Exploring Understandings of Genetic Testing: The Impact of Media Cases on Participant Perceptions

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ABSTRACT

Direct-to-consumer genetic testing has become really popular over recent years, as people are more curious to learn about their ancestry and health insights. However, consumers are often unaware of the privacy risks associated with using such services. Prior studies show that consumers are unaware of third-party access, data storage, data breaches, and the use of data by law enforcement agencies. This study aims to understand the privacy awareness and trust of consumers before and after exposing them to real-life scenarios through semi-structured interviews with 6 participants. After doing a thematic analysis of the data collected from the interviews, four key themes emerged. The four key themes are strong motivations that often overshadow privacy concerns, poor engagement of participants with terms and conditions, privacy risks are frequently underestimated by participants, and trust is based largely on company reputation and size.

1 Introduction

In the last couple of years, saliva-based DNA testing services have become really popular among the general public because of the services they provide. These companies provide services such as ancestry estimation, genetic relative matches, and some companies provide personalized health and wellness reports as well. Globally, 23andMe alone reports that 15 million people have used its service to generate DNA data [16]. While consumers can gain valuable insights about their ancestry, genetics, and personal health, consumers are often unaware of the privacy risks associated with using such services. To learn about their ancestry, genetics, and personal health, users are required to submit sensitive biological information, which can reveal personal information such as their identity and that of their relatives. A single consumer's decision to give up their genetic data can unintentionally expose the biological information about the entire family network, which can put them at unwanted risk. Without having a proper understanding of how their personal information might be used, consumers often accept lengthy terms and conditions filled with legal complexity.

The issue of data privacy is urgent because direct-to-consumer genetic testing companies may sell the data to third parties, such as pharmaceutical companies, or they might store the data indefinitely, and in some cases, they might provide law enforcement agencies with sensitive biological information to solve crimes. According to Hendricks-Sturrup et al. [3], the recent 23andMe breach compromised 6.9 million records which proved that consumers' data is not safe at all.

Prior research has shown that users are not aware that their data might be stored indefinitely, shared with third parties, such as drug companies and police [3]. Similarly, past research by Phillips et al. [10] shows that most users do not read or understand the terms and conditions due to the legal jargon and length of the terms and conditions.

Early studies by Jacobs et al. [17] have also found that direct-to-consumer genetic testing companies are under no obligation to update or notify the consumers of any changes to their terms and conditions. Moreover, Ruhl et al. [12] found that trust in these companies is relatively high, as consumers often trust these companies due to their size and reputation. Overall, prior studies show that consumers remain unaware of data collection practices, but their overall trust in these companies remains high.

Prior studies have examined consumers' attitudes towards direct-to-consumer genetic testing services, but there are limited studies done to measure the changes in consumers' trust and privacy awareness towards these companies before and after they are provided with real-life scenarios, eg, data breach, data access by law enforcement, and what happens to the consumers' data after the ownership of the companies changes.

This gap is of importance because real-world scenarios may influence consumers to think differently about these companies and the privacy of their data. This study aims to bridge that

gap by conducting six semi-structured interviews to understand the levels of trust and privacy awareness of consumers before and after they are provided with real-life scenarios.

This paper entails findings from six semi-structured interviews, followed by a thematic analysis to understand participants' motivations, privacy awareness, trust in companies, and their reactions to real-life data-use scenarios.

2 Related Work

2.1 Rise of Consumer-Directed Genetic Testing

Research conducted by Ramos & Weissman [11], explains that the rise of consumer-directed genetic testing has fundamentally shifted how individuals access genetic information. Studies done on DTC genetic testing services reveal that consumers are not fully aware of the privacy risks associated with using such services.

2.2 Consumer Awareness of Privacy Risks

Christofides & O'Doherty; Laestadius et al. [1, 4] highlight that a large number of consumers fail to understand how their data might be stored, shared, or used. A recent study done with DTC genetic services users noted that the users avoid reading the terms and conditions provided in detail due to their length and complexity [8, 10, 15]. A recent study done using surveys and social media discussions found that consumers were concerned about data breaches, data storage, and third-party involvement, but consumers were often unaware of how often these happened [5]. Consumers were also concerned about the potential access by insurers and employers [2]. Hendricks-Sturrup & Lu; Majumder et al. [3,6] found that consumers were unaware of their data being stored for an indefinite period or that they could be accessed by third parties. Another study done by Mladucky et al. [8] found that a small proportion of consumers were aware that their data might be used for purposes other than genetic testing. Recent research by Onstwedder et al. [9] also focuses on the fact that there is a gap between consumers' understanding of how their data might be used beyond testing. Prior studies conducted by Niemiec et al. [14] also reveal that a large number of consumers overestimate the control over their data, but very few understand retention policies, data sharing, and secondary uses.

