecting their job prospects [6, 124]).

As mentioned, DNA testing kits have also been used in Canada to aid in deportation cases, without informed consent from the individuals involved [137]. Despite its inaccuracy, the results of such testing were used as the basis of a legal argument involving other relatives of the user's family, who had not consented to their involvement [137]. The DNA testing service used was Family Tree DNA [*], a for-profit at-home DNA testing company based in the United States.

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[*] `https://www.familytreedna.com/`

5.3 Unclear policies

Given the dynamic, and often confusing, nature of privacy policies [104], there are several risks to participants on this front. We describe these risks below.

Permanence of data Although individuals may perceive control of their data, the intricate details of such policies may indicate otherwise. In our survey, significantly more users than non-users demonstrated the belief that DNA data would be deleted along with a deleted account. A technical issue at GEDmatch, however, revealed that this is not always the case [88]. Due to an error while merging information into their main database, deleted information temporarily reappeared in the respective users' accounts [88], suggesting it had remained stored somewhere on their system. While the parent company claims the data was permanently deleted after the merge [88], the incident reveals that data might not be deleted as quickly as some might believe.

Unauthorised access Even through regular business operations, a user's data may eventually end up somewhere to which they did not initially consent. Should a DNA testing company ever be sold, all the DNA data acquired by the original company will likely also transfer over [109]. Additionally, DNA data may be subject to access by third parties through court orders (even without the users' consent) [62].

Companies may also, at any given moment, enact changes to their privacy policy affecting who has access to users' data – a risk identified by only one of our interviewees. For example, prior to January 2021, users of the at-home DNA testing company GEDmatch were required to opt-in to share their DNA for use by law enforcement [46]. However, after a change in the company's terms of service, all users' DNA is implicitly shared with law enforcement for the purpose of identifying remains [47, 88]. The option to opt-in currently only applies to the use of such data for solving violent crimes [47, 48, 88]. Although advance notice was provided to consumers in this instance, privacy policies are generally difficult to understand, and largely unreadable [104]. Given this, it is plausible that many users did not understand the implications of the update, and, consequently, remain unaware of this change. In addition, prior to this change, more than two-thirds of GEDmatch users had opted-out of providing access to law enforcement (as of 2020) [136].

5.4 Recommendations

Based on the results of our research, we propose recommendations for privacy policy, user experiences, and technological solutions.

1. **Transparency, Control** Using clear, concise language, we recommend that users be provided the opportunity to choose for which services their data is used. This includes different classes of activities being conducted by the same entity. We also suggest users be provided the opportunity to delete all their data entirely. We urge transparency surrounding when, and the degree to which, DNA data can be deleted.

   Given participant uncertainty surrounding where DNA data goes, providing a diagram or list detailing, on a high-level (i) which entities have had access to the user's DNA in the past, (ii) which entities currently have access to the user's DNA, and (iii) the number of times the DNA has been accessed by each entity. Taking it one step further, we recommend adding the option for users to opt out of sharing their data with specific entities. Finally, adding tags to each entity that indicates the purposes for which the data may be used would help users make more informed choices. We recommend users be provided the ability to filter by category and change the permissions associated with their data, similar to how permissions are applied to applications in several mobile operating systems. While many DNA testing companies provide users with a higher-level option to decide whether they want their data being used for research or to aid law enforcement, adding this finer control would increase user autonomy over their data. In the implementation of such an interface, care must be taken to assure that these settings are, in fact, usable [79].

   In addition, being able to export this list into an easily readable document so that users can provide a copy to their family members to inform where their data has been, and where it is currently going.

2. **Informed consent** Potential users should be provided with the opportunity to consider implications of genetic testing to themselves and to others. Aside from

clearly communicating risks and limitations to accuracy prior to users taking a test, risks *specific* to biological family members should also be explicitly communicated. Specifically, the partial loss of family members' privacy should be expressed to potential users. Besides adding this information to the relevant sections of their websites, a just-in-time dialog box communicating this information to consumers before purchase would encourage them to reflect before confirming their choices. It may be argued that producers of such services may not want to decrease traffic to their product; hence we also suggest such information be easily accessible through reputable not-for-profit, governmental, or medical organizations. Similar to resources available to check for password compromises (e.g., the *haveibeenpwned* website), a resource providing a compilation of incidences of genetic data misuse in one place would also help provide participants a better understanding of the potential consequences of genetic testing.

3. **Terms of Service** Participants were uncertain of the specifics surrounding DNA data: how its stored and for how long, who has access to it, and what happens to it once accessed by other entities. Describing the flow of the data and avoiding vague language would help participants make more informed decisions relating to their data. Additionally, providing information on the security measures taken to protect this data, and privacy enhancing technology use, would increase transparency on the company's end.

4. **Privacy Enhancing Technologies**

   Researchers have suggested infrastructure that could utilise genetic data specifically for research without the involvement of other third parties [57, 68, 125], in an attempt to maintain inclusion, privacy, and autonomy. Hippocratic databases are a potential privacy enhancing technology (PET) that hide both the identity, and attributes, of users in the database [54]. By taking responsibility for stored information, they ensure that the data being contained is only used for purposes authorised by the owner of the data, accessed only by authorised individuals, and is only kept for as long as needed [54]. Another

PET credited with retaining user privacy in statistical databases is differential privacy; through hiding the individuals' attributes in the database, privacy is retained. This is done by adding noise to every database query, obfuscating the returned answer so that any modifications made are hidden. An implementation of differential privacy for use of genetic matching has previously been explored [134], however there is still room for further research into possible implementations for genetic privacy. Research and implementation of such PETs for the handling and storage of genetic information could allow individuals and their family members to retain their privacy, while simultaneously being given the choice to have their information used for purposes of their choice.

5. **Intermediary bodies** We suggest the application of an intermediary body between users and testing companies to anonymise, and manage, the DNA data provided by users. Such an entity would ensure the removal of personal identifiers from the data, and be subject to privacy regulation similar to those of academic institutions. Most Canadian provinces and territories impose privacy regulations on personal information collected by universities, schools, hospitals, and municipalities [96, 97]. This includes limited storage of the data, unless consented to otherwise.

   Participants have expressed their preference in providing academic institutions their data due to their privacy-protective policies. In addition, some have expressed the desire for an intermediary body: while there were mentions of government bodies that already deal with large quantities of confidential information (like Statistics Canada [†], Health Canada [‡]), others expressed their preference in completing such a test through their medical provider. Existing research [91] also suggests that individuals prefer sharing their data through a physician's office as an intermediary, as opposed to through other overarching entities (either governmental, or commercial).

[†] `https://www.statcan.gc.ca/en/start`

[‡] `https://www.canada.ca/en/health-canada.html`

6. **Legislation** Several of our privacy conscious participants expressed the desire for legislation protecting them, as biological relatives of the user, given that a "partial profile" (P1) of their DNA exists without their consent. In addition, many participants expressed the belief that health-related DNA tests were akin to medical devices. As such, they (incorrectly) expect DNA data to be treated with the same level of confidentiality that medical data receives in Canada under the *Personal Information Protection and Electronic Documents Act* (PIPEDA) [98].

5.5 Future Work

Our results indicate several areas for potential future research on genetic privacy.

User perceptions of familial privacy Given that users are potentially the sole decision makers when completing an at-home DNA test, understanding how they view the privacy of family members (if at all) in this context is a potential way forward. This includes the risks, benefits perceived to family members, and the degree to which family was, and should be, involved in the decision to take a genetic test. As such, the interviews may be repeated with individuals who are users to generate more insight.

Research instruments For genetic privacy research involving a comparison of different participant groups, the development of a research instrument that scores participants attitudes towards genetic privacy would be immensely helpful. For example, while this thesis uncovers three broad attitudes to familial privacy, completing a large-scale study to make comparisons between each group would be comparatively difficult. This is because it is near to impossible to determine which category a participant falls under without an interview; the development of a standardised instrument would help address this problem.

Factors shaping perceptions There is also limited research on how individuals develop their perceptions of at-home DNA testing. This is especially important in the case of familial privacy; many of our participants did not perceive any risks extending to them personally. As such, understanding where their perceptions of risk and benefit originate would provide insight into how the research community can address this divide.

Privacy protection of family members Finally, further research must be done to understand how relatives of consumers can be protected from the consequences of a user's at-home DNA test. This is especially important, since relatives may be equally affected, even though they themselves did not provide any of their personal data. Possible solutions may be regulatory, involving the addition of, or amendment, to policies addressing the privacy of genetic information. Technical solutions may also exist in the realm of privacy enhancing technologies.

5.6 Addressing our Research Questions

We review and answer the main research questions that have guided this research.

RQ1.1: Do privacy perceptions of at-home DNA testing differ based on whether it is for ancestry or health purposes?

Yes, they do. We conducted inferential statistics comparing the responses of ancestry users, and health users, in Study 1. We find that health-related DNA data was seen as more beneficial for purposes leading to the greater good, with significantly more health users thinking others should contribute their health data for a variety of purposes. While perceptive of possible benefits, this indicates a possibly limited understanding of the associated risks. of

Significantly more health users believed their data would be deleted should they decide to delete their account, compared to ancestry users, thus perceiving greater control of their data in this sense.

RQ1.2: Do users' and non-users' privacy perceptions of at-home DNA testing differ?

Yes, users and non-users perceptions differ across several dimensions. Non-users displayed more privacy-conscious attitudes and trends in their responses. They had more concerns, were more distrustful, and were less comfortable sharing their data with external parties, or having their data used for any third-party purposes. Significantly more non-users believed the government had control over a user's DNA data, and that several other entities also had access to this DNA data.

Significantly more users perceived their DNA tests to have largely positive effects on them, their families, friends, and colleagues. Due to an inflated sense of benefits, there seems to be little consideration of their family members' subsequent loss of privacy. Significantly more users also perceived positive effects in other aspects of their lives (like their government benefits), wherein there may be also be some degree of risk.

RQ2: What are biological relatives' privacy perceptions of how at-home DNA testing affects them?

Three broad attitudes towards privacy emerged in our interviews.

Privacy conscious participants perceived a loss of their own privacy with the user's at-home DNA test, felt resigned to this loss, and were concerned about potential risks. They would have preferred the opportunity to discuss the at-home DNA test with the user before the test was taken. Said discussion would involve the risks associated with at-home genetic testing, and possibly consideration of other options.

Those indifferent to privacy generally did not perceive any privacy loss to themselves, and largely did not consider themselves to be affected by the user's at-home DNA test. Some thought that family members should be shielded from personal information that they had not sought out. At minimum, participants thought that consent should be requested of and given by family members before the user reveals potentially upsetting information to them. This was the main risk perceived by participants in this category.

