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Master Thesis

**Genetic Data Privacy and Consumer Choice
Behavior: An Exploratory Study on
Direct-To-Consumer Genetic Testing**

MSc in Marketing and Consumption (MAC)

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Abstract

The rapid growth of the Direct-to-Consumer Genetic Testing (DTC-GT) industry has raised significant concerns regarding the collection, storage, and use of highly sensitive genetic information. This study aims to address the existing research gaps by examining consumer privacy and choice behavior in the context of DTC-GT. To accomplish this, an extensive literature review and a theoretical framework based on privacy calculus and trust theory was used to construct a research model. This explains the consumer choice of sharing genetic data by conducting DTC-GT through incorporating perceived benefits, privacy concerns, information sensitivity, privacy control, and the moderating effect of trust in governmental law and regulations. The model was tested through an online survey and quantitative data analysis, based on a sample of 242 members of a Swedish national genealogy association to ensure a high-quality sample comprising a substantial genetic test-takers rate. Findings indicate that consumers engage in cost-benefit analysis, weighing privacy concerns against perceived benefits in their decision to undertake DTC-GT. Further, findings suggest that the importance of privacy control diminishes when there is a high level of trust in the law and regulation. Through uncovering results and analysis, this study contributes to the existing knowledge of consumer privacy in the DTC-GT industry and provides valuable insights for consumers to protect personal privacy, regulators to develop uniform policies, and businesses to improve privacy communication.

Keywords: consumer privacy, privacy calculus theory, trust, genetic data privacy, direct-to-consumer genetic testing, consumer choice behavior

Abbreviations:

DTC: Direct-to-Consumer

DTC-GT: Direct-to-Consumer Genetic Testing

CAGR: Compound Annual Growth Rate

GDPR: General Data Protection Regulation

Introduction

Consumer data analysis has always been an essential aspect of marketing practices. The emergence of cutting-edge technologies has facilitated data processing and exponentially expanded the amount of consumer data available (Blasco-Arcas et al., 2022). At the same time, recent scandals regarding Cambridge Analytics and Facebook have highlighted the controversial aspects of data collection and misuse, exposing how data can be employed to create psychological profiles with the intention to “manipulate” individuals’ voting decisions (Confessore, 2018). Such scandals demonstrate the immense power wielded by data and its potential exploitation in dystopian ways that consumers have not considered before. This data management issue becomes even more complex when sensitive information is involved.

A prime example of highly sensitive information is genetic information, which refers to unique biometric data containing essentially an individual’s composition and characteristics, being a highly influential factor in defining who they are (Daviet, Nave & Wind, 2022).

While numerous benefits can be reaped from DNA data usage, privacy concerns need to be addressed. For example, the potential misuse could lead to severe consequences such as individuals facing discrimination in employment, damage of personal relationships, and increased insurance premiums leading to significant societal implications (Friend et al., 2018; Molnár-Gábor & Korbél, 2020; Nill, Laczniak & Thistle, 2019). Furthermore, Chinese authorities began utilizing DNA samples to track and identify individuals, particularly the Muslim Uighur ethnic minority, setting precedents for genetic surveillance (Wee & Mozur, 2019). Moreover, companies such as Spotify and Aeroméxico have started showing interest in owning the genetic data about their customers by launching innovative campaigns that require the upload of genetic information in exchange for personalized services (Moore, 2018; Vora, 2019). Businesses having access to such information could be potentially harmful to users in several cases, such as targeting and exploiting vulnerable individuals genetically prone to addiction (Daviet, Nave & Wind, 2022). Another concern relates to the re-identification of DNA data, meaning that

even the removal of protected health information may not prevent skilled data analysts from identifying individuals in an anonymized dataset (Gymrek et al., 2013; Saha et al., 2020). This re-identification process would pose higher risks in case of DNA data breaches. Besides, due to the nature of the genetic data, the privacy of one's relatives should also be carefully considered when conducting genetic tests. Genetic information not only relates to individuals who have done genetic testing but also extends to their relatives and future generations (Webborn et al., 2015). Above all, the presence of these numerous privacy concerns related to genetic data underscoring the necessity to handle it carefully.

However, consumers can now access their genetic data effortlessly through Direct-to-Consumer Genetic Testing (DTC-GT), where private companies sell genetic tests directly to individuals without the involvement of medical professionals. Further, the industry of DTC-GT is rapidly growing as the booming desire for such products among consumers is driven by curiosity (Friend et al., 2018) and other factors, including assessing disease risk, exploring ancestry, and contributing to scientific research (Mählmann et al., 2016). This industry has experienced substantial growth since its emergence over two decades ago (Lang & Winkler, 2021). In 2021, the global market for the DTC-GT industry was valued at around 1.2 Billion Euros and is expected to grow significantly over the next decade (Research and Markets, 2022). Particularly, the European DTC-GT market ranking second worldwide after the U.S. is anticipated to grow at a Compound Annual Growth Rate (CAGR) of 10.6% (Market Data Forecast, 2022). Essentially millions of people around the world have conducted DTC genetic tests, sharing their most unique and personal information, resulting in these companies collecting large databases of human DNA (Regalado, 2019). These databases are becoming progressively valuable assets for DTC-GT companies and society (Tillmar et al., 2021), and the use of genetic information by third parties is no longer a distant future scenario. For instance, DTC-GT providers have begun selling their customers' DNA databases to pharmaceutical companies for the production of new drugs' treatment (Fox, 2018; Pitts,

2017), recognizing the economic value of genetic data (Daviet, Nave & Wind, 2022; Human & Kazzazi, 2021). Furthermore, law enforcement has been able to use DTC-GT companies' databases to solve and track down suspects, as was the case with the Golden State Killer and, more recently, a double murder case in Sweden (Kolata & Murphy, 2018; Tillmar et al., 2021). This usage is sometimes undertaken without the consumer's consent (Haag, 2019; Schuppe, 2019), and may lead to innocent family members being under police surveillance (Robinson & Nelson, 2014). It is also worth noting that a notable number of people ordered DTC-GT for others without their consent, especially minors under the care of the person ordering the test (Christofides and O'Doherty's, 2016), which raises concerns as children are generally not considered capable of giving consent in such situation (Webborn et al., 2015). Therefore, aforementioned situations raise privacy concerns about individuals' lack of awareness regarding the collection and use of their genetic information when conducting DTC-GT, as well as the potential commodification of such data (Human & Kazzazi, 2021). It seems that consumers not only lack knowledge regarding the potential risks associated with genetic data (King, 2019), but also the data storage period and protection measures, including low knowledge about genetic data protection laws and a tendency not to read DTC-GT privacy policies (Baig et al., 2020; Christofides & O'Doherty, 2016; Mladucky et al., 2021).

Despite the rise of this industry and the accompanying increase in genetic privacy concerns, research on DTC-GT data privacy is still undeveloped. As stated by Clayton et al. (2018, p. 14), "the picture of genetic privacy that emerges from this systematic literature review is complex and riddled with gaps.". Understanding consumer privacy and choice behavior in the context of DTC-GT is extremely important due to the potentially severe and long-lasting consequences of mishandling genetic data for society at large. In addition, this field is dominated by the medical and, more recently, by human-computer interactions perspectives, with very little research done with a business and marketing focus ([Appendix 1](#); Nill & Laczniak, 2022). Marketers can offer valuable insights to this research field as experts in analyzing

individuals' behavior in consumable settings. Therefore, it is crucial for marketers to explore and provide insight for consumers, regulators, and businesses operating in the DTC-GT industry. This is especially important as the discussion on consumer genetic privacy is still in an exploratory stage, mainly being examined using qualitative methodologies ([Appendix 1](#)). So far, no research model has been used to understand how the underlying factors would influence the choice behavior of taking a DTC-GT hence sharing genetic data. This research gap needs further exploration since it is important to understand individuals' reasoning and investigate how genetic privacy concerns influence consumer decision-making as stressed by Clayton et al. (2018) and Hendricks-Sturup and Lu (2019). In specific, Clayton et al. (2018) underline the importance of comprehending the trade-offs between benefits and risks that lead to the decision to conduct DTC-GT. Besides, previous literature on the privacy perspective of DTC-GT has predominantly focused on the North American market with only one article aiming for a more global perspective, as indicated by [Appendix 1](#). This lack of representativity highlights the need to continue developing a global perspective, as emphasized by researchers such as Baig et al. (2020) and Saha et al. (2020). Additionally, trust in governmental law and regulations has been identified as a key variable affecting individuals' decision to undergo DTC-GT (Baig et al., 2020; Grandhi & Plotnick, 2022), varying considerably from different cultures and regions. Therefore, conducting such exploratory research from consumer perspectives in a different location, such as Europe, can underscore different conclusions.

Above all, this exploratory study aims to contribute to the existing knowledge of the consumer privacy field by investigating the decision to conduct DTC-GT in the context of highly personal and sensitive genetic information. This could shed light on the complex interplay of factors that influence consumer choice behavior and provide insights into consumers' perspectives about the collection, storage, and use of personal genetic data. Therefore, the following research questions were posed:

RQ: What factors impact the consumers' choice behavior of sharing genetic data by conducting

DTC-GT, and how do these factors subsequently affect sharing behavior?

It is pertinent to mention that this study defaultly deems the behavior of conducting DTC-GT to be synonymous with sharing behavior. Therefore, the term "conducting DTC-GT" is used in the following to refer to the behavior of sharing. In order to answer the research question, an extensive literature review will be performed to provide a comprehensive overview of DTC-GT background and consumer's privacy perspectives. These insights connect with a solid theoretical framework comprising Privacy Calculus and Trust Theory to derive hypotheses and build the research model. This research model will be tested through an online survey and further quantitative analysis. The findings will be further discussed regarding the influence of factors on consumers' decision to conduct DTC-GT. Lastly, the reflections on the research inadequacy and possible directions of future research hope to inspire more in-depth studies towards consumer perspectives of DNA data privacy in marketing.