2.3 Misconceptions About Data Retention and Use

Prior work done on DTC genetic testing shows that consumers have an inaccurate or incomplete understanding of what happens to their data afterwards. Laestadius et al. [4] found that consumers believe that their genetic data is discarded once they are done with testing; however, companies' policies allow data to be stored for a long time. Christofides & O'Doherty [1] conducted research on the mental model of DTC genetic testing consumers and discovered that most of the participants believed that their data was solely used for ancestry or health reports.

2.4 Trust in Direct-to-Consumer Genetic Testing Companies

Despite misunderstandings of the privacy risks associated with such companies, studies by Raz et al.; Ruhl et al. [13, 12] find that consumers tend to trust these companies with their data more than they should. A large portion of consumers believe that companies such as AncestryDNA and 23andMe will be handling their data responsibly.

2.5 Ethical and Professional Concerns

Healthcare professionals also raise concerns about the practices of these companies, practices such as not being fully transparent about data practices, lengthy legal policies, and weak protection against misuse can be really concerning [7].

3 Methodology

3.1 Participants

Six participants were recruited through a snowball method. No prior requirements were looked upon other than the participant's involvement with a DNA testing company in the past five years. This being said, participant gender and ages were recorded. In total, of the six participants, three identified as female, one as male, and two as non-binary and all participants were in their early to late 20s.

3.2 Technical

To conduct the experiment, two out of the three researchers entered in a Zoom call with the participant. One researcher would ask the questions with their camera on while the other would be in the background taking notes with their camera off to avoid distracting or overwhelming the participant. One accommodation was provided to a

participant due to unease of sharing their answers. For this interview, only one researcher was present in the meeting and was both taking notes and asking questions. Each participant was asked for permission on audio recording via the consent forms sent, and recordings were only conducted if permission was given through Audacity. All information, including audio recordings, was stored in a Google Drive with only the researchers invited and all information was deleted once the research process was completed.

3.3 Interview Procedure

Prior to the interview, participants were provided with the required consent form explaining the interview thoroughly. Once beginning the interview, participants were given another debrief.

After introductions were made, the lead researcher began following the interview script (Appendix. 6 Interview Script). The process followed a structured interview format that began with eight questions relating to the participants personal opinions, experiences, and understandings with DNA testing companies. Specifically, the questions fell into one of four categories: knowledge on terms and conditions, prior privacy concerns, opinions of risks such as data leakages and selling of information, and trust & distrust in companies. These questions aimed to understand the participant's point-of-view through personal experiences and looked at how their opinions were set before any real-life cases were presented to them.

After the general questions were completed, participants were introduced to two scenarios that depicted real-life events of DNA testing companies. Names of these companies were not detailed as researchers thought that if the participant's DNA company was stated with serious privacy claims then possible distress could be seen as a result. Participants were asked to imagine themselves in the customer's point-of-view for each scenario, and were informed that after each scenario two related questions focusing on participant's feelings and opinions would be asked.

Finally, the participants were asked one final question. This question focused on their current feelings towards DNA testing services, asking them if they would do the service right now if it was their first time. This aimed to focus on how the participant's thoughts on the service had changed from their past concerns and looked to have a final view on whether they found that the risks outweigh the benefits.

3.4 Data Collection

After interview completion, all answers were gathered together to begin analysis. Qualitative data was gathered through interviews and from the information found, question-related answers and thematic analysis were categorized. Thematic analysis results specifically were determined through an affinity diagram.