> Those who were unconcerned about privacy associated only benefits to themselves from the user's at-home DNA test. These participants intended on completing a test of their own at some point. They thought that the decision to take a test was personal and did not believe anyone else's opinion should be taken into consideration prior to completing an at-home DNA test.

5.7 Conclusion

Despite privacy concerns by individuals, the value of the at-home DNA testing market is expected to reach a record high within the next decade. While benefits are perceived by many, there continue to be many privacy risks associated with such services. We explored whether users and non-users perceive the privacy of such services differently through a survey with 310 participants. We gathered participants' perceptions of the benefits and risks of genetic testing, their understanding of data access and permanence, and the effects such tests have on their biological family members. We further compare whether these perceptions differ across ancestry and health data. We found users to be significantly less concerned about privacy than non-users, perceiving significantly more positive effects to themselves and others. In contrast, non-users displayed several privacy concerns, and were less comfortable sharing their data. In addition, health data was implied to be more valuable to the greater good, and potentially more sensitive.

To further expand on concerns regarding familial privacy, we conducted interviews with 10 biological relatives of users, who had not completed at-home DNA testing themselves. We found many to be unconcerned or indifferent to their privacy due to incomplete mental models of risk. As such, they believed the degree of involvement of family members in the decision to take such a test should be minimal. Participants concerned about privacy, however, were more conscious of their loss of personal data, and felt frustrated over the associated lack of control. Based on our research, we discuss common participant misconceptions surrounding privacy and risk, the implications of at-home DNA testing for biological family members, and provide recommendations to help improve the privacy of users and their biological relatives.

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Appendix A

Study 1: Descriptives (Mean, Standard Deviation, Median)

Deletion

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
Your raw DNA is deleted.	3.26 (0.79) (3)	3.50 (0.74) (4)	2.95 (0.85) (3)	3.52 (0.83) (4)
Your personally identifiable information is deleted (name, email address, mailing address, etc).	2.68 (0.90) (3)	3.07 (0.94) (3)	2.40 (0.85) (2)	3.04 (0.98) (3)
Your account is inaccessible indefinitely.	2.81 (0.74) (3)	3.01 (0.84) (3)	2.66 (0.79) (3)	3.11 (0.90) (3)
Your account can be reactivated.	2.08 (0.79) (2)	1.89 (0.74) (2)	2.25 (0.62) (2)	1.92 (0.83) (2)
Your ancestry/health DNA test results are deleted.	3.20 (0.78) (3)	3.53 (0.77) (4)	2.77 (0.84) (3)	3.47 (0.78) (4)
People can still find your account on the website.	2.76 (0.83) (3)	2.35 (0.94) (2)	2.89 (0.83) (3)	2.47 (1.01) (3)

Concerns

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
Your ancestry/health results influencing your job prospects.	2.76 (1.06) (3)	2.47 (1.04) (3)	2.50 (0.95) (3)	2.14 (1.01) (2)
Finding out unwanted ancestry/health information	2.80 (0.88) (3)	2.62 (1.03) (3)	2.25 (0.88) (2)	2.22 (0.92) (2)
Finding unwanted family secrets as a result of an ancestry DNA test.	2.87 (0.93) (3)	2.85 (1.01) (3)	2.42 (0.98) (2)	2.72 (0.97) (3)
Surveillance due to an ancestry/health DNA test.	2.28 (0.99) (2)	2.01 (1.05) (2)	2.24 (0.95) (2)	1.79 (0.91) (2)
Accuracy of ancestry/health at-home DNA tests.	2.28 (0.84) (2)	1.99 (0.99) (2)	1.90 (0.67) (2)	1.96 (0.92) (2)
Genetic discrimination as a result of an ancestry/health DNA test.	2.78 (1.01) (3)	2.10 (1.03) (2)	2.31 (1.02) (2)	2.01 (0.96) (2)
Ancestry/health information from a DNA test relevant to your immediate or extended family being public	2.41 (0.90) (2)	2.04 (0.92) (2)	2.25 (0.92) (2)	2.05 (0.90) (2)
Adjusted insurance rates due to an ancestry/health DNA test.	2.39 (1.05) (2)	1.90 (1.00) (2)	2.21 (0.83) (2)	1.78 (0.85) (2)
Your ancestry/health data being used for profit.	2.03 (0.86) (2)	1.38 (0.71) (1)	1.78 (0.89) (2)	1.55 (0.84) (1)

Control

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
The DNA company itself	1.37 (0.67) (1)	1.38 (0.77) (1)	1.44 (0.61) (1)	1.46 (0.81) (1)
The general public	3.47 (0.66) (4)	3.74 (0.47) (4)	3.51 (0.69) (4)	3.76 (0.48) (4)
Other users of the at-home DNA testing company	3.09 (0.91) (3)	3.36 (0.74) (4)	3.24 (0.80) (3)	3.39 (0.83) (4)
The government	3.01 (0.87) (3)	2.58 (0.96) (2)	2.84 (0.88) (3)	2.59 (0.95) (2)

For-profit partners of the company	2.67 (0.99) (3)	2.59 (1.07) (2)	2.87 (0.82) (3)	2.59 (1.14) (2)
Non-profit partners of the company	2.87 (0.85) (3)	2.73 (0.88) (3)	2.89 (0.76) (3)	2.79 (0.91) (3)
Investors	2.80 (0.92) (3)	2.64 (1.01) (3)	2.85 (0.81) (3)	2.78 (1.04) (3)
Yourself (the person completing the DNA test)	1.96 (1.03) (2)	1.94 (1.06) (2)	1.69 (0.83) (1.5)	1.94 (1.00) (2)

Who has access to your most recent ancestry/health DNA data?

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
The DNA company itself	1.28 (0.64) (1)	1.29 (0.72) (1)	1.44 (0.76) (1)	1.38 (0.85) (1)
The general public	3.61 (0.61) (4)	3.54 (0.57) (4)	3.64 (0.52) (4)	3.73 (0.47) (4)
Other users of the at-home DNA testing company	3.01 (0.94) (3)	2.96 (1.01) (3)	3.33 (0.84) (4)	3.27 (0.96) (4)
Your employer	3.67 (0.64) (4)	3.55 (0.66) (4)	3.42 (0.77) (4)	3.51 (0.61) (4)
The government	2.80 (1.03) (3)	2.39 (1.00) (2)	2.47 (0.99) (3)	2.52 (1.09) (2)
Law enforcement	3.05 (0.92) (3)	2.46 (1.01) (2)	2.84 (0.90) (3)	2.59 (1.11) (2)
Pharmaceutical companies	3.04 (0.86) (3)	2.58 (0.97) (3)	2.73 (0.88) (3)	2.46 (1.06) (2)
Insurance companies	3.22 (0.79) (3)	2.74 (1.00) (3)	2.78 (1.05) (3)	2.72 (0.96) (3)
Advertisers	3.21 (0.88) (3)	2.92 (1.00) (3)	3.11 (0.84) (3)	2.92 (1.03) (3)
For-profit companies	2.93 (0.98) (3)	2.59 (1.07) (3)	2.92 (0.90) (3)	2.86 (1.04) (3)
University researchers	2.95 (0.88) (3)	2.38 (0.84) (2)	2.59 (0.87) (2.5)	2.41 (0.98) (2)
Non-profit researchers	2.88 (0.91) (3)	2.54 (0.93) (3)	2.59 (0.92) (2)	2.59 (0.97) (3)
Investors in the DNA testing company	2.79 (0.90) (3)	2.59 (1.00) (2)	2.75 (0.89) (3)	2.76 (1.05) (3)

How comfortable are you with your data being used:

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
By the DNA-testing company to improve their services.	2.11 (0.87) (2)	2.70 (1.02) (3)	1.98 (0.81) (2)	2.84 (0.99) (3)
By the government for research.	2.68 (1.04) (3)	3.08 (0.90) (3)	2.41 (0.99) (2)	3.00 (0.90) (3)
By law-enforcement for research.	2.91 (1.06) (3)	3.25 (0.92) (4)	2.56 (1.02) (2)	3.34 (0.91) (4)
By law-enforcement for police investigations.	2.97 (1.01) (3)	3.44 (0.85) (4)	2.80 (0.98) (3)	3.38 (0.87) (4)
By pharmaceutical companies for research.	2.43 (1.01) (2)	2.85 (0.92) (3)	2.27 (0.94) (2)	2.92 (1.06) (3)
By academic institutions for research.	2.01 (0.87) (2)	2.32 (1.04) (2)	1.81 (0.77) (2)	2.40 (1.07) (2)
By non-profit organisations for research.	2.17 (0.93) (2)	2.52 (1.02) (2)	2.11 (0.86) (2)	2.54 (1.08) (2)

How comfortable would you be sharing your ancestry/health data with:

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
The DNA company itself	2.04 (0.93) (2)	2.89 (0.9) (3)	2.11 (0.84) (2)	3.06 (0.92) (3)
The general public	3.34 (0.79) (4)	3.78 (0.52) (4)	3.53 (0.71) (4)	3.86 (0.38) (4)
Other users of the at-home DNA testing company	2.96 (0.94) (3)	3.56 (0.73) (4)	3.22 (0.71) (3)	3.69 (0.58) (4)
Your employer	3.25 (0.94) (4)	3.81 (0.48) (4)	3.23 (0.89) (3)	3.76 (0.48) (4)
The government	3.29 (0.88) (4)	3.57 (0.76) (4)	3.08 (0.93) (3)	3.59 (0.70) (4)
Law enforcement	3.33 (0.84) (4)	3.60 (0.79) (4)	3.23 (0.85) (3)	3.59 (0.74) (4)
Pharmaceutical companies	3.09 (0.87) (3)	3.44 (0.85) (4)	2.77 (0.94) (3)	3.31 (0.93) (4)

Insurance companies	3.42 (0.84) (4)	3.74 (0.69) (4)	3.00 (0.99) (3)	3.71 (0.59) (4)
Advertisers	3.50 (0.72) (4)	3.87 (0.46) (4)	3.58 (0.64) (4)	3.89 (0.31) (4)
For-profit companies	3.32 (0.80) (4)	3.75 (0.58) (4)	3.36 (0.63) (3)	3.85 (0.36) (4)
University researchers	2.38 (0.94) (2)	2.75 (1.03) (3)	2.23 (0.79) (2)	2.69 (0.96) (3)
Non-profit researchers	2.57 (0.98) (2)	3.02 (1.09) (3)	2.38 (0.88) (2)	2.88 (1.00) (3)
Investors in the DNA testing company	3.29 (0.88) (4)	3.71 (0.59) (4)	3.08 (0.90) (3)	3.78 (0.52) (4)