Literature Review

Genetic Data and DTC-GT

DNA refers to a molecule that carries the large amount of genetic information contained in the human genome (National Research Council, 1988). The human genome comprises around 3 billion base pairs, the order of which determines the genetic information encoded in the DNA. It is essential to note, however, that the great majority of base pair positions stay the same across individuals, and less than two percent of base pair sequences actually differ, giving information that distinguishes one person from another (Daviet, Nave & Wind, 2022). Ultimately, this genetic information provides an incredible amount of information about an individual as it is unique and essentially unaltered biometric data. This is emphasized by behavioral genetics, which has shown that genetics influence human behavioral characteristics to a certain degree (Daviet, Nave & Wind, 2022). Additionally, by examining genetic variants or genome-wide association studies, numerous valuable insights for marketers can be extracted from one's genetic information, such as personality traits, the propensity to have specific health problems,

intolerance to certain foods, physical features, and others (Daviet, Nave & Wind, 2022). This indicates the broad range of possible applications for genetic information, which goes beyond ancestry and susceptibility to certain diseases. Specifically, this highlights the potential uses that genetic data could have for marketing in order to target, segment, and personalize services to customers and ultimately explain consumer behavior (Daviet, Nave & Wind, 2022).

Direct-to-Consumer Genetic Testing is simply a genetic test obtained without the involvement of traditional healthcare providers, offered by a private company. The customer is often required to give a saliva sample by spit or cheek swab, which is then analyzed in the company's laboratory (Christofides & O'Doherty, 2016; Medline Plus, n.d.). As stated in the companies' terms and conditions, this biological sample is frequently kept by the company for up to ten years (MyHeritage, 2023; 23andMe, 2022), from which the consumer's DNA can be extracted. Examining all the information base pairs in someone's DNA is expensive and, as previously observed, may reveal little significant information to an individual. As a result, firms extract just particular elements of one's genetic information and only analyze a limited number of genes and variants in order to expose information requested by the consumer following the type of test purchased (Medline Plus, n.d.). Nevertheless, this does not preclude companies from possibly conducting subsequent analyses on stored biological samples if they possess a financial incentive to do so.

Privacy Policies in DTC-GT Companies

Presenting transparent and comprehensible information on the privacy policies (i.e., terms and conditions and privacy statements) is essential to enable informed decision-making and explicit consent by the consumer. Notably, companies such as Ancestry (2023), MyHeritage (2023), FamilyTreeDNA (2022), and 23andMe (2022) provide detailed privacy statements, yet they vary in their level of specificity regarding the sharing of user data with third parties. Despite that, Christofides and O'Doherty (2016) and Niemiec and Howard (2016) suggest that many DTC-GT companies fail to provide sufficient information in privacy policies about how genetic data will be used

and shared by both the company and third parties, as well as other potential hazards of sharing such data, for instance, the risks of re-identification. Further, some companies do not provide a privacy policy, while others only provide enlightenment about website interactions (Christofides & O'Doherty, 2016). This is more accentuated in Eastern markets such as China since, according to a study by Du and Wang (2020), more than half of the DTC-GT providers do not present a privacy policy, and 94% do not have any informed consent forms. Besides, Skeva, Larmuseau, and Shabani (2020) noted that various DTC-GT providers state in their privacy policies that consumer data may be disclosed to government authorities when requested, often without warning to the consumer. It is also worth noting that for the usage of data for research purposes, firms such as Ancestry (2023), MyHeritage (2023), FamilyTreeDNA (2022), and 23andMe (2022) require additional consent, yet this is not applicable for all companies since, according to Laestadius, Rich, and Auer (2017), only a few companies require extra consent for health-related research. In general, it seems that companies do not provide clear or adequate information in privacy policies. This lack of transparency and information limits individuals' ability to make informed decisions about the use of their personal information and compromises the validity of the consent (Christofides & O'Doherty, 2016; Niemiec & Howard, 2016). Thus, this heterogenic problematic picture in companies' privacy policies highlights the importance of governmental law and regulations applicable to DTC-GT.

Governmental Law and Regulations

As seen previously, companies often fail to provide sufficient information for the user to make an informed and valid consent decision. In this sense, governmental regulation assumes an important position in protecting the consumer and its data. Europe portrays a relatively mature privacy regulation system fostered by the EU General Data Protection Regulation (GDPR), which strengthens data privacy protections for EU customers and imposes stricter regulations on genetic data (Shabani & Borry, 2018). The rights to data privacy and informed medical consent are two separate fundamental rights that EU consumers exercise when they buy online DTC genetic

tests (Mahmoud-Davis, 2020). Above all, GDPR enables a concise picture among European countries. However, despite the protection offered by the GDPR, the research exemption in the regulation allows companies to store sensitive data indefinitely and exempts them from informing individuals about the processing of their data (Human & Kazzazi, 2021).

In the context of DTC-GT, the law research in the country specifically discusses three aspects of the genetic testing process: medical supervision, genetic counseling, and informed consent (Hoxhaj et al., 2020). Each country has developed genetic data and privacy protections, with some having specific laws and others using general healthcare laws (Fears & Ter Meulen, 2013); Kalokairinou et al., 2018). For example, in Sweden, the national legislation named The Genetic Integrity Act (2006) only regulated DTC-GT when it came to the use of certain biotechnology or services for medical reasons or as part of the practice of medicine (Kalokairinou et al., 2018). Considering the perspectives of other countries, the French Law (Article 16–1 Civil Code) only allows individuals to conduct genetic tests for specific medical or scientific research purposes instead of any personal identification needed with third parties, not to say ordering for others (Borry et al., 2012). Borry et al. (2012) also found that although the law in Switzerland prohibited or strictly restricted the placing of DTC-GT devices on the market, it will somewhat tolerate DTC-GT as long as they are limited to personal use and do not pose a risk to public health. In Germany, the availability of DTC genetic tests is obviously constrained. Only after receiving appropriate information about the purpose, nature, and outcomes of the genetic test, as well as after receiving the patient's agreement, can a doctor perform a genetic test (Fukuda & Takada, 2018). The laws and regulations in Belgium, Portugal, and the Netherlands are more open for sharing genetic test data (Borry et al., 2012), yet still having unclear gray areas about provision of DTC-GT. It can be seen that laws and regulations vary among countries and keep evolving.

DTC-CT Consumer Privacy Perspectives

The research is currently limited when examining consumer privacy perspectives in the context of DTC genetic tests. [Appendix 1](#)

aims to provide a comprehensive overview of the existing literature on this topic which summarizes the key contributions of authors in the last ten years. The selected articles specifically focus on DTC genetic tests rather than traditional genetic testing conducted by medical professionals or for research purposes.

Prior research indicates that consumers expect companies to act in their best interests and prioritize privacy protection (Bollinger et al., 2013; Christofides & O'Doherty, 2016; King, 2019). At the same time, studies have shown that individuals are aware of the secondary use of their genetic data (Baig et al., 2020; Mladucky et al., 2021; Saha et al., 2020). Consumer attitudes towards sharing their genetic information with third-party entities vary depending on the entity and intended purpose. In previous studies, participants generally feel comfortable with their data being used for research purposes (Mladucky et al., 2021; Ruhl et al., 2019), and some studies even suggest that the potential contribution to medical advances and research can motivate individuals to participate in genetic information sharing (Haeusermann et al., 2017; Saha et al., 2020). However, participants seemed to be extremely against certain purposes, such as the usage by third parties, especially when it involves some kind of profit from their data (Baig et al., 2020; Critchley et al., 2015; Mladucky et al., 2021). Another common finding among previous research is the lack of knowledge regarding the potential risks associated with genetic data (King 2019; Roberts et al., 2017; Sahoo et al., 2022). Consumers were unsure about how long their data is stored and what happens after processing (Baig et al., 2020; Grandhi and Plotnick, 2022), and most individuals were unaware of laws protecting against genetic discrimination in the workplace and insurance despite expressing concerns about it (De Cristofaro, 2013; Mladucky et al., 2021; Sahoo et al., 2022). Additionally, many individuals did not read the DTC-GT privacy policy (Baig et al., 2020; Christofides & O'Doherty, 2016; Haeusermann et al., 2017; Mladucky et al., 2021). Despite that, only a few perceived this lack of knowledge as a potential threat (Baig et al., 2020). The findings of previous literature will be further explored in the following sections concerning the various constructs examined in this study.

Theoretical Framework

According to Westin (1967), information privacy relates to one's capacity to manage and control personal information collection, usage, and disclosure. Numerous theories and frameworks have been used to better understand the factors that influence people's decisions to give up control over their personal information. Among these, the privacy calculus perspective has received significant attention as one of the most frequently utilized approaches (Yun, Lee & Kim, 2019) and has even been pointed out as the best framework to be used in this context (Culnan & Bies, 2003). Moreover, privacy calculus is frequently combined with other theories to enhance its relevance in specific research contexts (Keith et al., 2013; Kordzadeh & Warren, 2017; Sun et al., 2015). This section extends privacy calculus by introducing trust theory focusing on governmental law and regulations trust.