4 Results

4.1 Question-Categorized Answers

4.1.1 Terms and Conditions

Only one out of six participants mentioned reading the terms and conditions. The other five read little-to-none and mainly skimmed through the basics of the information. Participants were seen not reading the terms and conditions but still understanding certain aspects of the contents provided, indicating that they were using previous data knowledge to determine the contents of the DNA testing service's terms. An example of this was P6 who had assumed that the DNA service would not sell their information to other third parties because they saw this statement in different companies terms and conditions.

"I mean, I think the biggest thing they sell you on before the terms and conditions is that they don't sell your info to third parties-."(P6)

Participants were taking past knowledge of terms relating to other platforms and applying it to their interpretations of DNA testing terms. This is a dangerous practice because of each platform being different to one another. Therefore, assuming the terms of one platform due to the content read from another is not ideal for effective research and understanding purposes. Even with platforms similar to one another such as two DNA companies, every company has their own intentions, goals, and cares for their users. Assuming that two platforms will have the same legal usages of data demonstrates the faults within the companies terms and condition and its inability to convey the correct information to its users, thus putting their users into danger without explicitly stating it.

4.1.2 Notification Updates

Participants revealed that no additional notifications were sent to their email addresses. No participants were given, or could remember, any details about updated terms and conditions or company announcements. Either companies failed to be transparent with their users or their current communication systems, especially with highly sensitive data-related events, were not successful.

The inactive approach these companies take contributes to a false sense of security that users get, with only getting serious information about their designated company through news outlets where, at that point, the risks involved have already been invoked.

4.1.3 Privacy Concerns & Access Permissions

A few participants revealed to have no privacy concerns prior to their DNA submission, claiming details such as that they have "nothing to hide", thus inferring that even participants in the 20s age group who are known to be more digitally advanced still struggle to recognize the dangers of their data being online. A participant discussed this mentality in their responses to privacy concern related questions and revealed that they thought this way due to them already owning a device, meaning that their data is already on the internet. There seemed to be a disconnect between the understanding of how online data such as social media accounts differ from medical data such as, and especially as unique as DNA.

"No, not really. I feel like I have nothing to hide. I think that my motivation outweighed privacy concerns and because I have a phone, my information is already out there." (P1)

Other participants however, did have some concerns over data leakages and how their data was being stored. These worries still did not constitute extra research on the topic as participants still did not understand who had access to their data and who could gain access to it in the future. Two of these participants expressed how they thought that only the DNA company had access to their data with no external parties being involved.

4.1.4 Scenarios

After participant personal responses, the scenarios began revealing more concerns of the participants when presented with certain situations that could occur to themselves.

With the change in participant responses going from little-to-no worry about their privacy, to more concerned answers when asked how they would feel in the scenarios provided, it was clear that their perspectives had shifted. Knowing that lawsuits and cases existed lowered the unrealistic speculations that they had created when choosing to continue with the DNA service.

New emotions were noticeable and words such as "violation" and "fear" became common among the answers. The majority of participants began to take on the perspective of the customer in each scenario seriously and started to question the usage of their data, some even returning back to the previously seen concern of comparing DNA with social media data.

"I would be very disappointed in the company just because it's like you trust this company with your DNA and DNA is something that's unique to you so it can't be something generic." (P3)

4.2 Thematic Analysis

The second results format was developed through thematic analysis, then organized into an affinity diagram using Miro where common themes among participants were discovered. In total, four key themes were found that define the average perspectives, opinions, and understandings that users of third-party DNA testing services have towards sharing their personal information.

4.2.1 Motivations Overshadow Concerns

Participants initially chose to take DNA tests due to their own motivations. These ranged from interest in heritage, family lineage, cultural interests, and health-related information. Motivations involving ancestry and family relations made the risks feel small to participants. Similarly, health-related motivations outweighed risks due to it being a necessity for further medical knowledge, making DNA sharing justifiable. P5 was a strong example of this where the participant found that the enjoyment involved in learning about their DNA outweighed any risks.

"No, [the risks do not outweigh the benefits] honestly I did it for fun so I basically just allowed people to get my literal DNA just to see slightly

more information about my ethnicity. It sounds dumb." (P5) (Figure 1)

Even with concerns and knowing risks, all participants still proceeded in the testing process. However, looking back, most participants stated that they would not take the test again after educating themselves, thus deepening their understanding of the privacy risks and confirming their initial concerns, causing these reasons to outweigh their original motivations. Only a few felt the benefits still overshadowed the risks. Each person may judge this balance differently, but overall, education and informed decision-making appear to play a major role in shifting how users evaluate the value of DNA testing.