Rate how much you would like others who have also completed the test to contribute their ancestry/health-related DNA data for the following purposes:

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
For research by the DNA-testing company to improve their services.	2.01 (0.97) (2)	2.96 (0.99) (3)	2.03 (0.98) (2)	2.89 (1.06) (3)
For research by the government.	3.11 (1.01) (3)	3.28 (0.83) (3)	2.61 (0.99) (2)	3.27 (0.92) (4)
For research by the police.	3.29 (0.91) (4)	3.55 (0.78) (4)	2.89 (0.98) (3)	3.47 (0.92) (4)
For police investigations.	3.28 (0.93) (4)	3.45 (0.89) (4)	2.81 (1.02) (3)	3.47 (0.95) (4)
For research by pharmaceutical companies.	2.63 (1.06) (3)	3.14 (0.87) (3)	2.28 (1.09) (2)	3.00 (1.10) (3)
For research by academic institutions.	2.16 (0.95) (2)	2.56 (1.07) (2)	1.66 (0.78) (1)	2.39 (1.08) (2)
For research by non-profit organisations.	2.49 (1.03) (2)	2.87 (1.02) (3)	2.11 (0.94) (2)	2.60 (1.09) (3)

Rate how you agree or disagree with each statement:

	Users Ancestry (UA)	Non-Users Ancestry (NUA)	Users Health (UH)	Non-Users Health (NUH)
I can be identified by the DNA sample I provided for ancestry testing.	2.00 (0.75) (2)	1.86 (0.89) (2)	2.06 (0.88) (2)	1.62 (0.80) (1)
My family might find out things they didn't want to know.	2.46 (0.82) (2)	2.28 (0.95) (2)	2.56 (0.74) (3)	2.31 (0.88) (2)
My DNA is my information and my information alone.	1.80 (0.79) (2)	1.46 (0.77) (1)	1.90 (0.72) (2)	1.44 (0.61) (1)
What I do with my DNA is my business.	1.49 (0.60) (1)	1.31 (0.62) (1)	1.58 (0.59) (2)	1.42 (0.70) (1)
My family have a right to be concerned about my ancestry DNA test.	2.56 (0.96) (2)	2.52 (1.08) (2)	2.17 (0.94) (2)	2.40 (0.92) (2)
I am interested in finding biological family with a DNA test.	2.32 (0.97) (2)	2.99 (0.92) (3)	2.34 (0.88) (2)	3.06 (0.88) (3)
I do not need anyone's consent to take an ancestry DNA test.	1.57 (0.76) (1)	1.80 (0.97) (2)	1.75 (0.93) (1.5)	1.79 (0.86) (2)
Making my ancestry DNA test results public adds to the community.	2.73 (0.89) (3)	3.24 (0.83) (3)	2.80 (0.89) (3)	3.29 (0.78) (3)
People who hide their ancestry DNA results annoy me.	3.32 (0.79) (3)	3.81 (0.42) (4)	3.30 (0.69) (3)	3.69 (0.54) (4)
Ancestry DNA data is just like any other data.	2.64 (0.99) (3)	3.29 (0.83) (3)	2.76 (0.89) (3)	3.20 (0.88) (3)

Rate the overall effect your ancestry genetic test results would have on each of the following entities:

	Users Ancestry (UA)	**Non-Users Ancestry (NUA)**	**Users Health (UH)**	**Non-Users Health (NUH)**
Yourself	1.26 (0.53) (1)	1.60 (0.64) (2)	1.17 (0.46) (1)	1.70 (0.80) (1)
Your employment prospects	2.00 (0.41) (2)	2.16 (0.40) (2)	1.92 (0.45) (2)	2.34 (0.59) (2)
Your siblings	1.55 (0.53) (2)	1.69 (0.58) (2)	1.50 (0.56) (1)	1.66 (0.67) (2)
Your friends	1.80 (0.43) (2)	2.00 (0.31) (2)	1.84 (0.41) (2)	1.95 (0.37) (2)
Your colleagues	1.92 (0.36) (2)	2.06 (0.24) (2)	1.95 (0.33) (2)	2.05 (0.41) (2)
Your insurance rates	2.08 (0.46) (2)	2.34 (0.53) (2)	1.87 (0.61) (2)	2.58 (0.59) (3)
Your parents	1.54 (0.55) (2)	1.71 (0.62) (2)	1.56 (0.53) (2)	1.86 (0.65) (2)
Your potential government benefits	2.03 (0.40) (2)	2.16 (0.53) (2)	1.82 (0.43) (2)	2.13 (0.65) (2)
Current, existing children	1.59 (0.55) (2)	1.74 (0.60) (2)	1.53 (0.57) (1.5)	1.61 (0.61) (2)
Future children	1.45 (0.53) (1)	1.75 (0.67) (2)	1.26 (0.48) (1)	1.58 (0.69) (1)

Appendix B

Study 1: Pre-screener

Start of Block: Prolific IDs

Q1 Please enter your Prolific ID.

____

- -

✱

Q20 Please **re-enter** your Prolific ID.

____

End of Block: Prolific IDs

Start of Block: Block 1

Q22 Which province do you reside in?

____

- -

Page Break

Q28 At-home DNA tests often consist of ancestry tests, and sometimes of health related tests.

Ancestry related tests are done for the purpose of understanding genetic ethnicity (ie: where your 'ancestors' were from), or seeing potential DNA matches (ie: others who may be related to you).
Health related tests

Health related tests are done for the purpose of understanding how your DNA might influence your overall health (e.g: how likely you are to develop a disease, how your DNA influences overall wellness, whether you are a carrier for certain genes, etc).

Q2
Have you ever completed an at-home DNA test for either **ancestry** or **health** related purposes?

○ For ancestry purposes only (7)

○ For health purposes only (2)

○ For both ancestry and health purposes (5)

○ I have never completed an at-home DNA test (6)

End of Block: Block 1

Start of Block: User block

Display This Question:

If Have you ever completed an at-home DNA test for either ancestry or health related purposes? != I have never completed an at-home DNA test

Q26 Please select which of the following DNA/genetic testing companies you have used the services of:

- ☐ 23andMe (1)
- ☐ Helix (2)
- ☐ GEDmatch (4)
- ☐ LivingDNA (5)
- ☐ HomeDNA (6)
- ☐ National Geographic Genographic Project (7)
- ☐ AncestryDNA (8)
- ☐ African Ancestry (9)
- ☐ Nebula Genomics (10)
- ☐ DNA Tribes (11)
- ☐ MyHeritage DNA (12)
- ☐ Family Tree DNA (13)
- ☐ FindMyPast DNA (14)
- ☐ Other (please list): (15) ____
- ☐ I have not used any at-home DNA/genetic testing company’s services (16)

End of Block: User block

Start of Block: Non-user block

Display This Question:

If Have you ever completed an at-home DNA test for either ancestry or health related purposes? = I have never completed an at-home DNA test

Q24 How comfortable are you with completing an at-home DNA test?

○ Very uncomfortable (1)

○ Uncomfortable (2)

○ Comfortable (3)

○ Very comfortable (4)

Display This Question:

If How comfortable are you with completing an at-home DNA test? = Very uncomfortable

Or How comfortable are you with completing an at-home DNA test? = Uncomfortable

Q25 Have you explicitly chosen **not** to complete an at-home DNA test?
That is, have you explicitly decided to **not** complete an at-home DNA test?

○ Yes (1)

○ No (2)

End of Block: Non-user block

Start of Block: Block 9

Q27 You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses (1)

○ I wish to withdraw from the pre-screener and have my data removed (2)

End of Block: Block 9

Appendix C

Study 1: Survey (Users, Ancestry)

Start of Block: Block 1

Q40 Please enter your Prolific ID.

____

*

Q41 Please **re-enter** your Prolific ID.

____

Page Break

Q27 In which province do you reside?

____

Q2 What is your gender?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Prefer to self-identify: (5) ____

○ Prefer not to answer (4)

Q3 What is your age?

○ Under 18 (1)

○ 18 - 24 (2)

○ 25 - 34 (3)

○ 35 - 44 (4)

○ 45 - 54 (5)

○ 55 - 64 (6)

○ 65 - 74 (7)

○ 75 - 84 (8)

○ 85 or older (9)

○ Prefer not to answer (10)

Q4 Choose either the level of education for which you are currently enrolled or the highest level of education you have completed.

○ Elementary school (1)

○ High school (2)

○ College (3)

○ Technical, trade school, or apprenticeship (4)

○ Undergraduate degree (Bachelor’s) (5)

○ Graduate degree (Master's, PhD) or professional degree (7)

○ Post-graduate certificate or diploma (6)

○ Other (please list): (8) ____

○ Prefer not to answer (9)

Q5

What is your occupation?

- ○ Student (please specify your program of study): (1) ____
- ○ Administrative Support (e.g., secretary, assistant) (2)
- ○ Art, Writing, Journalism (e.g., author, reporter, sculptor) (3)
- ○ Business, Management, and Financial (e.g., manager, accountant, banker) (4)
- ○ Education (e.g., teacher, professor) (5)
- ○ Legal (e.g., lawyer, law clerk) (6)
- ○ Medical (e.g., doctor, nurse, dentist) (7)
- ○ Science, Engineering, and IT Professional (e.g., researcher, programmer, IT consultant) (8)
- ○ Service (e.g., retail clerk, server) (9)
- ○ Skilled Labour (e.g., electrician, plumber, carpenter) (10)
- ○ Unemployed (11)
- ○ Retired (12)
- ○ Other (please specify): (13) ____
- ○ Prefer not to answer (14)

End of Block: Block 1

Start of Block: Block 3

Q40

All questions in this survey apply only to **ancestry** related genetic tests. That is, at-home DNA tests done to understand genetic ethnicity (where your 'ancestors' were from), or seeing potential DNA matches (others who may be related to you).

Page Break

Q9

Have you given consent to the DNA-testing company to have your ancestry DNA data used for research?

○ Yes (1)

○ No (2)

○ Unsure (3)

○ Prefer not to answer (4)

End of Block: Block 3

Start of Block: Block 4

Q13

Think of your most recent DNA test completed for **ancestry** purposes. Who currently has access to your most recent **ancestry** data?