Privacy Calculus

Privacy calculus is a theoretical framework commonly used to understand consumer decisions to disclose personal information (Yun, Lee & Kim, 2019). This framework was first introduced by Laufer and Wolfe (1977) and since then has been empirically supported by numerous studies (Dinev & Hart, 2006; Kim et al., 2019; Xu et al., 2009). Privacy calculus can be described as a cognitive process that antecedes behavioral reactions regarding one's privacy disclosure (Kim et al., 2019). Closely related to social exchange theory, this framework suggests that individuals engage in a cost-benefit analysis evaluating the benefits of disclosure data against the perceived risks or costs (Dinev et al., 2006). This framework has recently been tested further in experimental studies demonstrating the causality between privacy calculus and privacy behavior (Fu, Zhang & Li, 2023; Wottrich, van Reijmersdal, & Smit, 2018). According to Fu, Zhang, and Li (2023), individuals subconsciously categorize services based on their benefits, and privacy calculus impacts privacy decisions by determining the number of cognitive resources employed in a privacy decision. This suggests that individuals will devote greater cognitive resources if the costs outweigh the benefits, resulting in a decreased propensity to disclose personal information (Fu, Zhang & Li, 2023;

Dinev & Hart, 2006). Moreover, by examining several contexts, Kim et al. (2019) state that privacy calculus is more evident in the health context as individuals are less willing to disclose data for perceiving higher privacy risks. Some other studies have explored this framework in health information privacy contexts, focusing on highly sensitive information, including the choice to use wearable technology (Li et al., 2016); health devices (Princi & Kraemer, 2020); electronic health records (Cherif, Bezaz & Mzoughi, 2021); and contact tracking apps (Carlsson Hauff & Nilsson, 2023). As mentioned before, privacy risks are emphasized in health contexts (Kim et al., 2019), and this might be a reflection of a higher sensitivity to health-related information (Bansal & Gefen, 2010; Li et al., 2014). Privacy is a complex concept that requires the assessment of several variables affecting an individual's privacy decision-making process (Li, Sarathy & Xu, 2011; Liu, Yan & Hu, 2021). Taking this into consideration, privacy calculus is considered a flexible framework that can adapt to different scenarios and contexts through its positive and negative variables (Fox, 2020; Li et al., 2016), and several studies have explored multiple antecedents in different contexts.

Privacy calculus has not been used as a theoretical framework in prior literature on DTC-GT privacy perspectives. Nonetheless, several studies have found that participants evaluate the risks/costs and benefits of conducting the tests and frequently believe that the personal and social benefits outweigh the costs involved (King, 2019; Saha et al., 2020; Grandhi & Plotnick, 2022).

Perceived Benefits

Perceived Benefits in privacy calculus theory is defined as the ability to control what data is gathered, how it is used, and with whom it is shared (Yun, Lee & Kim, 2019). In the context of DTC-GT, it is common to see that consumers frequently over-optimistic towards perceived benefits and hence underestimate the risks of data sharing regarding DTC-GT (Grandhi & Plotnick, 2022; King, 2019; McGowan, Fishman & Lambrix, 2010; Saha et al., 2020). For instance, in the study of Grandhi and Plotnick (2022), participants perceived more benefits regarding DTC-GT, whereas risk perceptions had less impact on their decision.

The perceived benefits of DTC-GT may include: learning about ancestors and building a family tree (Baig et al., 2020); finding new and lost family members (Baig et al., 2020), gaining knowledge on health-related information and making informed decisions regarding their health and lifestyle (King, 2019; McGowan, Fishman & Lambrix, 2010); entertaining (King, 2019); and fulfilling an individual's interest (Dinev & Hart, 2006; Widjaja et al., 2019). Taking this into account, the hypothesis can be formulated as follows:

H1: Perceived benefits positively impact consumers' decision to conduct DTC-GT.

Privacy Concerns

Privacy concerns is a highly influential construct frequently employed by researchers to investigate various aspects of privacy behavior (Bélanger & Crossler, 2011; Shen et al., 2019). In this paper, privacy concerns assume the role of the cost factor in the privacy calculus cost-benefits analysis, which has been previously tested in earlier studies employing a privacy calculus model (Chen, 2018; Dienlin & Metzger, 2016; Li, Cho & Goh, 2019; Rehman, Manycam & Charchafchi, 2022). Furthermore, privacy concerns are confirmed to determine behavior in particular backgrounds and share an equally vital function as benefits (Dienlin & Metzger, 2016). Privacy concerns imply apprehension or fear often related to the potential risks of sharing private data from the standpoint of privacy calculus (Cherif, Bezaz & Mzoughi, 2021; Dinev & Hart, 2006). Multiple studies have shown privacy concerns to influence individuals' decision-making by negatively affecting their willingness to share personal information (Baruh, Secinti & Cemalcilar, 2017; Dinev et al., 2013). Accordingly, privacy concerns have greater significance in sensitive contexts (Li et al., 2016), such as the case of genetic information. Although studies from Mählmann et al. (2016) and King (2019) demonstrated low levels of concern accompanied by a lack of awareness regarding the potential risks of disclosing genetic data. Ruhl et al. (2020) and Christofides and O'Doherty (2016) reported that approximately half of the respondents were extremely concerned about DTC-GT companies failing to protect their identity and sharing their information without their consent. Variations in sample groups might explain these

considerable differences across research, as the first studies only considered persons who had done the test. Those who have already conducted DTC-GT generally have lower levels of privacy and security concerns, particularly from those who have not, especially those who express a lack of interest in taking the test in the future (Christofides & O'Doherty, 2016; Grandhi & Plotnick, 2022). Common concerns relate to unethical misuse of genetic data by third parties leading to discrimination by employers or insurance companies and government surveillance (Baig et al., 2020; Grandhi & Plotnick, 2022). Furthermore, some individuals express concerns regarding the privacy of their relatives or descendants (Grandhi & Plotnick, 2022; Haeusermann et al., 2018). These concerns can be significant enough to discourage individuals from using testing kits (Grandhi & Plotnick, 2022). Building on this, the hypothesis can be stated as follows:

H2: Privacy concerns negatively impact consumers' decision to conduct DTC-GT.

Information Sensitivity

According to McKnight, Lankton, and Tripp's (2011) definition, information sensitivity is the belief that disclosing certain information may lead to a loss of privacy when information is shared with individuals who have malicious intentions. There is typically a higher perceived sensitivity for health-related information (Li et al., 2016; Bansal & Gefen, 2010; Kim et al., 2019) in specific genetic information was considered highly sensitive data (Markos, Milne & Peltier, 2017; Schomakers et al., 2019). Additionally, perceptions of information sensitivity can vary significantly across individuals, cultural backgrounds and different countries' protective regulations (Markos, Milne & Peltier, 2017; Schomakers et al., 2019). In the case of DTC-GT, genetic data may be considered of especially concern by many as it constitutes highly personal information and is difficult to anonymize. Nevertheless, considering general perspectives of individuals regarding DTC-GT in previous literature, it is clear that many people do not consider DNA to be particularly sensitive personal information (King, 2019). Reasons may include not considering themselves as potential targets claiming they have nothing to hide; lack of understanding about the potential

interest and misuse of their DNA data; and lack of understanding of DNA data as numerous participants believe that sharing raw data, as opposed to personal identification information, does not pose significant risks to their privacy (Grandhi & Plotnick, 2022; Baig et al., 2020). Given that our sample comprises individuals who are highly involved in genealogy, it is unlikely that these limitations in consumer understanding and lack of knowledge will be significant. Drawing on this, the hypothesis can be articulated as:

H3: Information sensitivity negatively impacts consumers' decision to conduct DTC-GT.

Privacy Control

Privacy control is a distinct and significant factor in privacy-related models (Yang et al., 2020), which is defined as a strong feeling of anonymity, secrecy, and confidentiality from consumers over the disclosure and subsequent use of their personal information (Dinev et al., 2013; Xu et al., 2008). Most consumers believe they have little control over their personal data since they perceive the company and third parties to have the greatest control over its storage and use (Baig et al., 2020; Grandhi & Plotnick, 2022). Another insightful viewpoint is that due to unique life circumstances that made it possible for governmental, medical, insurance, and legal organizations to access people's data, people believed they had lost the ability to control particular information about themselves concerning third parties (Haeusermann et al., 2018). Respondents generally seek greater transparency and control in sharing their genetic data and insist that it should not be released without their explicit consent (Grandhi & Plotnick, 2022; Baig et al., 2020; Saha et al., 2020). Considering this, some individuals hesitate to undergo DTC-GT to maintain control over their data, while others opt to delete their data from the company database to regain partial or total control (Grandhi & Plotnick, 2022; Baig et al., 2020). Based on this evidence, the hypothesis can be formulated as follows:

H4: Privacy control positively impacts consumers' decision to conduct DTC-GT.

Trust Theory

Trust concept, in its numerous different variations, has been used in combination with

the privacy calculus framework by several researchers (Dinev & Hart, 2006; Krasnova, Veltri & Günther, 2012; McKnight, Choudhury & Kacmar, 2002; Naous et al., 2019; Premazzi et al., 2010; Xu et al., 2009). Despite being recognized as a critical element of social interactions in the literature, defining and quantifying trust remains challenging in empirical investigations, as its definition often varies in different scenarios (Rousseau et al., 1998). Nevertheless, according to Rousseau et al. (1998), the majority of academics agree on a basic definition of trust in which "confident expectations" and "willingness to be vulnerable" are essential parts of the concept. Following the definition of Mayer, Davis, and Schoorman (1995, p. 712), trust is "the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party." Considering this definition, it is relevant to consider the relationship between trust and control. In research, the connection between these two constructs has been a topic of debate, with some arguing that they are supplementary while others suggest they can substitute each other (Balboni, Marchi, & Vignola, 2018). Scholars such as Balboni, Marchi & Vignola (2018), Neves and Caetano (2006), and Das and Teng (1998) support the idea of a supplementary relationship, highlighting the moderating effects between trust and control. Specifically, Balboni, Marchi, and Vignola demonstrated the moderating effect of trust on control. Similarly, Andaleeb (1995) conducted experimental research to explore the impact of trust levels on control relationships, concluding that individuals with lower trust tend to seek higher levels of control compared to those with higher trust. Interaction between trust and control constructs was also proposed as a possibility in light of privacy calculus by Dinev and Hart (2004).