4.2.2 Poor Engagement with Terms and Conditions

A key theme across the interviews
was participants' limited engagement with the terms and conditions of DNA testing companies, showing how surface-level most users' understanding of data privacy truly is. Most participants admitted to reading little or none of the terms due to their length, complexity, low perceived risk, reliance on social media summaries, or general trust in large companies. This lack of engagement led to widespread misunderstandings, with many assuming their data was anonymized, accessible only to the company, and used strictly for testing. Participants also expressed a need for clearer consent practices (seen in Figure 2): P1 suggested "bite-sized" summaries, and P3 and P5 emphasized that consent should be revisited over time rather than given only once.

"I feel like there needs to be an accessible shorter text because people are not gonna read it. They need to give a bite-sized summary to be more fair. Also destruction of information would be more ethical if anything." (P1)

"- as a consumer I don't think Terms and Conditions are enough. I feel like the consumer has to be informed a little bit more." (P3)

4.2.3 Underestimation of Privacy Risks

Most participants initially underestimated the privacy risks associated with DNA testing. Many framed their decisions through simplified assumptions that minimized perceived danger, often comparing DNA data to everyday digital information. As P1 stated, "I have nothing to hide," reflecting a belief that because their data was already online, sharing their DNA would not introduce new risks. This view showed a misunderstanding of how genetic data differs in permanence, identifiability, and long-term implications.

This underestimation was also seen as static by many participants. With the idea that once they submit their DNA it will stay only within the testing company, which, after demonstrations of scenarios, was shown to be false for at least 23andMe and Ancestry.com as they were the two cases being referenced. The static interpretation that the participants assumed led to more privacy concerns as a false sense of security was established between the user and the company. In particular, P1's response to the scenarios presented revealed a stark contrast in comparison to their "nothing to hide" idea of data sharing.

"I don't even know what the risks are [with data-leaks and selling], it feels like an unknown. I can't fathom what they would do with my DNA." (P1) (Figure 3)

Even if users understood the dynamic approach companies take in terms of privacy and information sales, they were likely to believe in more ordinary data concerns such as selling information to advertising companies, not the long-term risks involved in unique data such as DNA. As mentioned previously, participants underestimated the difference between DNA data with other digital data making long-term risks more likely in these terms but still not acknowledged by users. Long term risks would include user specific mental and physical health, family members, and unique identification data that cannot be replicated to be exposed causing users who fall victim to the long term risks to become extremely vulnerable.

4.2.4 Context's Correlation to Trust

Throughout the participants there was a high level of trust of the DNA companies used. Specifically, a few participants mentioned the trust they had in larger companies such as 23andMe and Ancestry.com, noting how while they understood the risks, it feels safer to give genetic information as important as DNA to a larger company with resources rather than a smaller company. P5

explicitly describes this correlation, yet still admits a small degree of uncertainty.

"I guess it's slightly relieving to know that I'm less likely to get my information sold because it's with such a large company with so many users. I think that's how the odds work?" (P5)

However, as scenarios were introduced, several reported the distrust they had in these companies. While the scenarios provided did not mention specific companies, the actions performed by the anonymous companies resulted in participants responding to trust-related questions in a more violated and sceptical manner. Context was seen as the connection that broke participant trust as more truth diminished the assumptions the participant made prior to the interview (seen in Figure 4). The shift in perception suggests that the initial trust developed between the company and the user was shaped by branding, reputation, and familiarity rather than concrete knowledge and based on some participant answers this trust could have also been formed through the trust in others. For example, one participant mentioned using TikTok as their research platform. Seeing others trust certain companies, especially on an app that showcases openness of opinions and relatable creators, users begin to trust the content creators advertising these services, resulting in the user to then indirectly trust the company.