	No access (1)	Probably doesn't have access (2)	Probably has access (4)	Definitely has access (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing	○	○	○	○	○

company (12)

End of Block: Block 4

Start of Block: Block 6

Q15
How comfortable are you sharing your most recent ancestry data with:

	Very uncomfortabl e sharing (1)	Uncomfortable sharing (2)	Comfortable sharing (4)	Very comfortable sharing (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing company (12)	○	○	○	○	○

End of Block: Block 6

Start of Block: Control entities

Q35 Think back to your most recent **ancestry** at-home DNA test. How involved is each entity in deciding how your **ancestry** DNA data is managed? That is, who controls your DNA data?

	Not at all involved (1)	Uninvolved (2)	Involved (4)	Very involved (5)	Prefer not to answer (6)
The general public (1)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
The DNA company itself (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Please select "Uninvolved" (13)	○	○	○	○	○
For-profit partners of the company (5)	○	○	○	○	○
Non-profit partners of the company (6)	○	○	○	○	○
Investors (7)	○	○	○	○	○
Yourself (the person completing the DNA test) (8)	○	○	○	○	○

End of Block: Control entities

Start of Block: Block 8

Q17 Assuming that your ancestry DNA data has been stripped of identifiers (for example, your name), please indicate how comfortable you are with your data being used:

	Very uncomfortable (1)	Uncomfortable (2)	Comfortable (4)	Very comfortable (5)	Prefer not to answer (6)
By pharmaceutical companies for research. (1)	○	○	○	○	○
By academic institutions for research. (2)	○	○	○	○	○
By non- profit organisations for research. (3)	○	○	○	○	○
By the government for research. (4)	○	○	○	○	○
By law-enforcement for research. (5)	○	○	○	○	○
By law-enforcement for police investigations. (6)	○	○	○	○	○
By the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: Block 8

Start of Block: NEW ADD

Q29

Think of your most recent at-home DNA test completed for **ancestry** purposes. Please rate the degree to which would you like **others** who have also completed the test to contribute their **ancestry** DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (4)	Very much (5)	Prefer not to answer (6)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: NEW ADD

Start of Block: Block 11

Q20 Please rate how strongly you agree or disagree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Prefer not to answer (5)
I can be identified by the DNA sample I provided for **ancestry** testing. (2)	○	○	○	○	○
My family might find out things they didn't want to know. (6)	○	○	○	○	○
My DNA is my information and my information alone. (8)	○	○	○	○	○
What I do with my DNA is my business. (9)	○	○	○	○	○
My family have a right to be concerned about my **ancestry** DNA test. (11)	○	○	○	○	○
I am interested in finding biological family with a DNA test. (13)	○	○	○	○	○
You should select the most negative option for this statement.	○	○	○	○	○

(23)					
I do not need anyone's consent to take an **ancestry** DNA test. (16)	○	○	○	○	○
Making my **ancestry** DNA test results public adds to the community. (18)	○	○	○	○	○
People who hide their **ancestry** DNA results annoy me. (19)	○	○	○	○	○
Ancestry DNA data is just like any other data. (22)	○	○	○	○	○

Page Break

Q21 For the following question, if an option doesn’t apply to you, please answer hypothetically. Please rate the *overall* effect your ancestry genetic test results would have on each of the following entities:

	Negative (1)	No effect (2)	Positive (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your employment prospects (2)	○	○	○	○
Your siblings (3)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your insurance rates (6)	○	○	○	○
Your parents (7)	○	○	○	○
Your potential government benefits (9)	○	○	○	○
Current, existing children (16)	○	○	○	○
Future children (18)	○	○	○	○

Page Break

Q22 Think of your most recent ancestry DNA test.
When you delete your account, how likely is it that:

	Very unlikely (1)	Unlikely (2)	Likely (3)	Very likely (4)	Prefer not to answer (5)
Your raw DNA is deleted. (1)	○	○	○	○	○
Your personally identifiable information is deleted (name, email address, mailing address, etc). (2)	○	○	○	○	○
Your account is inaccessible indefinitely. (3)	○	○	○	○	○
Your account can be reactivated. (4)	○	○	○	○	○
Your **ancestry** DNA test results are deleted. (5)	○	○	○	○	○
Any family trees made are deleted. (6)	○	○	○	○	○
People can still find your account on the website. (7)	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q32 Below, you are presented with a series of potential scenarios.
Please rate:
- whether each scenario is possible,
- how likely each scenario is to occur **in Canada**,
- how likely each scenario is to occur **in general (worldwide).**

	Is this possible?		Is this likely in Canada?		Is this likely in general?	
	Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)

The number 4 divided by 4 being 30. (19)	○	○	○	○	○	○
Individuals being detained at a border having their DNA collected for **ancestry** tests. (1)	○	○	○	○	○	○
Ancestry at-home DNA tests being used to assist in deportation cases. (16)	○	○	○	○	○	○
A potential employer coming across your **ancestry** DNA test results online, and using them in their decision to hire you. (2)	○	○	○	○	○	○
Your life insurance rates increasing based on your **ancestry** at-home DNA test. (3)	○	○	○	○	○	○
Your child being prevented from attending	○	○	○	○	○	○

school due to the result of an at-home **ancestry** genetic test they completed. (4)						
Ancestry data that you agreed to be used for research being used by for-profit companies. (5)	○	○	○	○	○	○
Ancestry at-home DNA tests being used to provide proof of indigenous status. (7)	○	○	○	○	○	○
An **ancestry** at-home DNA test helping you detect a medical condition. (8)	○	○	○	○	○	○
Databases of users' **ancestry** DNA results helping law enforcement successfully solve cold cases. (9)	○	○	○	○	○	○
Submitting an animal's	○	○	○	○	○	○

DNA to an at-home DNA testing company for humans producing error-free **ancestry** results. (20)						
Individuals with certain **ancestry** traits having their data stored by the government indefinitely. (10)	○	○	○	○	○	○
Being falsely suspected in a criminal investigation based on **ancestry** at-home DNA testing results. (11)	○	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q39 In your own life, please rate your level of concern with each of the following:

	Very unconcerned (1)	Unconcerned (2)	Concerned (3)	Very concerned (4)	Prefer not to answer (5)
Your **ancestry** results influencing your job prospects. (17)	○	○	○	○	○
Finding out unwanted **ancestry** information (18)	○	○	○	○	○
Finding unwanted family secrets as a result of an **ancestry** DNA test. (19)	○	○	○	○	○
Surveillance due to an **ancestry** DNA test. (20)	○	○	○	○	○
Accuracy of **ancestry** at-home DNA tests. (21)	○	○	○	○	○
Genetic discrimination as a result of an **ancestry** DNA test. (22)	○	○	○	○	○
Ancestry information from a DNA test relevant to your immediate or extended family being	○	○	○	○	○

public (23)					
Adjusted insurance rates due to an **ancestry** DNA test. (26)	○	○	○	○	○
Your **ancestry** data being used for profit. (28)	○	○	○	○	○

Page Break

Q40
Please list the reasons why you have taken an at-home DNA test for **ancestry** purposes. You can use bullet points.

If you prefer not to answer, please enter 'prefer not to answer'.

____

____

____

____

____

End of Block: Block 11

Start of Block: Ending block

Q39
You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses (4)

○ I wish to withdraw from the study and have my data removed. I understand that I will not be paid (5)

End of Block: Ending block

Appendix D

Study 1: Survey (Users, Health)

Start of Block: Block 1

Q40 Please enter your Prolific ID.

____

*

Q41 Please **re-enter** your Prolific ID.

____

Page Break

Q27 In which province do you reside?

____

Q2 What is your gender?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Prefer to self-identify: (5)
____

○ Prefer not to answer (4)

Q3 What is your age?

○ Under 18 (1)

○ 18 - 24 (2)

○ 25 - 34 (3)

○ 35 - 44 (4)

○ 45 - 54 (5)

○ 55 - 64 (6)

○ 65 - 74 (7)

○ 75 - 84 (8)

○ 85 or older (9)

○ Prefer not to answer (10)

Q4 Choose either the level of education for which you are currently enrolled or the highest level of education you have completed.

○ Elementary school (1)

○ High school (2)

○ College (3)

○ Technical, trade school, or apprenticeship (4)

○ Undergraduate degree (Bachelor’s) (5)

○ Graduate degree (Master's, PhD) or professional degree (7)

○ Post-graduate certificate or diploma (6)

○ Other (please list): (8) ____

○ Prefer not to answer (9)

Q5

What is your occupation?

○ Student (please specify your program of study): (1) ____

○ Administrative Support (e.g., secretary, assistant) (2)

○ Art, Writing, Journalism (e.g., author, reporter, sculptor) (3)

○ Business, Management, and Financial (e.g., manager, accountant, banker) (4)

○ Education (e.g., teacher, professor) (5)

○ Legal (e.g., lawyer, law clerk) (6)

○ Medical (e.g., doctor, nurse, dentist) (7)

○ Science, Engineering, and IT Professional (e.g., researcher, programmer, IT consultant) (8)

○ Service (e.g., retail clerk, server) (9)

○ Skilled Labour (e.g., electrician, plumber, carpenter) (10)

○ Unemployed (11)

○ Retired (12)

○ Other (please specify): (13) ____

○ Prefer not to answer (14)

End of Block: Block 1

Start of Block: Block 3

Q40
All questions in this survey apply only to health related genetic tests. That is, at-home DNA tests done to understand how your DNA might influence your overall health (for example, how likely you are to develop a disease, how your DNA influences overall wellness - like whether you are more/less likely to be affected by caffeine - and whether you are a carrier for certain genes).

Page Break

Q9

Have you given consent to the testing company to have your health-related DNA data used for research?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)
- ○ Prefer not to answer (4)

End of Block: Block 3

Start of Block: Block 4

Q13
Think of your most recent DNA test completed for health purposes. Who currently has access to your most recent **health** data?

	No access (1)	Probably doesn't have access (2)	Probably has access (4)	Definitely has access (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing company (12)	○	○	○	○	○

End of Block: Block 4

Start of Block: Block 6

Q15

How comfortable are you sharing your most recent health data with:

	Very uncomfortable sharing (1)	Uncomfortable sharing (2)	Comfortable sharing (4)	Very comfortable sharing (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing company (12)	○	○	○	○	○

End of Block: Block 6

Start of Block: Control entities

Q35
Think back to your most recent health-related at-home DNA test.How involved is each entity in deciding how your **health-related** DNA data is managed? That is, who controls your DNA data?