In the context of genetic testing and following the definition of Rousseau et al. (1998), Raz et al. (2020) define DTC-GT user trust as the willingness of users to engage while assuming that the organization would uphold its commitments, regardless of the user's ability to observe or control the organization's behavior. Trust becomes fragile at the consumer level in DTC-GT, unlike the traditional healthcare

industry, in which medical secrecy governs the connection between patients and healthcare professionals, fostering ongoing mutual trust (Cherif, Bezaz & Mzoughi, 2021). Nevertheless, looking at previous literature, it is notorious that many individuals still turn to their country's regulation to create this feeling of trust and alleviate any concerns associated with their genetic privacy (Baig et al., 2020; Grandhi & Plotnick, 2022; Haeusermann et al., 2018). The findings of Critchley et al. (2015) suggest that regulation is vital to explain consumer choice behavior and highlights that enhancing regulation would significantly boost markets for DTC genetic tests. Trust in governmental law and regulation is therefore a topic frequently mentioned by consumers in numerous DTC-GT consumer perspective studies assuming a central position on one's decision to conduct DTC-GT. For those reasons, this study focuses on this aspect of trust.

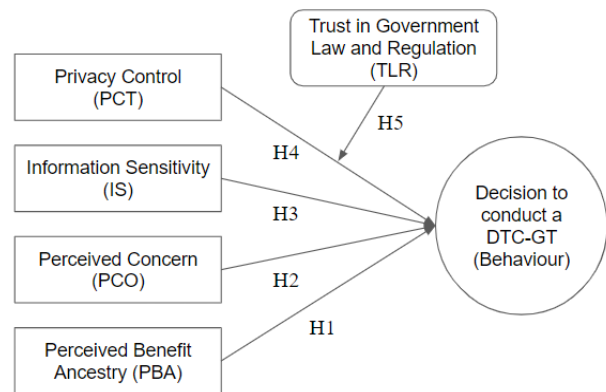
Trust in governmental law and regulation

Taking inspiration from Xu et al. (2009) and Krasnova and Veltri (2010), trust in governmental law and regulation can be defined as the belief that the legal framework ensures the protection of personal data by also securing that businesses comply with government regulations regarding the appropriate collection and usage of personal information. Information sharing is significantly impacted by data protection laws, such as the GDPR in Europe, which mandate consent for the processing of personal information (Zaeem & Barber, 2020). Therefore, if regulatory mechanisms provide a secure environment where service providers have restrictions and limitations on using consumers' personal information, individuals can feel comfortable disclosing their information (Naous et al., 2019). Grandhi and Plotnick's (2022) findings report that many individuals decide to divulge their private genetic data to DTC-GT firms because they have faith in a number of systems, including social, political, and legal ones. Remarkably, participants showed confidence in their nation's rules and laws, believing that they would protect their genetic information from prejudice or other undesirable effects (Grandhi & Plotnick, 2022). Following the participant statement presented in Grandhi and Plotnick (2022), "I just don't worry about things like

this. So what if someone gets my DNA results? I don't live in China." it becomes clear that the individual feels less necessity of controlling who has access to their genetic information due to trust in systems operating in their country, ultimately resulting in a low level of concern. This is also supported by Baig et al.'s (2020) study as it found that some participants feel more secure because they live in Canada rather than in other countries lacking stricter privacy laws and regulations. Additionally, the findings of Haeusermann et al. (2018) indicate that individuals trust the legislation systems of their countries of residence regarding genetic discrimination laws making one feel more protected. In this sense, it can be argued that when one trusts government law and regulation to protect one's data, control becomes less significant in the decision to conduct DTC-GT. In light of this, the hypothesis can be formulated as:

H5: The relationship between privacy control and consumer's decision to conduct DTC-GT is negatively affected by one's trust in governmental law and regulation.

Based on the hypothesis presented previously in this section, the following research model was created:



Methodology

In order to answer the research question, the online survey was chosen to collect practical materials and investigate the impact of independent variables, namely perceived benefit ancestry, privacy concerns, information sensitivity, and privacy control, on the dependent variable of sharing behavior. Furthermore, it analyzes the moderating effect of trust in law and regulation as well as privacy

control in the relationship between the independent variable of privacy control and the dependent variable of sharing behavior within the context of DTC-GT. The selection of a quantitative research approach is appropriate for this research paper. Firstly, it offers valuable assistance in formulating generalizable conclusions and predicting outcomes, laying the groundwork for in-depth exploratory study (Yilmaz, 2013). Surveys, in particular, serve as a highly effective tool for this purpose, exhibiting traits such as cost-effectiveness, flexibility, and the ability to gather data from a sizable sample (Bowling & Ebrahim, 2005). Additionally, a quantitative approach can examine the relationships between selected variables and provide more subjective explanations for specific issues in the social realm (Yilmaz, 2013). Qualtrics, an online survey software, was selected to acquire and assemble the necessary data for the research purpose.

Survey Design

The survey design procedure was divided into four steps: construct improvement, questionnaire setting details, experts' suggestions, and language translation. Firstly, as for the measurement items, the existing constructs were chosen and improved to fit the theoretical background, except for perceived benefits. Since the benefits associated with these products are highly specific and no prior scales exist in this domain, new scales were created based on insights gathered from previous qualitative results research (see [Appendix 2](#)). Privacy concerns' construct adapted from Xu et al. (2011) was modified to be more specifications of genetic data. The privacy control construct was adapted from Xu et al. (2008) and Dinev et al. (2013) to suit the specific genetic test context. Combining two constructs into this construct was necessary to comprehensively quantify privacy control for genetic data usage, not only on acquisition (i.e., PC1 who can access and PC4 what data will be collected), but also on dissemination (i.e., PC2 how companies use and PC3 which data will be released), in order to illustrate the entire information chain. The construct of trust in governmental law and regulations was adapted from the study of Naous et al. (2019). The information sensitivity construct adapted from Dinev et al. (2013) was modified specifically to

suit genetic data context and DTC-GT particularities, and item IS1 was set as a reversed question to deter respondents from providing hasty responses and aid in removing agreement bias (Hair et al., 2013).

After ensuring the improvement of constructs, the questionnaire was designed as five parts with a general introduction, filter questions, constructs, demographic questions, and open feedback. At the beginning of the questionnaire, participants were informed that all procedures for data collection are anonymous under the requirement of research ethics. Identifying information, including the names and email addresses of the participants, was not collected to ensure confidentiality. Followed by the purpose and context of the research, filter questions regarding having knowledge about DTC-GT were settled mainly to target valuable participants owning basic knowledge about genealogy, as well as distinguish people who have/have not done the test. Then, five constructs were measured with a 5-point Likert scale where 1= "strongly disagree" and 5="strongly agree". The 5-point scale is more suitable in accordance with Geuens and De Pelsmacker's (2017) recommendations considering characteristics of the target sample, which is made up of participants who might not have much experience with online questionnaires. The bipolar scale format will also simplify interpreting the two poles of the potential replies (Geuens & De Pelsmacker, 2017). As for demographic questions, except for the ordinary collection of gender and educational background, the question of age was asked with exact birth year instead of intervals not to compromise information accuracy and improve data quality. Personal assessment of their knowledge on DNA tests was also set here to better understand sampling features. Lastly, the fifth part contained free text feedback as supplementary that will enlighten the future improvement in industry.

Moreover, experts with decades of experience in the field were consulted to ensure the accuracy of terminologies mentioned in the questionnaire and to back up the convincingness of genealogy knowledge. The results were used to adjust the questionnaire's overall details. It is also worth noting that the questionnaire was translated into Swedish and

back-translated into English to ensure comparability and equivalence in meaning (Brislin, 1970). For example, DTC-GT will be clarified as the “at-home genetic test” in English and “DNA test” in Swedish. The pre-tests sent out among native speakers also assisted in improving question settings in a more comprehensive way.

Sampling and Data Collection

The study focuses on analyzing the perspectives of Swedish individuals who have conducted and have not conducted DTC-GT. Although there is limited information on the number of Swedes who have undergone DTC-GT, Swedish murder investigator Bo Lundqvist estimated that less than 0.5% of the population, approximately 40,000 individuals, have shared their genetic information with such companies (The Local, 2018). As a result, and to ensure a high-quality sample with a significant percentage of test takers, this research focused on Swedish individuals who are interested in genealogy. This population may not be fully representative of the entire Swedish population as it is biased towards individuals with a strong interest in genealogy and further in genetic testing, but selecting this population will secure a higher level of interest and familiarity with DTC-GT overcoming potential knowledge gaps. It is also important to note that these highly involved individuals will likely experience greater benefits due to their high interest in genealogy. To reach the population, Swedish communities of highly involved individuals in ancestry and genealogy were considered. In this paper, a Swedish national genealogy association, *Genealogiska Föreningen*, was selected to represent the Swedish market. This is one of the oldest and most influential genealogy associations in Sweden (Genealogiska Föreningen, 2023), therefore their members are likely to have a strong interest in genetic testing.

The survey was administered inside the association's community newsletter to all the current 2833 member's email contacts. Among these, 2238 people opened the email and were informed of the survey's existence there. The survey link remained active for one week after the newsletter went out in April 2023, during which time 275 responses were recorded. Participation in the survey was voluntary.

Nevertheless, to encourage participation and ensure member exclusivity, two reminders without the direct survey link were disseminated via the association's Facebook group, prompting members to check the newsletter in their email and participate in the survey. Of the 275 responses, 31 were excluded as participants did not complete at least 50% of the questionnaire, and 2 additional responses were removed as participants did not meet the screening requirement of demonstrating knowledge about DTC-GT. As a result, the final sample consisted of N=242 responses, yielding a response rate of approximately 10,81% when accounting for those who opened the email and were thus aware of the invitation to participate. No effort was made to exclude or include specific members to confirm that the sample was representative of the association's members. Additionally, the survey link was distributed only once to each participant to ensure that they only took the survey once.