"- I went to Tiktok and saw people's experiences." (P1)

Overall, the findings showed that users often entered DNA testing with strong motivations but limited awareness of the privacy concerns. Participants tended to underestimate risks, have limited engagement with terms and conditions, and placed trust in companies based on size or familiarity rather than informed understanding. Participants often relied on social media or general knowledge to shape their view of these companies with little to no further investigation prior to sending in their DNA samples. However, once presented with more context or real-world scenarios, many participants reassessed their views and expressed greater concern or regret towards going through with these services. These themes highlight a need for clearer communication, stronger consent practices, and improved education on informed decision-making about extremely personal data such as DNA.

5 Discussion

In this section the team discusses the findings found, their implications, and possible solutions based on researcher and participant recommendations.

5.1 Findings

While participants were found to have varying opinions of the worth surrounding DNA testing services, a common trait among the majority of participants was the lack of knowledge and care with their privacy. Participants were found joking with their family members about privacy concerns, skimming through the terms and conditions, and not even paying attention to the risks involved in handing over the DNA. Only one-to-two participants seemed to have taken great care into researching the privacy risks involving the service. Based on input provided it became clear that there were many flaws in the company's informative process as participant responses contained concerning answers.

5.2 Terms and Conditions

Five out of six participants expressed that their knowledge on their DNA company's terms and conditions was little-to-none. While users should research privacy-related topics, especially when revolving around their DNA, the blame should not be put on the user's shoulders. They have responsibilities, yes, but it is clear that the companies failed at expressing the serious repercussions of their service, especially when their service could be used "just for fun" or for personal hobbies.

Terms and conditions should provide essential information while remaining accessible and comprehensible. However, participants consistently described these documents as overly long, complex, and saturated with technical or legal terminology. This indicates a need for clearer, more user-friendly disclosures that define the risks, data practices, and company motives in straightforward language. Improving the clarity and accessibility of these materials would help ensure that users can make genuinely informed decisions about their genetic data

5.3 Privacy Mental Models

With companies not having effective terms and conditions, participants began to follow common mental models of their own. One common model was assumption that the participant data is safe if they use the service of a larger company such as 23andMe or Ancestry.com. Participants' models consisted of them aiming to understand the risks involving their privacy through company size. Larger companies were seen to have more funds, resulting in their data being more secure due to higher security regulations. Additionally, larger companies brought the mentality that due to the vast number of users and data collected, the likelihood of anything serious happening to a specific user's data is low.

This mental model caused a few participants to justify their usage of the service, viewing them as the "safer option" compared to smaller lesser-known companies. These models had their own dangers as they rely on perceived rather than verified security practices, leading participants to overlook the faults of the companies they trust. As a result, users underestimated how their personal DNA was being used within and outside of the company.

The simplified mental model shifts the consumer through a more passive, perception-based reasoning to use the service where they trust brand reputation over intensive research. Ultimately, mental models highlight a short reasoning for users to choose distrustful companies.

5.4 Design Solutions

Both participants and researchers defined possible solutions relating to the results found. Although participants were not directly asked to provide solutions, a few offered suggestions within their answers.

A recurring theme was the need for clearer, more accessible terms and conditions. Participants emphasized that information should remain detailed yet easy to understand. For example, P2 described a preference for "bite-size summaries," while P3 stressed the importance of making the terms more informative. To balance complexity with readability, the research team proposes a hybrid approach to the participant suggestions: companies should present full, legally required documentation but pair it with brief, user-friendly summaries of key points surrounding possible concerns. Within the initial consent screen and in user profile settings, platforms could include dedicated sub-sections detailing (1) the who, what, where, when, and how's of user data, (2) the company's motives and intentions, including procedures in emergencies, and (3) simplified data security details, to the extent that disclosure is safe. Each topic could be presented as a short, two-to-four-paragraph summary.

Participants and the research team also identified concerns about the sale or transfer of user data to external buyers. A user-centered solution would involve providing a clear, direct explanation of any data-sharing practices and offering straightforward opt-out mechanisms. During account creation, users could select their preferred contact method (email or phone) and receive a notification if their data is to be sold or transferred via their preferred method to reduce unread notices. This message should immediately state the purpose of the sale in a simplified format, followed by clear details about the receiving company's policies, using the same accessible format described above for the terms and conditions. Most importantly, the opt-out option must be prominently displayed and free from deceptive design practices to ensure users can make an informed, unobstructed decision.

5.5 Limitations

While the study uncovered many issues revolving around DNA testing, the study design provided some limitations within answer variety.