	Not at all involved (1)	Uninvolved (2)	Involved (4)	Very involved (5)	Prefer not to answer (6)
The general public (1)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
The DNA company itself (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Please select "Uninvolved" (13)	○	○	○	○	○
For-profit partners of the company (5)	○	○	○	○	○
Non-profit partners of the company (6)	○	○	○	○	○
Investors (7)	○	○	○	○	○
Yourself (the person completing the DNA test) (8)	○	○	○	○	○

End of Block: Control entities

Start of Block: Block 8

Q17
 Assuming that your health-related DNA data has been stripped of identifiers (for example, your name), please indicate how comfortable you are with your data being used:

	Very uncomfortable (1)	Uncomfortable (2)	Comfortable (4)	Very comfortable (5)	Prefer not to answer (6)
By pharmaceutical companies for research. (1)	○	○	○	○	○
By academic institutions for research. (2)	○	○	○	○	○
By non-profit organisations for research. (3)	○	○	○	○	○
By the government for research. (4)	○	○	○	○	○
By law-enforcement for research. (5)	○	○	○	○	○
By law-enforcement for police investigations. (6)	○	○	○	○	○
By the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: Block 8

Start of Block: NEW ADD

Q29 Think of your most recent at-home DNA test completed for **health** purposes. Please rate the degree to which would you like others who have also completed the test to contribute their **health-related** DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (4)	Very much (5)	Prefer not to answer (6)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: NEW ADD

Start of Block: Block 11

Q20 Please rate how strongly you agree or disagree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Prefer not to answer (5)
I can be identified by the DNA sample I provided for **health** testing. (2)	○	○	○	○	○
My family might find out things they didn't want to know. (6)	○	○	○	○	○
My DNA is my information and my information alone. (8)	○	○	○	○	○
What I do with my DNA is my business. (9)	○	○	○	○	○
My family have a right to be concerned about my **health-related** DNA test. (11)	○	○	○	○	○
I am interested in finding biological family with a DNA test. (13)	○	○	○	○	○
You should select the most negative option for this statement.	○	○	○	○	○

(23)					
I do not need anyone's consent to take a **health-related** DNA test. (16)	○	○	○	○	○
Making my **health** DNA test results public adds to the community. (18)	○	○	○	○	○
People who hide their **health** DNA results annoy me. (19)	○	○	○	○	○
Health DNA data is just like any other data. (22)	○	○	○	○	○

Page Break

Q21 For the following question, if an option doesn't apply to you, please answer hypothetically. Please rate the *overall* effect your **health-related** genetic test results would have on each of the following entities:

	Negative (1)	No effect (2)	Positive (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your employment prospects (2)	○	○	○	○
Your siblings (3)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your insurance rates (6)	○	○	○	○
Your parents (7)	○	○	○	○
Your potential government benefits (9)	○	○	○	○
Current, existing children (16)	○	○	○	○
Future children (18)	○	○	○	○

Page Break

Q22 Think of your most recent **health-related** DNA test.
When you delete your account, how likely is it that:

	Very unlikely (1)	Unlikely (2)	Likely (3)	Very likely (4)	Prefer not to answer (5)
Your raw DNA is deleted. (1)	○	○	○	○	○
Your personally identifiable information is deleted (name, email address, mailing address, etc). (2)	○	○	○	○	○
Your account is inaccessible indefinitely. (3)	○	○	○	○	○
Your account can be reactivated. (4)	○	○	○	○	○
Your **health-related** DNA test results are deleted. (5)	○	○	○	○	○
People can still find your account on the website. (7)	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q32 Below, you are presented with a series of potential scenarios.
Please rate:
- whether each scenario is possible,
- how likely each scenario is to occur **in Canada**,
- how likely each scenario is to occur **in general (worldwide).**

	Is this possible?		Is this likely in Canada?		Is this likely in general?	
	Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)

Individuals being detained at a border having their DNA collected for **health-related** tests. (1)	○	○	○	○	○	○
Health-related at-home DNA tests being used to assist in deportation cases. (16)	○	○	○	○	○	○
A potential employer coming across your **health** DNA test results online, and using them in their decision to hire you. (2)	○	○	○	○	○	○
Your life insurance rates increasing based on your **health-related** at-home DNA test. (3)	○	○	○	○	○	○
Your child being prevented from attending school due to the result of an at-home **health-**	○	○	○	○	○	○

related genetic test they completed. (4)						
Health data that you agreed to be used for research being used by for-profit companies. (5)	○	○	○	○	○	○
The number 4 divided by 4 being 30. (19)	○	○	○	○	○	○
Health-related at-home DNA tests being used to provide proof of indigenous status. (7)	○	○	○	○	○	○
A **health-related** at-home DNA test helping you detect a medical condition. (8)	○	○	○	○	○	○
Databases of users' **health** DNA results helping law enforcement successfully solve cold cases. (9)	○	○	○	○	○	○

Submitting an animal's DNA to an at-home DNA testing company for humans producing error-free **health-related** results. (20)	○	○	○	○	○	○
Individuals with certain **health** traits having their data stored by the government indefinitely. (10)	○	○	○	○	○	○
Being falsely suspected in a criminal investigation based on **health-related** at-home DNA testing results. (11)	○	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q39 In your own life, please rate your level of concern with each of the following:

	Very unconcerned (1)	Unconcerned (2)	Concerned (3)	Very concerned (4)	Prefer not to answer (5)
Your **health** results influencing your job prospects. (17)	○	○	○	○	○
Finding out unwanted **health** information (18)	○	○	○	○	○
Finding unwanted family secrets due to a **health** DNA test. (19)	○	○	○	○	○
Surveillance due to a **health-related** DNA test. (20)	○	○	○	○	○
Accuracy of **health-related** at-home DNA tests. (21)	○	○	○	○	○
Genetic discrimination as a result of a **health-related** DNA test. (22)	○	○	○	○	○
Health information from a DNA test relevant to your immediate or extended family being public (23)	○	○	○	○	○

Adjusted insurance rates due to a **health-related** DNA test. (26)	○	○	○	○	○
Your **health** data being used for profit. (31)	○	○	○	○	○

Page Break

Q40
Please list the reasons why you have taken an at-home DNA test for health purposes. You can use bullet points.

If you prefer not to answer, please enter 'prefer not to answer'.

____

____

____

____

____

End of Block: Block 11

Start of Block: Ending block

Q39
You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses (4)

○ I wish to withdraw from the study and have my data removed. I understand that I will not be paid (5)

End of Block: Ending block

Appendix E

Study 1: Survey (Non-users, Ancestry)

Start of Block: Block 1

Q40 Please enter your Prolific ID.

____

*

Q41 Please **re-enter** your Prolific ID.

____

Page Break

Q27 In which province do you reside?

____

Q2 What is your gender?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Prefer to self-identify: (5)
____

○ Prefer not to answer (4)

Q3 What is your age?

○ Under 18 (1)

○ 18 - 24 (2)

○ 25 - 34 (3)

○ 35 - 44 (4)

○ 45 - 54 (5)

○ 55 - 64 (6)

○ 65 - 74 (7)

○ 75 - 84 (8)

○ 85 or older (9)

○ Prefer not to answer (10)

Q4 Choose either the level of education for which you are currently enrolled or the highest level of education you have completed.

○ Elementary school (1)

○ High school (2)

○ College (3)

○ Technical, trade school, or apprenticeship (4)

○ Undergraduate degree (Bachelor's) (5)

○ Graduate degree (Master's, PhD) or professional degree (7)

○ Post-graduate certificate or diploma (6)

○ Other (please list): (8) ____

○ Prefer not to answer (9)

Q5

What is your occupation?

○ Student (please specify your program of study): (1)

____

○ Administrative Support (e.g., secretary, assistant) (2)

○ Art, Writing, Journalism (e.g., author, reporter, sculptor) (3)

○ Business, Management, and Financial (e.g., manager, accountant, banker) (4)

○ Education (e.g., teacher, professor) (5)

○ Legal (e.g., lawyer, law clerk) (6)

○ Medical (e.g., doctor, nurse, dentist) (7)

○ Science, Engineering, and IT Professional (e.g., researcher, programmer, IT consultant) (8)

○ Service (e.g., retail clerk, server) (9)

○ Skilled Labour (e.g., electrician, plumber, carpenter) (10)

○ Unemployed (11)

○ Retired (12)

○ Other (please specify): (13)

____

○ Prefer not to answer (14)

End of Block: Block 1

Start of Block: Block 3

Q40
All questions in this survey apply only to **ancestry** related genetic tests. That is, at-home DNA tests done to understand genetic ethnicity (where your 'ancestors' were from), or seeing potential DNA matches (others who may be related to you).

Page Break

Q9

Would you give consent to a DNA-testing company to have your ancestry DNA data used for research?

○ Yes (1)

○ No (2)

○ Unsure (3)

○ Prefer not to answer (4)

End of Block: Block 3

Start of Block: Block 4

Q13

Assume you have completed a DNA test for **ancestry** purposes. Who would have access to your **ancestry** data?

	No access (1)	Probably doesn't have access (2)	Probably has access (4)	Definitely has access (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing	○	○	○	○	○

company (12)

End of Block: Block 4

Start of Block: Block 6

Q15

How comfortable would you be sharing your ancestry data with:

	Very uncomfortable sharing (1)	Uncomfortable sharing (2)	Comfortable sharing (4)	Very comfortable sharing (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing company (12)	○	○	○	○	○

End of Block: Block 6

Start of Block: Control entities

Q35 Assume you have completed an **ancestry** at-home DNA test. How involved would each entity be in deciding how your **ancestry** DNA data is managed? That is, who controls your DNA data?