Descriptive Statistics

To address the issue regarding the low response rate, the researchers conducted additional tests to assess the representativeness of the sample in relation to the characteristics of *Genealogiska Föreningen* members. Our sample closely matches the demographic characteristics of members of the Swedish genealogy association, particularly in terms of gender and age distribution. Not considering the 14 participants who chose not to answer the gender question, the sample included 49.6% male, 48.7% female, and 1.8% preferred not to say, which is almost the same as the association features (51.4% male and 48.6% female). As for age, the one-sample T-test was selected to compare the sample's mean (68 years old) with the association's mean (70 years old). The 2-tailed sig.=0.007<0.05 and low standardized error present that there is no significant difference. Above all, these criteria reflect the representativeness of the sample (SPSS, n.d.). Further, even though age was measured using birth year, the following results are reported in age categories to simplify the analysis. The majority of participants were aged between 60-79, with 32% aged 60-69 and 37% aged 70-79, while about 9% did not respond. Age distribution also aligns with members' characteristics regarding the relevant age groups. Nevertheless, individuals over 80 years

old were underrepresented in our sample, potentially due to lower usage of internet technology among this age group (Anderberg et al., 2020). Moving to the education level, the majority of participants were highly educated, with 31.9% holding a Bachelor's degree and 25.2% having a Master's degree. However, about 9.3% of the respondents chose not to reply to this question. Regarding knowledge about DNA testing, the mean was 3.9, with 24.6% of participants reporting having extensive knowledge about it, with about 8.4% of participants choosing not to reply to this question.

Regarding the number of people who have conducted DNA tests, 81,4% of the sample had taken the test (197), while only 18,6% had not. Among those who took the test, the majority took more than one test, with only 42.1% of the participants taking a single test. Most participants (67%) had taken their last test more than two years ago. The most commonly used companies for DNA testing were FamilyTreeDNA, Ancestry, and MyHeritage. In terms of the types of tests taken, the grand majority of participants had taken an ancestry test. Among those who had not taken the test, the intention to take it in the future was distributed fairly, with a mean of 2.91 on a 5-point Likert scale. About 24.4% stated that they would not take the test, while 22.2% stated that they would. Overall, the data suggests that the sample consisted of individuals who are relatively knowledgeable about DNA testing and have primarily taken ancestry tests (see [Table 1](#)).

Data Analysis

After data collection, exploratory factor analysis (EFA) was conducted to reveal the potential correlation among the constructs in the model. The decision to employ EFA is based on the absence of a predecessor model and the unfamiliarity of the dataset, as stated by Hair et al. (2013). Followed by EFA, Binary logistic regression with a moderator was employed to test the hypotheses. This approach was chosen to guide and explore further the relationship between independent variables and binary dependent variables. Most importantly, EFA and regression analysis offers the advantages of enabling indirect, multi-step hypothesis testing

and evaluating model validity and reliability (Bell, Bryman & Harley, 2022).

Table 1 Characteristics of sample

	Frequency	Valid Percent
Gender		
Male	113	49.60%
Female	111	48.70%
Prefer not to say	4	1.80%
Age		
less than 49	14	6.19%
50- 59	26	11.50%
60- 69	73	32.30%
70-79	85	37.61%
more than 80	28	12.39%
Educational Level		
Primary school or similar	4	1.80%
Secondary school or similar	73	32.30%
Bachelor's degree	72	31.90%
Master's degree	57	25.20%
Postgraduate degree	20	8.80%
Knowledge about DNA test		
1 - Little	1	0.40%
2	4	1.80%
3	68	29.80%
4	99	43.40%
5 - A lot	56	24.60%
Taking the Test		
Yes	197	81.40%
No	45	18.60%
If Yes		
Number of Tests		
1	83	42.10%
2	54	27.40%
3 or more	60	30.50%
Last test taken time		
less than 1 year ago	34	17.30%
1 to 2 years ago	31	15.70%
more than 2 years ago	132	67.00%
Companies used		
FamilyTreeDNA	159	
Ancestry	82	
MyHeritage	60	
23andMe	27	
Other	13	
Type of Test		
Ancestry	196	
Health	20	
Other	4	
If No		
Willingness to take the test		
1 - strongly disagree	11	24.40%
2	8	17.80%
3	10	22.30%
4	6	13.30%
5 - strongly agree	10	22.20%

EFA, Validity & Reliability

The planned research model consists of a single-item binary variable named sharing behavior (i.e., Behavior) and 18 observed items measuring 5 constructs: perceived benefits, privacy concerns, information sensitivity, privacy control, and trust in government law and regulation. The underlying dimensions of the items were initially determined by previous literature, thus appearing in the send-out survey. However, the constructs changed after conducting the exploratory factor analysis (EFA) employing principal component analysis (PCA) using the Varimax rotation method, which is one of the commonly available methods of rotation when the sample structure is clear (Corner, 2009). According to Bennett (2001), a missing data rate higher than 10% is problematic as it may result in biased statistical analysis. Considering this, as the missing rate of items in the constructs' observed items is always below 5%, replacement of the missing items is not concluded (Schafar, 1999). Based on EFA, three items were dropped in total due to two of them (PB3 and PB4) owning low communalities, and another one (IS1) with low factor loading difference between 2 factors and improved Cronbach's alpha dramatically after dropping (see [Table 3](#)). Notably, after deleting PB3 and PB4, the perceived benefits are related purely to ancestry, emphasizing finding family members and genealogy. Besides, regarding the extraction result of PCA, 5 factors were suggested to explain 89.38% data. According to Hair et al. (2013), both KMO and Bartlett's test in the factor analysis are satisfied with KMO=0.863 and p-value=0.000, which confirmed there were enough correlations between the items to move forward. In summary, following the results of EFA, 5 updated constructs are named: Perceived Benefits Ancestry (PBA), Privacy Concern (PCO), Privacy Control (PCT), Trust in Law and Regulation (TLR), and Information Sensitivity (IS) were created with 15 items. Besides, it can also be observed from [Table 2](#) that PBA has the higher mean (M=4,59) while Privacy Concern has the lowest mean (M=2,48).

To further test the reliability and validity, the following values are interpreted (see [Table 3](#)). As for reliability, firstly, Cronbach's alpha (α) of constructs are all acceptable subjected to the

role of thumb of values superior to 0.8 from Hair et al. (2013), ranging between 0.815 to 0.965), thus demonstrating that these reliable items can be summated. Moreover, the inter-item of each construct correlates highly with values between 0.697 and 0.891, well above the standard of 0.2 (Hair et al., 2013). Moving to validity, the logic is to compare the obtained result of the correlation coefficient against the critical values of the Pearson correlation (Laksita et al., 2021). After confirming the statistical significance (2-tailed) at 0.05 level, each item's sums are far above the 0.087 standard that validates the result (Niño-Zarazúa, 2012).

Table 2 Descriptive Statistics

	Items	Mean	S.D.
Dependent variable			
Behavior		0.81	0.39
Constructs			
Perceived Benefits Ancestry (PBA)	2	4.58	0.72
Privacy Concern (PCO)	4	2.48	1.18
Information Sensitivity (IS)	2	3.12	1.16
Privacy Control (PCT)	4	2.98	1.13
Trust in Governmental Law and Regulation (TLR)	3	2.81	1.02

Binary Logistic Regression Analysis

In this section, binary logistic regression is separated into two steps in order to test hypotheses. The first regression analysis aims to explore the relationship between dependent variable Behavior (BH) and independent variables: Perceived Benefit Ancestry (PBA), Privacy Concern (PCO), Privacy Control (PCT), Trust in Law and Regulation (TLR), and Information Sensitivity (IS). It lays the groundwork for the second regression with Trust in Law and Regulation (TLR) as a moderator to affect the relationship between the dependent variable, Behavior (BH), and the independent variable Privacy Control (PCT). Moreover, in the second step, the final model was constructed and shows the correlation between the dependent variable Behavior (BH) and independent variables: Perceived Benefit Ancestry (PBA), Privacy Concern (PCO),

Privacy Control (PCT), and Information Sensitivity (IS).

To begin with, the result of the first regression represents the statistical significance of the model (sig.<0.001) and its satisfied overall goodness of fit ($R^2=0.292$, Hosmer and Lemeshow Test sig.=0.102>0.05, Overall Percentage increased from 81.0 to 84.8). Using BH as the dependent variables, PBA and PCO are the only two significant independent variables, with the former positively affecting BH with Beta=0.904 and Sig.=0.003, and the latter negatively impacting on BH with Beta=-0.407, Sig.=0.013. It can be seen that PBA has the greatest effect on the model. However, to further profile data based on theory that emphasizes the synergy between trust and control, regression with moderating effects is taken into consideration in the next step.

As Field (2013) claimed, when the relationship between two variables depends on a third variable, this phenomenon is referred to as moderation (also known as effect modification). Firstly, the model exhibits statistical significance and demonstrates good overall fitness. This will be explained in accordance with the rule of thumb outlined by Tranmer and Elliot (2008), as follows: (1) The significance level (sig.) of <0.001 indicates a significant improvement in fit compared to the null model. (2) With an R^2 value of 0.314 >0.3, approximately 31.4% of the variance in the criterion variable can be attributed to the predictor variables in the model. (3) The Hosmer and Lemeshow Test, with a significance level of 0.584 >0.05, suggests no significant difference between the observed and predicted model. (4) The overall percentage has increased from 81.0 to 84.4. Although slightly lower than the first regression with 84.8, it still indicates a high accuracy rate for the model. Based on it, the moderator effects of TLR and PCT were tested, significantly and negatively influencing the relationship between dependent variable BH and independent variable PCT (Beta=-0.308 and Sig.=0.043), thus accepting H5. It means that the more consumers trust in government law and regulation, the less privacy control impacts on conducting DTC-GT. Nevertheless, there is no significant correlation between PCT itself with BH; hence H4 is rejected. Moreover, in the model, PBA and

PCO are still the only two independent variables significantly affecting with the former positively affecting BH with Beta=0.924 and Sig.=0.003, and the latter negatively impacting it with Beta=-0.439, Sig.=0.022, thus accepting H1 and H2. Compared with the first regression, the coefficients of both two increase moderately, and PBA continues to strongest influence BH. Lastly, with quite a low coefficient (0.068), there is no significant relationship between IS and BH; thus, H3 is rejected (see [Table 4](#)).