The study had a very limited sample size as participants were difficult to gather due to the requirement of previous genetic testing. Additionally, limitations were found with how the team was allowed to gather participants as university rules had to be followed, resulting in more reduction in the sample size. The team was not allowed to gather participants through posts either online (team's social media) or physically such as flyers around the university. A reduced sample size caused the variety of answers to be very small as less comparisons could be made from participant-to-participant.

Another limitation of this study was the narrow age range of participants. All six participants were in their early to late 20s. Although age was not directly used in the results, it can reasonably be assumed that participants had a baseline familiarity with digital technologies and general online privacy practices, having grown up during a period of technological growth. This

shared generational background may have influenced their comfort with digital services, their expectations of online privacy, and their interpretations of data risks. As a result, the findings may not fully reflect the perspectives of older or younger users, particularly those with less exposure to digital environments or different levels of privacy literacy

6 Conclusion

This study conducted semi-structured interviews with six participants who completed DTC genetic testing with companies such as AncestryDNA and 23&Me. The goal of this study was to get an understanding of the privacy awareness consumers have and their trust in these companies. This was achieved by asking questions related to their knowledge of the terms and conditions on these websites as well as comparing the level of trust consumers had before and after introducing real-life scenarios of how data breaches and bankruptcy affected customers of these companies. The findings revealed that there were four key themes among the data collected: the participants' motivation to get DNA tests often overshadowed any privacy concerns they had, participants engaged minimally with the terms and conditions of these DNA companies, participants underestimated the privacy risks associated with the storing of DNA data, and 'reputable' large companies were seen as more trustworthy. Considering these results, it exposes a lack of communication between the consumer and DNA testing companies. Furthermore, it reveals the need for stronger and more user centered consent practices as users often expressed wanting to opt out of certain agreements in the terms. Finally, a focus on educating customers prior to undergoing a DNA test can result in more informed decision making in regards to DNA data being collected and stored.

While this study contributes an in depth outlook of participant's understandings and concerns involving DNA testing and data storing, there were several limitations to this study that call for future research. To extend this study, future investigation may work with a larger and more diverse group of participants of several age ranges as this could result in an increase in varied outlooks on the matter of DNA testing. Another path for future research would be to investigate more in depth on how customers of DNA companies would want to interact with the terms and conditions and privacy policies in a way that is more accessible and user-friendly. In collecting specific needs of the consumers, it may further push the demand and progression for more transparent and two-sided interactions between DNA companies and their customers.

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APPENDIX

6 Interview Script

Hi **[Participant Name]**, thank you for taking the time to speak with us today. I am **[Primary Researcher Name]**, and this is **[Secondary Researcher Name]**, they will not talk during the interview and will just be in the background.

We are doing this interview to gather research to understand how people feel about sending their DNA to third-party companies.

There are no right or wrong answers, I am just interested in your honest thoughts and reactions. Everything you share will be kept confidential and used only for research purposes.
You can skip any question or stop at any time if you wish.

Do you have any questions before we start?

Questions:

1. What was the main motivation for using DNA testing services?
2. When setting up your account, did you read through the terms and conditions thoroughly?

3. How would you describe what you agreed to from the terms and conditions presented to you?
4. Have you ever received a notification or read an updated version of the terms and conditions since creating your account? If yes, what changed?
5. Did you have any prior privacy concerns before sending in your sample?
6. Who do you think has access to your genetic information once you submit it to the company?
7. What are your thoughts on the risks associated with your DNA being stored by a private company? (such as data-leakages and selling of information). Do you think these risks outweigh the benefits of these services?
8. What makes you trust or distrust DNA testing companies with storing your DNA?

Now, I'd like to share two short real-world scenarios with you.
These are based on things that have actually happened with major DNA testing companies.
As you listen, please imagine yourself as a customer in each situation.
Each scenario will be pasted in the Zoom chat and we can re-read it if needed.

Scenario 1:
Imagine you took a DNA test with a company to learn about your family history.
A few years later, you find out that the company was sold to another business. As part of that sale, your genetic data and personal information, including your DNA results, name, and contact details, were transferred to the new owners.