	Not at all involved (1)	Uninvolved (2)	Involved (4)	Very involved (5)	Prefer not to answer (6)
The general public (1)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
The DNA company itself (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Please select "Uninvolved" (13)	○	○	○	○	○
For-profit partners of the company (5)	○	○	○	○	○
Non-profit partners of the company (6)	○	○	○	○	○
Investors (7)	○	○	○	○	○
Yourself (the person completing the DNA test) (8)	○	○	○	○	○

End of Block: Control entities

Start of Block: Block 8

Q17
Assuming you completed a DNA test, and your ancestry DNA data has been stripped of identifiers (for example, your name), please indicate how comfortable you would be with your data being used:

	Very uncomfortable (1)	Uncomfortable (2)	Comfortable (4)	Very comfortable (5)	Prefer not to answer (6)
By pharmaceutical companies for research. (1)	○	○	○	○	○
By academic institutions for research. (2)	○	○	○	○	○
By non- profit organisations for research. (3)	○	○	○	○	○
By the government for research. (4)	○	○	○	○	○
By law-enforcement for research. (5)	○	○	○	○	○
By law-enforcement for police investigations. (6)	○	○	○	○	○
By the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: Block 8

Start of Block: NEW ADD

Q29

Assume that you have completed an at-home DNA test for **ancestry** purposes. Please rate the degree to which would you like **others** who have also completed the test to contribute their **ancestry** DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (4)	Very much (5)	Prefer not to answer (6)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: NEW ADD

Start of Block: Block 11

Q20 Please rate how strongly you agree or disagree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Prefer not to answer (5)
I can be identified by the DNA sample I provided for **ancestry** testing. (2)	○	○	○	○	○
My family might find out things they didn't want to know. (6)	○	○	○	○	○
My DNA is my information and my information alone. (8)	○	○	○	○	○
What I do with my DNA is my business. (9)	○	○	○	○	○
My family have a right to be concerned about my **ancestry** DNA test. (11)	○	○	○	○	○
I am interested in finding biological family with a DNA test. (13)	○	○	○	○	○
You should select the most negative option for this statement.	○	○	○	○	○

(23)					
I do not need anyone's consent to take an **ancestry** DNA test. (16)	○	○	○	○	○
Making my **ancestry** DNA test results public adds to the community. (18)	○	○	○	○	○
People who hide their **ancestry** DNA results annoy me. (19)	○	○	○	○	○
Ancestry DNA data is just like any other data. (22)	○	○	○	○	○

Page Break

Q21 For the following question, if an option doesn't apply to you, please answer hypothetically. Please rate the *overall* effect your ancestry genetic test results would have on each of the following entities:

	Negative (1)	No effect (2)	Positive (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your employment prospects (2)	○	○	○	○
Your siblings (3)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your insurance rates (6)	○	○	○	○
Your parents (7)	○	○	○	○
Your potential government benefits (9)	○	○	○	○
Current, existing children (16)	○	○	○	○
Future children (18)	○	○	○	○

Page Break

Q22 Assume you have completed a DNA test for **ancestry** purposes.
If you were to delete your account, how likely is it that:

	Very unlikely (1)	Unlikely (2)	Likely (3)	Very likely (4)	Prefer not to answer (5)
Your raw DNA is deleted. (1)	○	○	○	○	○
Your personally identifiable information is deleted (name, email address, mailing address, etc). (2)	○	○	○	○	○
Your account is inaccessible indefinitely. (3)	○	○	○	○	○
Your account can be reactivated. (4)	○	○	○	○	○
Your **ancestry** DNA test results are deleted. (5)	○	○	○	○	○
Any family trees made are deleted. (6)	○	○	○	○	○
People can still find your account on the website. (7)	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q32 Below, you are presented with a series of potential scenarios.
Please rate:
- whether each scenario is possible,
- how likely each scenario is to occur **in Canada**,
- how likely each scenario is to occur **in general (worldwide).**

	Is this possible?		Is this likely in Canada?		Is this likely in general?	
	Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)

Individuals being detained at a border having their DNA collected for **ancestry** tests. (1)	○	○	○	○	○	○
Ancestry at-home DNA tests being used to assist in deportation cases. (16)	○	○	○	○	○	○
A potential employer coming across your **ancestry** DNA test results online, and using them in their decision to hire you. (2)	○	○	○	○	○	○
Your life insurance rates increasing based on your **ancestry** at-home DNA test. (3)	○	○	○	○	○	○
Your child being prevented from attending school due to the result of an at-home **ancestry**	○	○	○	○	○	○

genetic test they completed. (4)						
Ancestry data that you agreed to be used for research being used by for-profit companies. (5)	○	○	○	○	○	○
The number 4 divided by 4 being 30. (19)	○	○	○	○	○	○
Ancestry at-home DNA tests being used to provide proof of indigenous status. (7)	○	○	○	○	○	○
An **ancestry** at-home DNA test helping you detect a medical condition. (8)	○	○	○	○	○	○
Databases of users' **ancestry** DNA results helping law enforcement successfully solve cold cases. (9)	○	○	○	○	○	○
Submitting an animal's	○	○	○	○	○	○

DNA to an at-home DNA testing company for humans producing error-free **ancestry** results. (20)						
Individuals with certain **ancestry** traits having their data stored by the government indefinitely. (10)	○	○	○	○	○	○
Being falsely suspected in a criminal investigation based on **ancestry** at-home DNA testing results. (11)	○	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q39 In your own life, please rate your level of concern with each of the following:

	Very unconcerned (1)	Unconcerned (2)	Concerned (3)	Very concerned (4)	Prefer not to answer (5)
Your **ancestry** results influencing your job prospects. (17)	○	○	○	○	○
Finding out unwanted **ancestry** information (18)	○	○	○	○	○
Finding unwanted family secrets as a result of an **ancestry** DNA test. (19)	○	○	○	○	○
Surveillance due to an **ancestry** DNA test. (20)	○	○	○	○	○
Accuracy of **ancestry** at-home DNA tests. (21)	○	○	○	○	○
Genetic discrimination as a result of an **ancestry** DNA test. (22)	○	○	○	○	○
Ancestry information from a DNA test relevant to your immediate or extended family being	○	○	○	○	○

public (23)					
Adjusted insurance rates due to an **ancestry** DNA test. (26)	○	○	○	○	○
Your **ancestry** data being used for profit. (28)	○	○	○	○	○

Page Break

Q40
Please list the reasons why you choose **not** to take an at-home DNA test for **ancestry** purposes. You can use bullet points.

If you prefer not to answer, please enter 'prefer not to answer'.

____

____

____

____

____

End of Block: Block 11

Start of Block: Ending block

Q39
You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses (4)

○ I wish to withdraw from the study and have my data removed. I understand that I will not be paid (5)

End of Block: Ending block

Appendix F

Study 1: Survey (Non-users, Health)

Start of Block: Block 1

Q40 Please enter your Prolific ID.

____

✱

Q41 Please **re-enter** your Prolific ID.

____

Page Break

Q27 In which province do you reside?

____

Q2 What is your gender?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Prefer to self-identify: (5) ____

○ Prefer not to answer (4)

Q3 What is your age?

○ Under 18 (1)

○ 18 - 24 (2)

○ 25 - 34 (3)

○ 35 - 44 (4)

○ 45 - 54 (5)

○ 55 - 64 (6)

○ 65 - 74 (7)

○ 75 - 84 (8)

○ 85 or older (9)

○ Prefer not to answer (10)

Q4 Choose either the level of education for which you are currently enrolled or the highest level of education you have completed.

○ Elementary school (1)

○ High school (2)

○ College (3)

○ Technical, trade school, or apprenticeship (4)

○ Undergraduate degree (Bachelor's) (5)

○ Graduate degree (Master's, PhD) or professional degree (7)

○ Post-graduate certificate or diploma (6)

○ Other (please list): (8) ____

○ Prefer not to answer (9)

Q5

What is your occupation?

○ Student (please specify your program of study): (1)

____

○ Administrative Support (e.g., secretary, assistant) (2)

○ Art, Writing, Journalism (e.g., author, reporter, sculptor) (3)

○ Business, Management, and Financial (e.g., manager, accountant, banker) (4)

○ Education (e.g., teacher, professor) (5)

○ Legal (e.g., lawyer, law clerk) (6)

○ Medical (e.g., doctor, nurse, dentist) (7)

○ Science, Engineering, and IT Professional (e.g., researcher, programmer, IT consultant) (8)

○ Service (e.g., retail clerk, server) (9)

○ Skilled Labour (e.g., electrician, plumber, carpenter) (10)

○ Unemployed (11)

○ Retired (12)

○ Other (please specify): (13)

____

○ Prefer not to answer (14)

End of Block: Block 1

Start of Block: Block 3

Q40
All questions in this survey apply only to health related genetic tests. That is, at-home DNA tests done to understand how your DNA might influence your overall health (for example, how likely you are to develop a disease, how your DNA influences overall wellness - like whether you are more/less likely to be affected by caffeine - and whether you are a carrier for certain genes).

Page Break

Q9

Would you give consent to a testing company to have your health-related DNA data used for research?

○ Yes (1)

○ No (2)

○ Unsure (3)

○ Prefer not to answer (4)

End of Block: Block 3

Start of Block: Block 4

Q13

Assume you have completed a DNA test for **health** purposes. Who would have access to your **health** data?

	No access (1)	Probably doesn't have access (2)	Probably has access (4)	Definitely has access (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing	○	○	○	○	○

company (12)

End of Block: Block 4

Start of Block: Block 6

Q15

How comfortable would you be sharing your health data with:

	Very uncomfortable sharing (1)	Uncomfortable sharing (2)	Comfortable sharing (4)	Very comfortable sharing (5)	Prefer not to answer (6)
The DNA company itself (1)	○	○	○	○	○
The general public (13)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
Your employer (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Law enforcement (5)	○	○	○	○	○
Pharmaceutical companies (6)	○	○	○	○	○
Insurance companies (7)	○	○	○	○	○
Advertisers (8)	○	○	○	○	○
For-profit companies (9)	○	○	○	○	○
University researchers (10)	○	○	○	○	○
Non-profit researchers (11)	○	○	○	○	○
Investors in the DNA testing company (12)	○	○	○	○	○

End of Block: Block 6

Start of Block: Control entities

Q35

Assume you have completed a **health-related** at-home DNA test. How involved would each entity be in deciding how your **health** related DNA data is managed? That is, who controls your DNA data?