Table 4 Binary Logistic Regression

<i>Step 1</i>		
Dependent Variable: BH Omnibus Tests of Model Coefficients Sig.<0.001; Nagelkerke $R^2=0.292$; Hosmer and Lemeshow Test Sig.=0.102; Overall Percentage from 81.0 to 84.8.		
Variable	Beta	Sig.
Perceived Benefit Ancestry (PBA)	0.904	0.003
Privacy Concern (PCO)	-0.474	0.013
Privacy Control (PCT)	0.366	0.096
Trust in Law and Regulation (TLR)	-0.109	0.636
Information Sensitivity (IS)	0.016	0.935
<i>Step 2</i>		
Dependent Variable: BH; Moderator: TLR Omnibus Tests of Model Coefficients Sig.<0.001; Nagelkerke $R^2=0.314$; Hosmer and Lemeshow Test Sig.=0.584; Overall Percentage from 81.0 to 84.4.		
Variable	Beta	Sig.
Perceived Benefit Ancestry (PBA)	0.924	0.003
Privacy Concern (PCO)	-0.439	0.022
Moderator (TLR*PCT)	-0.308	0.043
Privacy Control (PCT)	0.305	0.132
Information Sensitivity (IS)	0.068	0.745

Table 3 EFA results

	Component					Communalities	Inter-item correlation matrix	Cronbach's α	Total significance (2-tailed)	Pearson Correlation
	1	2	3	4	5					
PB1: Taking an at-home genetic test is beneficial to help people find family members and relatives. PB2: Taking an at-home genetic test is beneficial as it can enable people to know more about genealogy and ancestry. #PB3: Taking an at-home genetic test is beneficial as it can provide valuable knowledge about genetic health risks. #PB4: Taking an at-home genetic test is beneficial as people can learn more about themselves.	/				0.849 0.897	0.838 0.861	1.000 0.697	PBA 0.815	0.005 0.002	0.182** 0.200**
PCO1: I am concerned that the genetic data submitted to at-home genetic test companies could be misused. PCO2: I am concerned that unauthorized people can find personal genetic data from at-home genetic test companies. PCO3: I am concerned about providing genetic data to genetic test companies because of what others (individuals or organizations) might do with it. PCO4: I am concerned about providing genetic data to at-home genetic test companies because it could be used in a way I did not foresee.	0.885 0.878 0.899 0.907					0.895 0.904 0.915 0.904	1.000 0.884 0.852 0.843	PCO 0.963	<0.001 0.008 0.001 <0.001	0.262** 0.171** 0.210** 0.237**
PCT1: I believe that people who do at-home genetic tests have control over who can access the genetic data they provide to at-home genetic test companies. PCT2: I believe that individuals have control over how at-home genetic test companies use their genetic data. PCT3: I think individuals have control over which genetic data is released by at-home genetic test companies. PCT4: I believe individuals have control over what genetic data is collected by at-home genetic test companies.		0.876 0.904 0.892 0.893				0.867 0.940 0.918 0.894	1.000 0.891 0.844 0.819	PCT 0.965	<0.001 <0.001 <0.001 <0.001	0.522** 0.523** 0.481** 0.512**
TRU1: Government regulations protect genetic data provided to at-home genetic test companies. TRU2: Government regulations protect individuals from any misuse of their genetic data by at-home genetic test companies. TRU3: Government regulations protect individuals from unauthorized use of their genetic data disclosed on at-home genetic test companies.			0.910 0.932 0.894			0.896 0.946 0.898	1.000 0.888 0.823	TRU 0.952	<0.001 <0.001 <0.001	0.503** 0.558* 0.528**
#IS1: I feel comfortable with the type of data (genetic data) that individuals have to submit when taking at-home genetic tests. IS2: I feel at-home genetic test companies gather highly personal data. IS3: The genetic data individuals have provided to at-home genetic test companies is very sensitive.				/		/	/	IS 0.842	/	/
<p>Note: # means an item dropped after the Exploratory Factor Analysis (EFA). Note: / means dropped item did not account for EFA. Note: The baseline for inter-item correlation matrix is always the first item (i.e. PB1, PCO1, PCT1, TRU1 and IS2). Note: **Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).</p> <p>Scale: 1=strongly disagree... 5=strongly agree. Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. Total variance explained (TVE)= 89.38%; KMO = 0.863; Bartlett's test: df = 105, p-value = 0.000.</p>										

Discussion

This research aims to investigate the factors influencing consumers' decision to undergo Direct-to-Consumer Genetic Test (DTC-GT) by employing the privacy calculus framework and integrating trust theory. Through an extensive literature review, developed research model, systematic data collection, and rigorous data analysis, the analysis yields significant findings regarding the impact of perceived benefits, privacy concerns, information sensitivity, privacy control, and trust in governmental law and regulation on individuals' decision-making process concerning DTC-GT. Furthermore, it explores the influence of trust in law and government on the relationship between privacy control and sharing behavior. The following section will delve deeper into the study's findings.

Perceived Benefits and Concerns

The findings support the hypothesis that perceived benefits significantly and positively impact consumers' decision to pursue DTC-GT (**H1**). The participants in this research demonstrated a strong inclination towards the ancestry benefits associated with DTC-GT. This preference can be attributed to the fact that the sample consisted of individuals with a high interest in genealogy. Notably, the mean score for this construct was 4.59 out of 5, indicating that the participants perceived these benefits to be of utmost significance. Moreover, perceived benefits was the most significant variable of individuals' decision to engage in DTC-GT, considering the largest coefficient of 0.924. Consistent with the privacy calculus framework and prior research, our analysis demonstrates that privacy concerns exert a significant and negative influence on consumers' decision to participate in DTC-GT; thus, **H2** is accepted. This finding underscores the significance of both concerns and benefits in individuals' decision-making process, emphasizing the core principle of privacy calculus, wherein decisions are shaped by weighing the costs against the benefits. This observation aligns with the assertions by Fu, Zhang, and Li (2023) and Dinev and Hart (2006), suggesting that consumers engage in a cognitive process involving a cost-benefit analysis when deciding whether to disclose personal information. However, it is crucial to note that although privacy concerns acted as a deterrent for

individuals considering DTC-GT, they had a relatively minor impact (-0.439) compared to the influence of benefits (0.924). This can be attributed to consumers generally maintaining an optimistic outlook regarding genetic data sharing and holding the belief that their personal information will be safeguarded rather than exposed (Grandhi & Plotnick, 2022;; King, 2019; Roberts et al., 2017; McGowan, Fishman & Lambrix, 2010). Hence, it is reasonable to deduce that individuals perceive the benefits associated with ancestry as more influential than their concerns when deciding to engage in DTC-GT and share genetic data. Additionally, another critical thing to consider is that the sample generally did not perceive a high level of concern (Privacy Concern mean is 2.48). This can be explained by the low percentage of non-test-takers in the sample since, as previous literature suggests, test-takers tend to perceive fewer concerns (Christofides & O'Doherty, 2016; Grandhi & Plotnick, 2022).

Information Sensitivity

Interestingly, the hypothesis that information sensitivity significantly and negatively impacts consumers' decision to conduct DTC-GT (**H3**) was rejected by the data analysis, indicating an insignificant relationship. Despite the high self-assessed knowledge of the DNA test among our sample, they did not perceive DNA as particularly sensitive personal information, as indicated by a mean score of 3.12. These results differ from statements by Markos, Milne, and Peltier (2017) and Schomakers et al. (2019), which emphasized a perception of high sensitivity concerning genetic information. Nevertheless, these align with previous research conducted by King (2019), Grandhi and Plotnick (2022), and Baig et al. (2020), which demonstrated that individuals generally do not perceive DNA as sensitive information. Previous studies highlighted a lack of understanding about DNA as a reason for this perception (Grandhi & Plotnick, 2022; Baig et al., 2020). Given the characteristics of our sample, it was anticipated a higher level of sensitivity to information; however, the results do not support this expectation. The findings suggest that even individuals with a comprehensive understanding of DNA privacy do not consider genetic data to be highly sensitive information. Therefore, the lack of sensitivity toward genetic data among individuals deeply involved in genealogy

cannot be solely attributed to a lack of comprehension. Nonetheless, it is important to consider that this phenomenon may also be explained by the Dunning-Kruger effect, which posits that individuals often overestimate their knowledge and literacy skills (Dunning, 2011). Thus, it suggests that the sample may not possess as much knowledge about DNA as reported in their self-assessment and may not fully comprehend the potential risks of compromising their genetic privacy and the sensitivity of this data.

Privacy Control and Trust in Governmental Law and Regulation

When examining the association between trust in governmental law and regulation and privacy control, it is noteworthy that while privacy control alone does not exert a significant impact on sharing behavior, thus leading to the rejection of **H4**, the moderating effect between these two variables is significant and negative, thus confirming **H5**. This indicates that trust is crucial in shaping the relationship between privacy control and sharing behavior. The negative relationship between privacy control and sharing behavior is weaker for individuals with higher levels of trust. In other words, when individuals have greater trust in the legal and regulatory framework governing privacy, their need for privacy control has a diminished influence on their decision-making process. This finding aligns with prior research emphasizing the complementary nature of general trust and control, specifically highlighting the moderating role of trust on control (Balboni, Marchi & Vignola, 2018) and supporting the notion that individuals with lower levels of trust are more inclined to seek heightened control compared to those with higher levels of trust (Andaleeb, 1995). Given this context, it is unsurprising to observe the prominent role of trust in law and regulation within the model. Contrasting DTC-GT with the traditional healthcare industry, trust itself becomes a delicate element, prompting consumers to seek additional protection from authoritative entities such as governmental laws and regulations (Baig et al., 2020; Grandhi & Plotnick, 2022; Haeusermann et al., 2018). In summary, these findings provide valuable insights into the intricate interplay between privacy control, trust in government law and regulation, and sharing behavior. They underscore the significance of trust in shaping

individuals' attitudes and behaviors related to sharing information, particularly when privacy control mechanisms are involved.

