

BIOETHICS, REUNIFICATION, AND GENETIC TESTING ALONG THE US MEXICO BORDER: IS “23ANDME” THE ANSWER?

Matt Artz, MS MBA, Azimuth Labs | Doug Henry, PHD, University of North Texas | Carolina Severiche Mena, MD, Azimuth Labs



Introduction

As of August 16, 565 immigrant children remained in government custody, 366 of whom have already had their parents deported by the United States government¹. To address the separation, consumer genetic testing companies such as 23andMe and MyHeritage have offered to help. Based on a previous ethnography of consumer genetics, we contend this raises moral and bioethical questions regarding the genomic literacy of minors, the informed consent process, and the ownership and fair use of their genetic data.

Background

When purchasing a direct-to-consumer genetic (DTCG) test, consumers provide consent via an online contract that grants DTCG companies control over the use of their biocapital, possibly without the consumer being aware of the terms².

THE TYPICAL DTCG CONSENT PROCESS:

1. Visit the website & begin the checkout process.
2. A clickwrap or browsewrap contract is displayed.
3. If clickwrap, the consumer must click “I Agree.”
4. If browsewrap, they may not even see the terms, as it requires the user to click a hyperlink to open it.
5. On purchase, consumer agrees to their data being used by the DTCG companies per the contract terms.



Previous Research

An ethnography of DTCG was conducted to better understand the sociocultural forces affecting the diffusion, adoption, and satisfaction of consumer genetic testing³. The study included two groups of adult US users:

CONSUMERS OF GENETIC GENEALOGY TESTS:

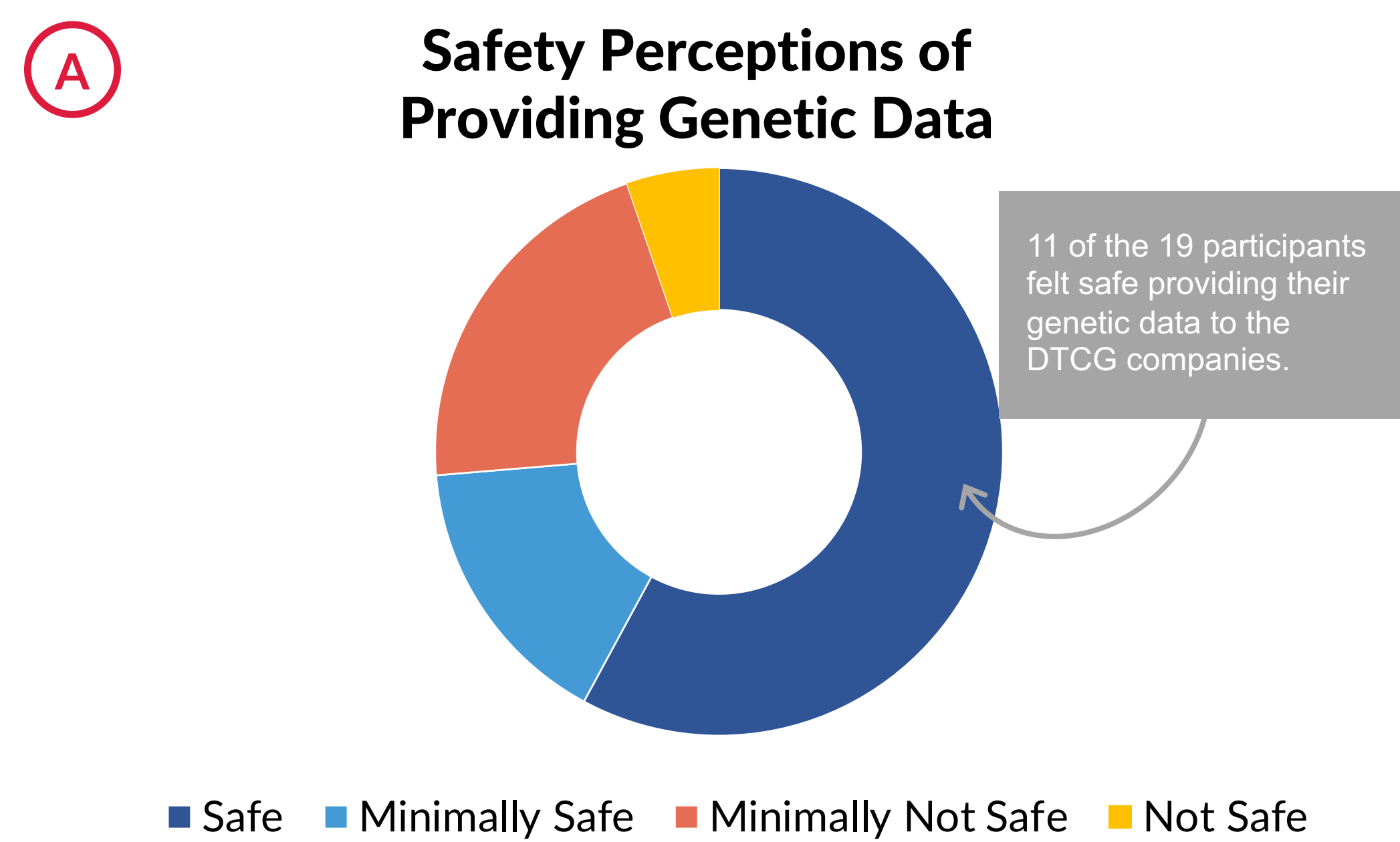
- 10 Genetic Genealogy Testing Consumers
- Semi-Structured Interviews