	Not at all involved (1)	Uninvolved (2)	Involved (4)	Very involved (5)	Prefer not to answer (6)
The general public (1)	○	○	○	○	○
Other users of the at-home DNA testing company (2)	○	○	○	○	○
The DNA company itself (3)	○	○	○	○	○
The government (4)	○	○	○	○	○
Please select "Uninvolved" (13)	○	○	○	○	○
For-profit partners of the company (5)	○	○	○	○	○
Non-profit partners of the company (6)	○	○	○	○	○
Investors (7)	○	○	○	○	○
Yourself (the person completing the DNA test) (8)	○	○	○	○	○

End of Block: Control entities

Start of Block: Block 8

Q17
Assuming you completed a DNA test, and your health-related DNA data has been stripped of identifiers (for example, your name), please indicate how comfortable you would be with your data being used:

	Very uncomfortable (1)	Uncomfortable (2)	Comfortable (4)	Very comfortable (5)	Prefer not to answer (6)
By pharmaceutical companies for research. (1)	○	○	○	○	○
By academic institutions for research. (2)	○	○	○	○	○
By non-profit organisations for research. (3)	○	○	○	○	○
By the government for research. (4)	○	○	○	○	○
By law-enforcement for research. (5)	○	○	○	○	○
By law-enforcement for police investigations. (6)	○	○	○	○	○
By the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: Block 8

Start of Block: NEW ADD

Q29

Assume that you have completed an at-home DNA test for **health** purposes. Please rate the degree to which you would like **others** who have also completed the test to contribute their **health** DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (4)	Very much (5)	Prefer not to answer (6)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: NEW ADD

Start of Block: Block 11

Q20 Please rate how strongly you agree or disagree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Prefer not to answer (5)
I can be identified by the DNA sample I provided for **health** testing. (2)	○	○	○	○	○
My family might find out things they didn't want to know. (6)	○	○	○	○	○
My DNA is my information and my information alone. (8)	○	○	○	○	○
What I do with my DNA is my business. (9)	○	○	○	○	○
My family have a right to be concerned about my **health-related** DNA test. (11)	○	○	○	○	○
I am interested in finding biological family with a DNA test. (13)	○	○	○	○	○
You should select the most negative option for this statement.	○	○	○	○	○

(23)					
I do not need anyone's consent to take a **health-related** DNA test. (16)	○	○	○	○	○
Making my **health** DNA test results public adds to the community. (18)	○	○	○	○	○
People who hide their **health** DNA results annoy me. (19)	○	○	○	○	○
Health DNA data is just like any other data. (22)	○	○	○	○	○

Page Break

Q21 For the following question, if an option doesn't apply to you, please answer hypothetically. Please rate the *overall* effect your health-related genetic test results would have on each of the following entities:

	Negative (1)	No effect (2)	Positive (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your employment prospects (2)	○	○	○	○
Your siblings (3)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your insurance rates (6)	○	○	○	○
Your parents (7)	○	○	○	○
Your potential government benefits (9)	○	○	○	○
Current, existing children (16)	○	○	○	○
Future children (18)	○	○	○	○

Page Break

Q22 Assume you have completed a DNA test for **health** purposes.
If you were to delete your account, how likely is it that:

	Very unlikely (1)	Unlikely (2)	Likely (3)	Very likely (4)	Prefer not to answer (5)
Your raw DNA is deleted. (1)	○	○	○	○	○
Your personally identifiable information is deleted (name, email address, mailing address, etc). (2)	○	○	○	○	○
Your account is inaccessible indefinitely. (3)	○	○	○	○	○
Your account can be reactivated. (4)	○	○	○	○	○
Your **health-related** DNA test results are deleted. (5)	○	○	○	○	○
People can still find your account on the website. (7)	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q32 Below, you are presented with a series of potential scenarios.
Please rate:
- whether each scenario is possible,
- how likely each scenario is to occur **in Canada**,
- how likely each scenario is to occur **in general (worldwide).**

	Is this possible?		Is this likely in Canada?		Is this likely in general?	
	Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)

Individuals being detained at a border having their DNA collected for **health-related** tests. (1)	○	○	○	○	○	○
Health-related at-home DNA tests being used to assist in deportation cases. (16)	○	○	○	○	○	○
A potential employer coming across your **health** DNA test results online, and using them in their decision to hire you. (2)	○	○	○	○	○	○
Your life insurance rates increasing based on your **health-related** at-home DNA test. (3)	○	○	○	○	○	○
Your child being prevented from attending school due to the result of an at-home **health-**	○	○	○	○	○	○

related genetic test they completed. (4)						
Health data that you agreed to be used for research being used by for-profit companies. (5)	○	○	○	○	○	○
The number 4 divided by 4 being 30. (19)	○	○	○	○	○	○
Health-related at-home DNA tests being used to provide proof of indigenous status. (7)	○	○	○	○	○	○
A **health-related** at-home DNA test helping you detect a medical condition. (8)	○	○	○	○	○	○
Databases of users' **health** DNA results helping law enforcement successfully solve cold cases. (9)	○	○	○	○	○	○

Submitting an animal's DNA to an at-home DNA testing company for humans producing error-free **health-related** results. (20)	○	○	○	○	○	○
Individuals with certain **health** traits having their data stored by the government indefinitely. (10)	○	○	○	○	○	○
Being falsely suspected in a criminal investigation based on **health-related** at-home DNA testing results. (11)	○	○	○	○	○	○

End of Block: Block 11

Start of Block: Block 11

Q39 In your own life, please rate your level of concern with each of the following:

	Very unconcerned (1)	Unconcerned (2)	Concerned (3)	Very concerned (4)	Prefer not to answer (5)
Your **health** results influencing your job prospects. (17)	○	○	○	○	○
Finding out unwanted **health** information (18)	○	○	○	○	○
Finding unwanted family secrets due to a **health** DNA test. (19)	○	○	○	○	○
Surveillance due to a **health-related** DNA test. (20)	○	○	○	○	○
Accuracy of **health-related** at-home DNA tests. (21)	○	○	○	○	○
Genetic discrimination as a result of a **health-related** DNA test. (22)	○	○	○	○	○
Health information from a DNA test relevant to your immediate or extended family being public (23)	○	○	○	○	○

Adjusted insurance rates due to a **health-related** DNA test. (26)	○	○	○	○	○
Your **health** data being used for profit. (31)	○	○	○	○	○

Page Break

Q40
Please list the reasons why you choose not to take an at-home DNA test for health purposes. You can use bullet points.

If you prefer not to answer, please enter 'prefer not to answer'.

____

____

____

____

____

End of Block: Block 11

Start of Block: Ending block

Q39
You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses (4)

○ I wish to withdraw from the study and have my data removed. I understand that I will not be paid (5)

End of Block: Ending block

Appendix G

Study 2: Pre-screener (non-users)

DNA-Testing Pre-screener Survey

Q0 Please enter your Prolific ID.

____

*

Q0 Please **re-enter** your Prolific ID.

____

Page Break

-

-

Q1 In which province do you reside?

____

Q2 What is your gender?

○ Genderfluid

○ Cis man

○ Cis woman

○ Trans man

○ Trans woman

○ Non-binary

○ Two-Spirit

○ I don’t identify with any of the options provided, I am: ____________________

○ Prefer not to answer

Q3 What is your age?

○ My age is: _____

○ Prefer not to answer

Q4 Choose either the level of education for which you are currently enrolled or the highest level of education you have completed.

○ Elementary school (1)

○ High school (2)

○ College (3)

○ Technical, trade school, or apprenticeship (4)

○ Undergraduate degree (Bachelor's) (5)

○ Graduate degree (Master's, PhD) or professional degree (7)

○ Post-graduate certificate or diploma (6)

○ Other (please list): (8) ____

○ Prefer not to answer (9)

Q5 What is your occupation?

○ Student (please specify your program of study): (1) ____

○ Administrative Support (e.g., secretary, assistant) (2)

○ Art, Writing, Journalism (e.g., author, reporter, sculptor) (3)

○ Business, Management, and Financial (e.g., manager, accountant, banker) (4)

○ Education (e.g., teacher, professor)   (5)

○ Legal (e.g., lawyer, law clerk) (6)

○ Medical (e.g., doctor, nurse, dentist) (7)

○ Science, Engineering, and IT Professional (e.g., researcher, programmer, IT consultant) (8)

○ Service (e.g., retail clerk, server)   (9)

○ Skilled Labour (e.g., electrician, plumber, carpenter) (10)

○ Unemployed (11)

○ Retired (12)

○ Other (please specify): (13) ____

○ Prefer not to answer (14)

End of Block: Block 1

Start of Block: Block 3

Q5 Have **you** ever used the services of an at-home DNA/genetic testing company meant for humans, like AncestryDNA or 23andMe?

○Yes

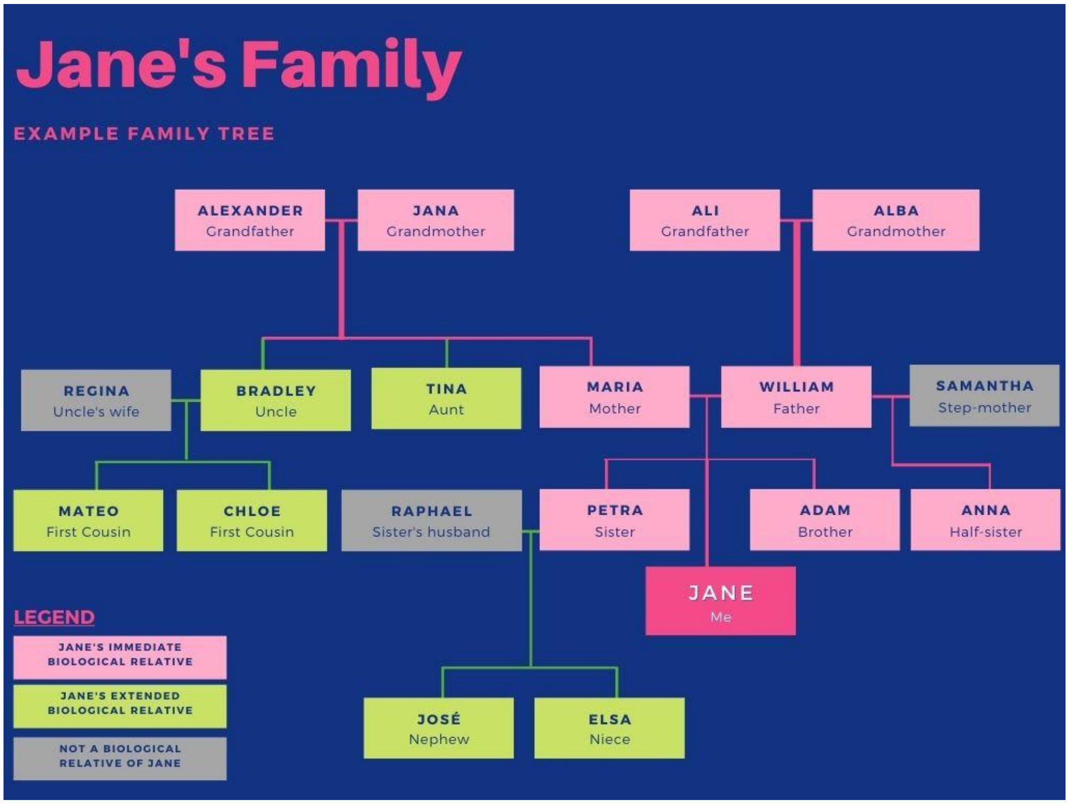
○No

○Prefer not to answer

In a family tree, biological relationships are categorised as follows:

Grandparents: your mother's parents OR your father's parents
Parents: your mother and your father
Siblings: your parents' children (**brothers**, **sisters**, **siblings**)
Half-siblings: your sibling that shares **one** parent with you (half-brother, half-sisters)
Aunts: your mother's sisters OR your father's sisters
Uncles: your mother's brothers OR your father's brothers
First cousins: your aunt's children OR your uncles' children
Niblings: your siblings' children (**niece**, **nephew**, **nibling**)

Using these terms, below is an example family tree of **Jane Santos**. Each person is a **biological relative** of Jane (as they are biologically related), and their relationship to Jane is written beneath their names.