Conclusions and Implications

Overall, with a pioneering research model, this research contributes to understanding consumers' decision-making process regarding DTC-GT by employing the privacy calculus framework and trust theory. The findings emphasize the importance of perceived benefits, privacy concerns, privacy control, and trust in shaping individuals' decisions to engage in DTC-GT. After carefully examining the findings and answering the research question, it can be concluded that a combination of perceived benefits and privacy concerns influences the decision to pursue Direct-to-Consumer Genetic Testing (DTC-GT). The opposing effect of these components on the decision to conduct DTC-GT implies that the customer performs a cost-benefit analysis. Moreover, the level of trust in governmental laws and regulations plays a significant role in moderating the impact of privacy control on consumers' decision-making process. In this sense, privacy control becomes less critical whenever there is a high level of trust in the law and regulation. Given its consumer-centric focus, this study also tries to inspire genetic data protection by monitoring industry advancements and legislative developments in the DTC-GT industry. Following the study's findings, a detailed analysis of the potential implications is carried out.

Consumers

From the DTC-GT consumers' point of view, it is strongly recommended to prioritize protecting personal data privacy by gaining a comprehensive understanding of the associated cost factor and increasing sensitivity to potential risks. It is crucial to recognize that, in addition to considering the benefits, the cost factor also holds significant importance. Compared with our sample of participants demonstrating a certain level of knowledge in genealogy, it is essential for the general public to actively seek knowledge regarding risks and concerns in order to better safeguard their privacy in DTC-GT. This could be achieved by thoroughly reviewing the terms and conditions companies provide to assess the level of

support they offer in protecting user data. Furthermore, it is imperative for the public to regard their genetic data as sensitive information. Acknowledging the characteristics imposed by the nature of genetic data is crucial to understand the risks regarding re-identification, latent discrimination, and potential implications for relatives and future generations.

Governmental Law and Regulation

As reinforced by the findings, the European legal system must strike a balance between the unique circumstances of each country and achieve a consensus when regulating DTC-GT. Moreover, diligent oversight of commercial companies is also essential to enhance harmonization provisions and ensure compliance with established rules. Specifically, while the General Data Protection Regulation (GDPR) is hailed as a vital milestone in data privacy regulation, safeguarding the data of EU citizens (Zaeem & Barber, 2020), the varying and ambiguous requirements concerning DTC-GT across European countries impede the adequate protection of user privacy. Regarding the Swedish context, there is a need to consider broader regulations for DTC-GT rather than confining them solely to specific biotechnology or medical services. Establishing a clear, secure, and comprehensive legal framework that instills confidence in consumers and empowers them to maintain control over their data is crucial. To establish this, regulators can be inspired by focusing on common DTC-GT concerns in Europe and hearing the suggestions from layman's perspectives (Schaper et al., 2020). However, legislative changes alone are insufficient. It is equally critical to monitor and enforce compliance among companies to prevent the manipulation of data privacy clauses or the conduction of inconsistent policies. One approach to regulating them is to provide standardized templates for privacy policies, thereby preventing companies from exploiting legal loopholes to modify policies at their discretion.

Industry

Turning into the DTC-GT industry, it is imperative for companies to adhere to the general regulatory framework and to present simplified and transparent information while actively providing comprehensive privacy details. Besides, companies should also

emphasize their social and ethical responsibility regarding genetic data protection. Concerning data privacy policies, the survey's free text responses reveal a prevailing sense of limited control over genetic data among participants, stemming from a lack of knowledge regarding data usage, storage practices, company background, along with others. While DTC-GT companies such as Ancestry provide explanations within their terms and conditions (Ancestry, 2023), the presence of convoluted and complex language often confuses consumers rather than offering clear guidance, leading to time and patience investments for consumers to verify such information. Furthermore, many participants express uncertainty regarding the applicability of GDPR to America-based DTC-GT companies operating in Europe, thus perceiving a risk associated with sharing their DNA. Given the circumstances above, there remains considerable room for improvement in privacy policies within the DTC-GT industry, and data subjects have the right to receive proactive updates on any changes to company privacy policies. Moreover, companies should prioritize establishing public trust by assuming ethical responsibility. Previous research demonstrates that sharing genetic data with research institutions and official medical organizations garners more public trust compared to commercial third parties, potentially due to the perceived benefits of altruism and selflessness in advancing medical research (Shabani, Bezuidenhout & Borry, 2014; Haeusermann et al., 2017). Collaborating with authoritative institutions can serve as a means for companies to enhance their reputation among the public, but still, stringent supervision must be exercised throughout the entire process.

Limitation and Future Research

Despite the findings presented, it is essential to acknowledge and address certain limitations within the scope of this research. As for the sample feature, the distribution of samples is uneven, with a higher representation of individuals who have done DTC-GT than those who have not. This discrepancy makes it challenging to compare the cost factors between these two groups, as people who have taken DTC-GT tend to evaluate lower risks or concerns than those who have not (Christofides & O'Doherty, 2016; Grandhi & Plotnick,

2022). Further, the sample primarily consists of expert individuals in genealogy, which does not adequately represent the entire population of Sweden or other countries. Consequently, the prominence of perceived benefits related to ancestry is specific to our sample in comparison with health and trait benefits, which are also important motivators for conducting DTC-GT. Besides, while the privacy calculus framework is widely used to understand individuals' decision-making process regarding DTC-GT, it is crucial to recognize its limitations in accurately predicting consumer behavior. A number of researchers have pointed out that other factors and heuristics beyond the rational privacy calculus model will influence individuals' decision-making in this context (Cherif, Bezaz & Mzoughi, 2021; Kang & Namkung, 2019; Keith et al., 2013; Wilson & Valacich, 2012), hence leading to possible improvement of the theoretical framework in future.

Future research could benefit from exploring a wider context of privacy implications by addressing the concerns related to the privacy of relatives and future generations, as well as concerns regarding being submitted to DNA tests without consent. Additionally, this research indicates that even individuals who perceive themselves as highly knowledgeable in DNA tests still tend to view genetic information as relatively non-sensitive, contradicting theoretical expectations. In this sense, future research could delve further into exploring this phenomenon to gain a deeper understanding of the reasons why there is this disparity between users' perceptions and the factual sensitivity of genetic data. Besides, previous studies have indicated that vulnerable social groups, such as ethnic or sexual minorities, are more likely to experience privacy-related harm (Haeusermann et al., 2018). Haeusermann et al. (2018) also state that wealthier individuals tend to perceive fewer privacy-related risks and are thus more inclined to share their private data. Therefore, in the future, research should take less privileged socioeconomic and ethnic minority groups into consideration in order to prevent sample biases. In addition, previous research pointed out that privacy concerns may prompt DNA test-takers to request the removal of their data from the DTC-GT companies' database in order to protect their privacy (Baig et al., 2020). This

could inspire future research to explore privacy protection behaviors from people who conducted genetic tests using the research model introduced in this paper.

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Appendix 1 Previous literature on Consumer Privacy Perspectives on DTC-GT

Article	Research Field	Research Method	Sample Features	Major Findings
Baig et al. (2020)	Human-Computer Interaction	Qualitative - interview	- Sample (n=27); - Canada; - Customers of the DTC-GT services.	- Participants were unsure about how long their data is stored and what happens after processing. - Some participants trusted companies' ethical standards, while others believed data sharing happens without their consent. - Most participants expressed a lack of control over their data, while some expressed partial or complete control due to the ability to delete the data. Despite that, some participants believe they will not be able to fully delete their data. Many feel resigned over the loss of control over their data. - Some people considered that DNA data was non-sensitive and harmless, especially if they do not see themselves as potential targets.

				<ul style="list-style-type: none"> - Participants feel more secure because they rely on their government's protection systems. - Most participants did not read the terms and conditions, and few viewed that as a privacy risk. - Participants trust non-profits and academic institutions more than profit-driven entities with their DNA data, given their altruistic motives.
Bollinger et al. (2013)	Genetic Testing and Molecular Biomarkers	Quantitative - survey	<ul style="list-style-type: none"> - Sample (n=1046); - U.S.; - Customers of three DTC-GT companies. 	<ul style="list-style-type: none"> - Every consumer preferred a policy that prevented insurers and law enforcement from seeing their information. - Most customers showed strong confidence in the company's service regarding privacy protection.
Christofides and O'Doherty (2016)	Contemporary Biosciences	Quantitative - survey	<ul style="list-style-type: none"> - Sample (n=415); - Canada; - Individuals who had considered but decided not to do the test (n=235) and individuals who have done the test (n=180). 	<ul style="list-style-type: none"> - Around a third of participants reported ordering a test about someone else. Of those, only less than two thirds reported obtaining permission to do so. - Less than half of the participants read the DTC-GT company's privacy policy. - Less than half of the participants felt they received enough information about how DTC-GT. companies treat their data. - Participant expectations were vastly different from actual company practices. Most participants expected DTC-GT companies to share test results only with them and destroy their samples after testing. - Only 38% of the participants identified risks associated with DTC-GT, and this percentage was lower for those who had purchased DTC-GT. - Nearly half of the participants were worried about the company sharing their information, particularly those who considered but did not buy DTC-GT. - Participants did not want their information to be shared without their consent. - Privacy and security of data were cited as reasons for not purchasing DTC-GT.
Critchley et al. (2015)	Public Understanding of Science	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=1000); - Australia; - General public. 	<ul style="list-style-type: none"> - Markets for DTC genetic tests would grow dramatically if regulation improved confidence in privacy protection and access to knowledge. - Participants perceived more trust in the genetic test's regulation, after-care and privacy from professional doctors rather than DTC companies. - Participants preferred obtaining tests from doctors due to their higher level of comfort in privacy. - Australians were supportive of genetic testing in general and genomic testing in particular. However, they did not favor commercial DTC testing and were unlikely to order a test outside of the traditional healthcare system.
De Cristofaro (2013)	Computer Science	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=16); - U.S.; - People with some level of genetic knowledge. 	<ul style="list-style-type: none"> - Users sought to maintain control over their genetic data and frequently expressed worries about trust and discrimination, especially in the workplace and in healthcare. - Users prefer that doctors rather than specialist personal genomics companies deliver medical genetic tests, driven by issues about trust. - Participants were more concerned with insurance companies or employers doing genetic discrimination than with hackers accessing their genetic information.
Grandhi and Plotnick (2022)	Human-Computer Interaction	Quantitative and Qualitative - online survey	<ul style="list-style-type: none"> - Sample (n=510); - Majority from U.S.; - Individuals who have done DTC-GT and individuals who have not. 	<ul style="list-style-type: none"> - The benefits of DTC-GT outweighed the risks for many individuals. - Non-test-takers, particularly non-willing test-takers, had higher privacy and security concerns than DTC test-takers. - Respondents expressed apprehension about the possible exploitation and misuse of their DNA information by government agencies, law enforcement, marketing companies, and employers and feared genetic discrimination or manipulation - Individuals had varying perceptions of the privacy risks and benefits of DTC-GT, indicating lack of understanding of genetic data privacy. - Those with low privacy concerns trusted systems such as companies, regulations, and laws to protect their data. - Some participants viewed DNA information as non-sensitive information. - Respondents felt that they should have control over their DNA data, and that it should not be shared without their consent. Some participants felt resigned to their lack of control over DNA protection.
Haeusermann et al. (2017)	Biology and Life Science	Quantitative - survey	<ul style="list-style-type: none"> - Sample (n=550); - Majority from the U.S.; - Users who have done DTC-GT and submitted their results in result-sharing platforms. 	<ul style="list-style-type: none"> - The majority of respondents read little about privacy and confidentiality in the terms and conditions when sharing their data. - Many participants thought it was almost impossible that their genetic data could be completely deleted. - Health was the major influencing factor to conduct DTC-GT, nevertheless other benefits also motivated respondents. - Numerous participants had used ancestry and genomic profiling businesses, presenting that 23andMe was the most popular, subsequent to Family Tree DNA and Ancestry. Other platforms, such as National Geographic and the Personal Genome Project, were also mentioned to a lesser extent.