You weren't asked to provide written consent, and you weren't given the chance to delete your data or opt out before the sale. The company says this transfer was allowed under its Terms and Conditions, but privacy experts argue that such agreements do not meet legal standards for informed consent when it comes to sharing genetic information.

Questions:
1. How would you feel if your DNA and personal data were shared with a new company without your written permission?
2. Do you think agreeing to Terms and Conditions is enough consent for this kind of data transfer?

Scenario 2:
Imagine you took a DNA test to learn about your ancestry and health.
A couple of years later, you find out that the company was hacked, and the personal and genetic data of millions of users, including yours, was leaked online. Many users weren't told right away, and reports show the company's security was weak.

Because of these issues, the company eventually went bankrupt. As part of the bankruptcy process, it sold user DNA data and profiles to other organizations without asking for consent, meaning your information was shared again, and you had no control over it.

Questions:
1. How would you feel if your DNA and personal information were leaked in a situation like this?
2. What do you think about a company selling user DNA data after going bankrupt?

Last Question:
1. Considering these two scenarios, if you were deciding for the first time whether to send in your DNA, would you still go through with it?

Thank you for your help. As we stated before all your answers will be confidential and only our team will have access to them. If you have any questions or concerns please feel free to reach out to us about them.

Thank you again for contributing to our study.

Figure 1. Affinity diagram for the theme "Motivation Overshadowing Concerns"

Figure 2. Affinity diagram for the theme "Poor Engagement with Terms and Conditions"

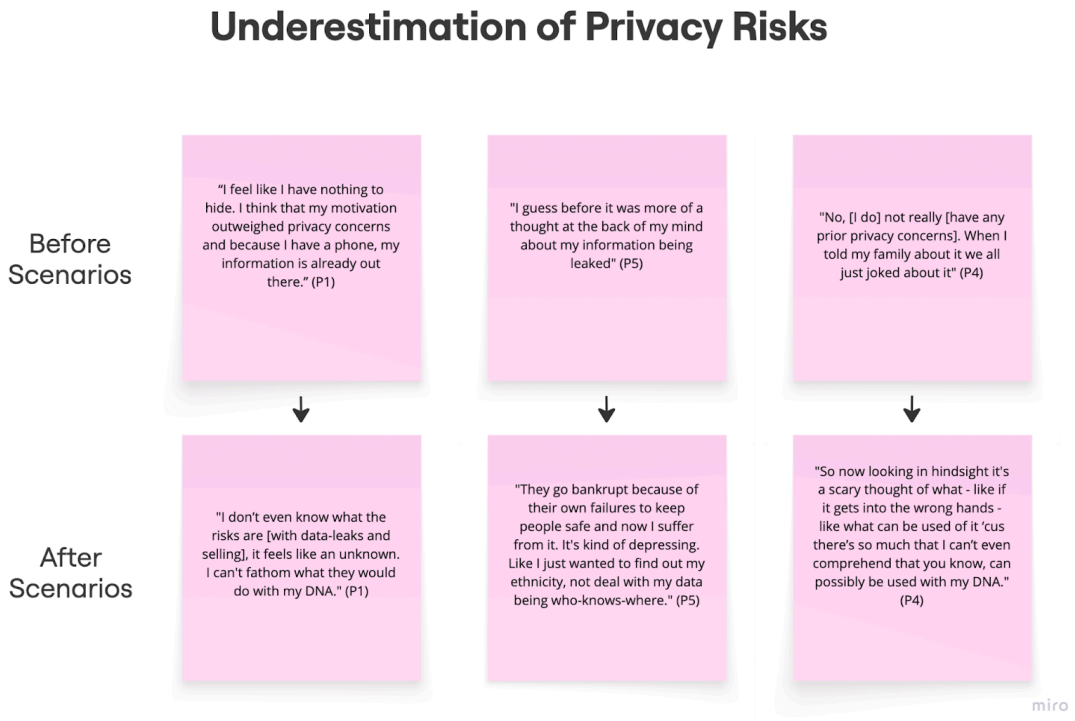

Figure 3. Affinity diagram for the theme "Underestimation of Privacy Risks". Shows the before scenario and after scenario of answers from the same participants.

Figure 4. Affinity diagram for the theme "Context's Correlation to Trust". Shows the before scenario and after scenario of answers from the same participants.