Q6 Have any of your **biological relatives** used the services of an at-home DNA/genetic testing company like AncestryDNA or 23andMe?
If unsure of what a term means, use the family tree above for reference by putting yourself in Jane’s place. Otherwise, please elaborate in the textbox.

○ Yes:

- ☐ Immediate biological relatives (grandparents, grandchildren, parents, siblings, half-siblings, children)
- ☐ Extended biological relatives (aunts, uncles, first cousins, niblings (nieces, nephews))
- ☐ Other (please specify): ______________________

○ No

○ Unsure

○ Prefer not to answer

Page Break

The questions in this survey apply to any **at-home** related genetic tests for humans, done for either ancestry or health purposes.

Ancestry at-home DNA tests are often done to understand genetic ethnicity (where your 'ancestors' were from), and/or seeing potential DNA matches (others who may be related to you), or for health purposes.

Health-related at-home DNA tests are often done to understand how your DNA might influence your overall health (for example, how likely you are to develop a disease, how your DNA influences overall wellness - like whether you are more/less likely to be affected by caffeine - and whether you are a carrier for certain genes).

Page Break

{If the answer to ***Q5 Have you ever used the services of an at-home DNA/genetic testing company like AncestryDNA or 23andMe? == No****, this version of the questions are displayed.*

If the answer to ***Q5 Have you ever used the services of an at-home DNA/genetic testing company like AncestryDNA or 23andMe? == Yes****, the questions in Appendix_D1 are displayed.*

If the answer to ***Q5 Have you ever used the services of an at-home DNA/genetic testing company like AncestryDNA or 23andMe? == Unsure*** *or* ***Prefer not to answer****, no further questions are asked.}*

Q7B If you were to complete an at-home DNA test, would you provide consent to the DNA-testing company to have your DNA data used for research purposes?

○ Yes (1)

○ No (2)

○ Unsure (3)

○ Prefer not to answer (4)

End of Block: Block 3

Start of Block: Block 4

Start of Block: NEW ADD

Q8.0B How have each of the following influenced your perceptions of at-home DNA testing:

	Not at all (1)	A little bit (2)	Somewhat (3)	Very much (4)	Prefer not to answer (5)
News articles	○	○	○	○	○
Media (television, movies, YouTube)	○	○	○	○	○
Biological relatives	○	○	○	○	○
Social Networking Sites (like Facebook, Instagram)	○	○	○	○	○
Advertising for DNA-testing services	○	○	○	○	○
Online forums (like Reddit)	○	○	○	○	○

Q8.1B Assume you have completed an at-home DNA test. Please rate how comfortable you are contributing your DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (3)	Very much (4)	Prefer not to answer (5)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

Q8.2B Assume you have completed an at-home DNA test. Please rate the degree to which would you like **others** who have also completed the test to contribute their DNA data for the following purposes:

	Not at all (1)	A little bit (2)	Somewhat (3)	Very much (4)	Prefer not to answer (5)
For research by pharmaceutical companies. (1)	○	○	○	○	○
For research by academic institutions. (2)	○	○	○	○	○
For research by non-profit organisations. (3)	○	○	○	○	○
For research by the government. (4)	○	○	○	○	○
For research by the police. (5)	○	○	○	○	○
For police investigations. (6)	○	○	○	○	○
For research by the DNA-testing company to improve their services. (7)	○	○	○	○	○

End of Block: NEW ADD

Start of Block: Block 11

Q9B Please rate how strongly you agree or disagree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	Prefer not to answer (5)
I can be identified by a DNA sample I provide for testing. (2)	○	○	○	○	○
My family might find out things they didn't want to know with an at-home DNA test. (6)	○	○	○	○	○
My DNA is my information and my information alone. (8)	○	○	○	○	○
What I do with my DNA is my business. (9)	○	○	○	○	○
My family members have a right to be concerned about me completing a DNA test. (11)	○	○	○	○	○
I am interested in finding biological relatives with	○	○	○	○	○

a DNA test. (13)					
You should select “Strongly disagree” for this statement. (23)	○	○	○	○	○
I do not need anyone's consent to take an at-home DNA test. (16)	○	○	○	○	○
Making at-home DNA test results public adds to the community. (18)	○	○	○	○	○
People who hide their DNA test results annoy me. (19)	○	○	○	○	○
DNA data is just like any other data. (22)	○	○	○	○	○

Page Break

Q21.1B For the following question, if an option doesn’t apply to you, please answer hypothetically.
Please rate the *overall* effect at-home DNA test results would have on each of the following entities:

	Negative (1)	No effect (2)	Positive (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your employment prospects (2)	○	○	○	○
Your siblings (3)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your insurance rates (6)	○	○	○	○
Your parents (7)	○	○	○	○
Your potential government benefits (9)	○	○	○	○
Current, existing children (16)	○	○	○	○
Future children (18)	○	○	○	○
Your grandparents	○	○	○	○

Page Break

Q21.2B For the following question, if an option doesn't apply to you, please answer hypothetically.
Please select whether each of the following entities should be involved in the decision to take an at-home DNA test:

	No (1)	Yes (2)	Maybe (3)	Prefer not to answer (4)
Yourself (1)	○	○	○	○
Your siblings (2)	○	○	○	○
Your friends (4)	○	○	○	○
Your colleagues (5)	○	○	○	○
Your parents (7)	○	○	○	○
Your grandparents (8)	○	○	○	○
Current, existing children (16)	○	○	○	○

Q21.3 Please list anyone else who should be involved in making this decision.

____

Q23A - Please list the reasons why you have taken an at-home DNA test. You can use bullet points.

Q23B - Please list the reasons why you chose **not** to take an at-home DNA test. You can use bullet points.

If you prefer not to answer, please enter 'prefer not to answer'.

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Q24B We will be conducting follow-up **audio-recorded** online interviews with a subset of interested participants. These interviews will be anonymous (we will not receive any information other than your Prolific ID). Please indicate your interest in participating below. You may still decline participation once contacted, if you change your mind.

○ Yes, I’m interested.

○ No, do not contact me for an interview.

Page Break

Q24B You have reached the end of the questionnaire. If you select "submit" and advance to the next screen, you will no longer be able to withdraw your data.

○ Submit my responses.

○ I wish to withdraw from the study and have my data removed. I understand that I will not be paid.

End of Block: Ending block

Appendix H

Study 2: Interview Script

The interviewer may not ask all of these questions, but will use them as prompts as needed to learn about the participants' understanding and opinion of the process.

Introductory questions

Q1: How many times has your family member completed at-home DNA testing?
- Has your family member uploaded their raw DNA data elsewhere for post-processing? Can you tell me more about this?

Q2: How are you biologically related to the person who has completed the DNA test? (mention the options)

- Immediate family (child, sibling, half-sibling, parent, grandparent)
- Extended family (uncle, aunt, cousin)

Q3: Why did you refrain from taking an at-home DNA test?

Q4: Is there anyone you would encourage to do a DNA test? (Anyone in your family?) Why/why not?
Under what circumstances would you recommend someone do an at-home DNA test?

Understanding of the process

Q5: How does the process work?
- What happens after the swab is mailed in?
- What happens to the swab itself?

Q6: For what purposes does the company store the tester's data?

Q7: How accurate or inaccurate do you think an at-home DNA test is for ancestry purposes?
Q8: How accurate or inaccurate do you think an at-home DNA test is for health purposes?
If not explained, ask: Why do you feel that way?

Discussions with family (non-users, users)

[If there were multiple tests completed, ask them to focus on the one(s) they felt was most impactful.]

Q9: When were you informed about your family member’s at-home DNA test? (Before or after completing it?)

- How were you informed?

Q10: What were your initial thoughts/what was your initial reaction/how did you feel about it at the time?

If they found out after the test was done: If the family member had discussed this with you beforehand, what would you have said/thought about it? (Would you have encouraged, discouraged, or been indifferent to it?) Please explain.

Q11: How do you feel about that now (after some time has passed)?

Q12: Were you curious about the results? Why/ why not?

Q13: Were the results shared with you? Why/why not?

Q14: Where did your family member share the at-home DNA testing results?

If no: what are your thoughts on them sharing their results with friends? With other family? On social media?

If yes: what are your thoughts on that?

Q15: Are there any protective measures you wish your family member had taken before/when doing the DNA test?

Effects of DNA test on the family member

Q16: Does your family member’s DNA test affect you in any way? Does it affect the rest of their family?

Q17.1: What benefits, if any, are there to your family member from this DNA test?
Q17.2: What risks, if any, are there to your family member from this DNA test?

Q18.1: What risks, if any, are there to you from this DNA test?
Q18.2: What risks, if any, are there to you from this DNA test?

Q19: Would/does the results of a DNA test have similar or different impact on biological family members of different ages (e.g., on grandparents vs siblings vs children)? How might it affect them?

Q20 *[Ask if participant was uncomfortable with the DNA test]:*
Are there any actions your family member can take now that would make you feel more comfortable about the DNA test?

Ownership
Q21: Who should have a say/be involved in whether someone decides to take an at-home DNA test? Why/why not?

Q22: Who owns the results of an at-home DNA test? Who *should* own the results of an at-home DNA test?

Survey answers
Earlier, you had completed a survey as part of this study. I am now going to ask you for details on some of the questions. *[Go over survey answers].*

[The section "Third parties" will only be asked if there are at least 10 minutes remaining of the interview time].

Third parties
I'm going to list some institutions and ask for your opinion on them.
Q23: Would it affect either you or your family if X had your family member's DNA data?
Replace X with each bullet point, one by one.

- Law enforcement
- The government
- Academic institutions
- Pharmaceutical companies
- The DNA testing company itself
- The government (specifically immigration)
- Insurance companies
- An employer

Are there any other institutions you think should be mentioned in this list?
If yes: Why?

Concluding questions

Q24: Do you have any advice for someone considering an at-home DNA test?

Q25: Do you have any final comments? What are the most important points that you’d like me to remember from our conversation?