Haeusermann et al. (2018)	Empirical Bioethics	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=13); - Majority from the U.S.; - Users who have done DTC-GT and submitted their results in result-sharing platforms. 	<ul style="list-style-type: none"> - Participants who publish their genetic information openly online are insensitive to genetic privacy. - Open genetic data sharing is motivated by more than just an altruistic desire to advance science. - For users, genetic privacy not only encompassed preventing illegal access to their information, but also emphasized the necessity of addressing social and health discrimination and other privacy-related negative effects. - Participants recognized that ethnic or sexual minority social groups deemed particularly vulnerable would be more likely to encounter privacy-related harm. Moreover, it is hard to stretch research data from impoverished classes since the differences between socioeconomic groups. - People living in nations where genomic discrimination is illegal shared their genomic data without worrying about privacy concerns.
King (2019)	Human-Computer Interaction	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=10); - U.S.; - Customers of the DTC-GT service 23andMe. 	<ul style="list-style-type: none"> - Little concern and lack of awareness were expressed by participants about providing DNA information. - Participants expected anonymity, privacy, and no adverse consequences from DTC-GT companies. - Participants did not perceive immediate risks and did not consider future risks, possibly due to the intangibility. - Respondents did not view genetic data as particularly personal or sensitive.
Mladucky et al. (2021)	Public Health Genomics	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=20); - U.S.; - Consumers of DTC-GT between January 2016 and November 2018. 	<ul style="list-style-type: none"> - Most participants said that they had not read or had just read a portion of the privacy policy. - Most participants believed that the DTC-GT company used the data for other purposes, specifically to enhance their products and services. Some participants speculated that the data may be used for health research, third-party sales, law enforcement enforcement, or insurance discrimination. - Participants tolerated the usage of their data for research purposes. Views on data usage for law enforcement varied. The majority of participants disapproved of selling their data to third parties due to concerns about companies profiting out of their data. - Participants were unaware of laws protecting against genetic discrimination.
Roberts et al. (2017)	Public Health Genomics	Quantitative - survey	<ul style="list-style-type: none"> - Sample (n=1648); - U.S.; - Consumers who have done direct-to-consumer personal genomic testing (DTC-PGT) with or without receiving testing results. 	<ul style="list-style-type: none"> - Before conducting DTC-PGT, many people did not have a deep understanding of the importance of potential risk. - The vast majority of consumers claimed that they were interested in knowing more about the DTC-PGT benefits (i.e. ancestry and trait) compared with genetic risk information for various medical diseases. - Participants overall stated a low level of decisional regret considering, such as information privacy in DTC-PGT, showing more perceived benefits from it rather than adverse impacts.
Ruhl et al. (2019)	Biomedical and Health informatics	Quantitative - online survey	<ul style="list-style-type: none"> - Sample (n=1026); - U.S.; - People from one marketplace who have done the test and people who have not (the majority). 	<ul style="list-style-type: none"> - About half of the respondents were highly concerned about their identity protection by DTC-GT companies. - Nearly half of the respondents expressed deep concern about their information being shared without their consent. - Most respondents were comfortable sharing their data with academic institutions, but only a fifth were comfortable sharing it with the government. Just over a third felt comfortable sharing data with third-party companies, when given equivalent privacy safeguards as DTC-GT companies.
Saha et al. (2020)	Human-Computer Interaction	Qualitative - interview	<ul style="list-style-type: none"> - Sample (n=24); - U.S.; - Individuals who have taken or contemplated taking a DTC genetic test. 	<ul style="list-style-type: none"> - Participants were motivated to engage in DTC-GT to experience the benefits of ancestry and enhance their medical knowledge. Additionally, they noted the potential to contribute to medical research improvements, contribute future generations, and assist adoptees. - Privacy was the concern more cited among participants, but concerns did not transfer into any action or behavior to safeguard one's privacy. - Participants acknowledged and disapproved of data sharing with third parties. - Participants desired for clear and transparent communications. - Risks were overshadowed by the perceived benefits and feelings of privacy resignation.
Sahoo et al. (2022)	Data Privacy	Qualitative - interviews	<ul style="list-style-type: none"> - Sample (n=60); - U.S.; - Individuals that have and have not done DTC-GT. 	<ul style="list-style-type: none"> - Respondents exhibited some privacy concerns about DNA data sharing but lack complete understanding of risks associated with the nature of DNA. - Non-test takers had higher privacy concerns. - Test-takers had low expectations of privacy. - Participants were willing to share DNA data for research with credible organizations in the presence of clear information on data usage. - Data sharing with law enforcement made individuals feel powerless against others' decisions.

				<ul style="list-style-type: none"> - History of discrimination and race biases influenced people's privacy perceptions, leading to concerns over data access by law enforcement and governments. - Some Asian participants worried about data sharing with their home country's government.
Schaper et al. (2020)	Social and Psychological Impacts of Genomic Risk Communication	Qualitative - focus groups	<ul style="list-style-type: none"> - Sample (n=99); - Germany, Israel, Netherlands and UK; - General public. 	<ul style="list-style-type: none"> - Participants generally expressed concerns about privacy and data protection, particularly about potential data misuse. - UK and Dutch participants anticipated and were concerned about DTC-PGT firms profiting from consumer data. - German participants were concerned about data protection due to skepticism regarding online businesses and their privacy policies. - Participants from Israel expressed concerns particularly about genetic discrimination and business exploitation of genetically vulnerable individuals. - Participants expressed a desire for regulation regarding DTC-PGT to guarantee confidentiality and accountability. - Only a minority of the participants argued for a regulation ban on DTC-PGT.

Appendix 2 Survey construct

Construct	Item	Wording	Description
Perceived Benefits	PB1	Taking an at-home genetic test is beneficial to help people find family members and relatives.	Original Construct, inspired on the results of Baig et al.(2020); Grandhi and Plotnick (2022); King (2019); Ruhl et al. (2019); Saha et al. (2022)
	PB2	Taking an at-home genetic test is beneficial as it can enable people to know more about genealogy and ancestry.	
	PB3	Taking an at-home genetic test is beneficial as it can provide valuable knowledge about genetic health risks.	
	*PB4	Taking an at-home genetic test is beneficial as people can learn more about themselves.	
Privacy Concerns	PCO1	I am concerned that the genetic data submitted to at-home genetic test companies could be misused.	Based on Xu et al. (2011)
	PCO2	I am concerned that unauthorized people can find personal genetic data from at-home genetic test companies.	
	PCO3	I am concerned about providing genetic data to genetic test companies because of what others (individuals or organizations) might do with it.	
	PCO4	I am concerned about providing genetic data to at-home genetic test companies because it could be used in a way I did not foresee.	
Privacy Control	PCT1	I believe that people who do at-home genetic tests have control over who can access the genetic data they provide to at-home genetic test companies.	Based on Xu et al. (2008); Dinev et al. (2013)
	PCT2	I believe that individuals have control over how at-home genetic test companies use their genetic data.	
	PCT3	I think individuals have control over which genetic data is released by at-home genetic test companies.	
	PCT4	I believe individuals have control over what genetic data is collected by at-home genetic test companies.	
Trust in governmental law and regulation	TRU1	Government regulations protect genetic data provided to at-home genetic test companies.	Based on Naous et al. (2019)
	TRU2	Government regulations protect individuals from any misuse of their genetic data by at-home genetic test companies.	
	TRU3	Government regulations protect individuals from unauthorized use of their genetic data disclosed on at-home genetic test companies.	
Information Sensitivity	*IS1	I feel comfortable with the type of data (genetic data) that individuals have to submit when taking at-home genetic tests.	Based on Dinev et al. (2013)
	IS2	I feel at-home genetic test companies gather highly personal data.	
	IS3	The genetic data individuals have provided to at-home genetic test companies is very sensitive.	

Note: *Items were dropped after the exploratory factor analysis (EFA)