CONSUMERS OF GENETIC HEALTH TESTS:

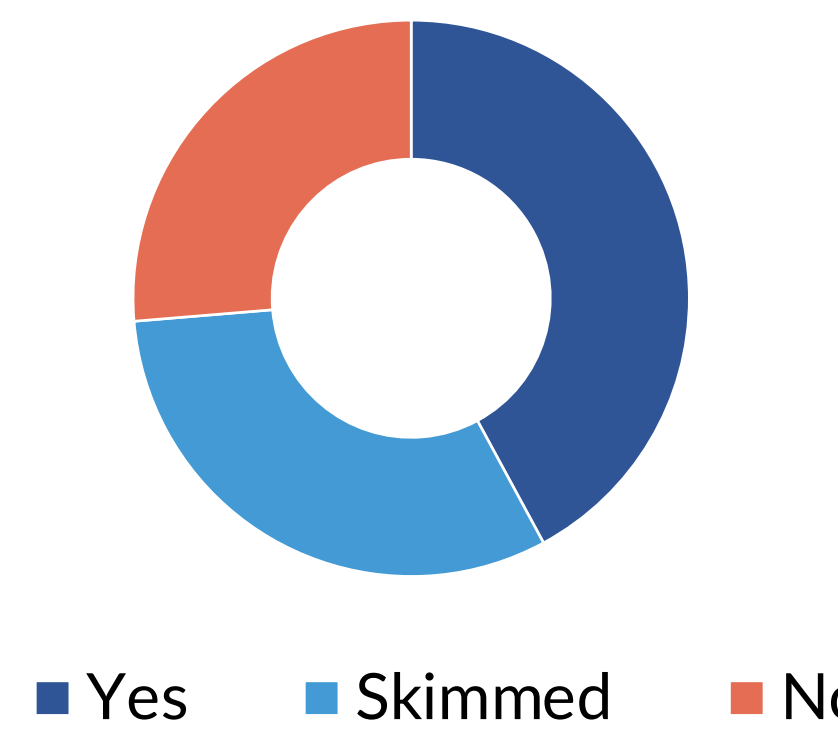
- 9 Genetic Health Testing Consumers
- Observations and Semi-Structured Interviews

The Results

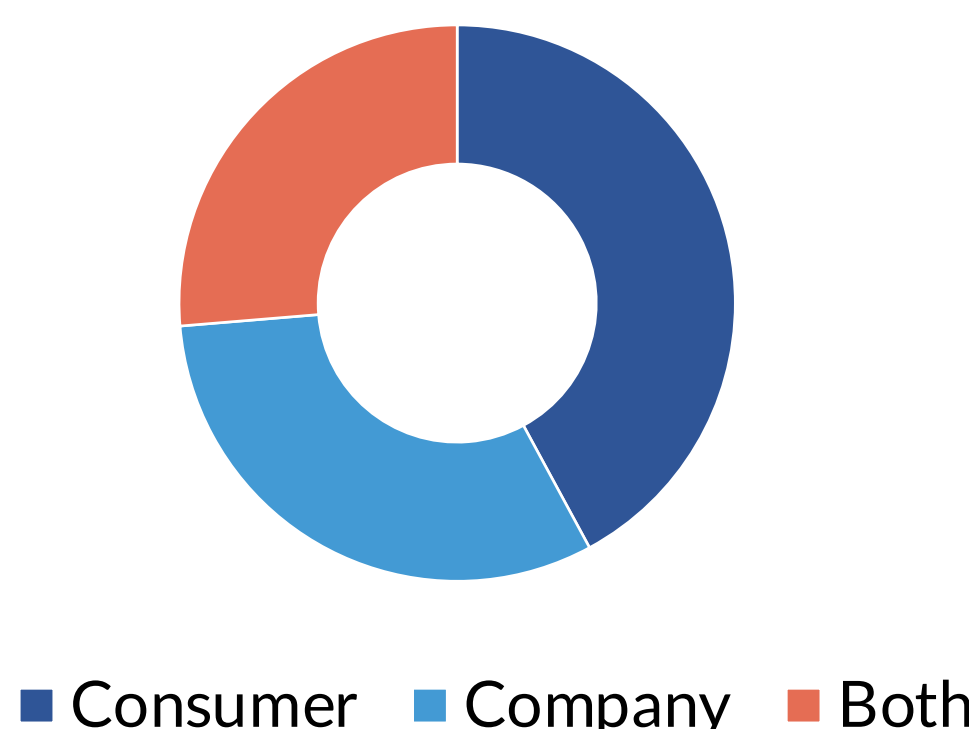
The data was qualitatively analyzed using thematic analysis to understand the similarities and differences in perceived safety, consent, and beliefs about data ownership and use.



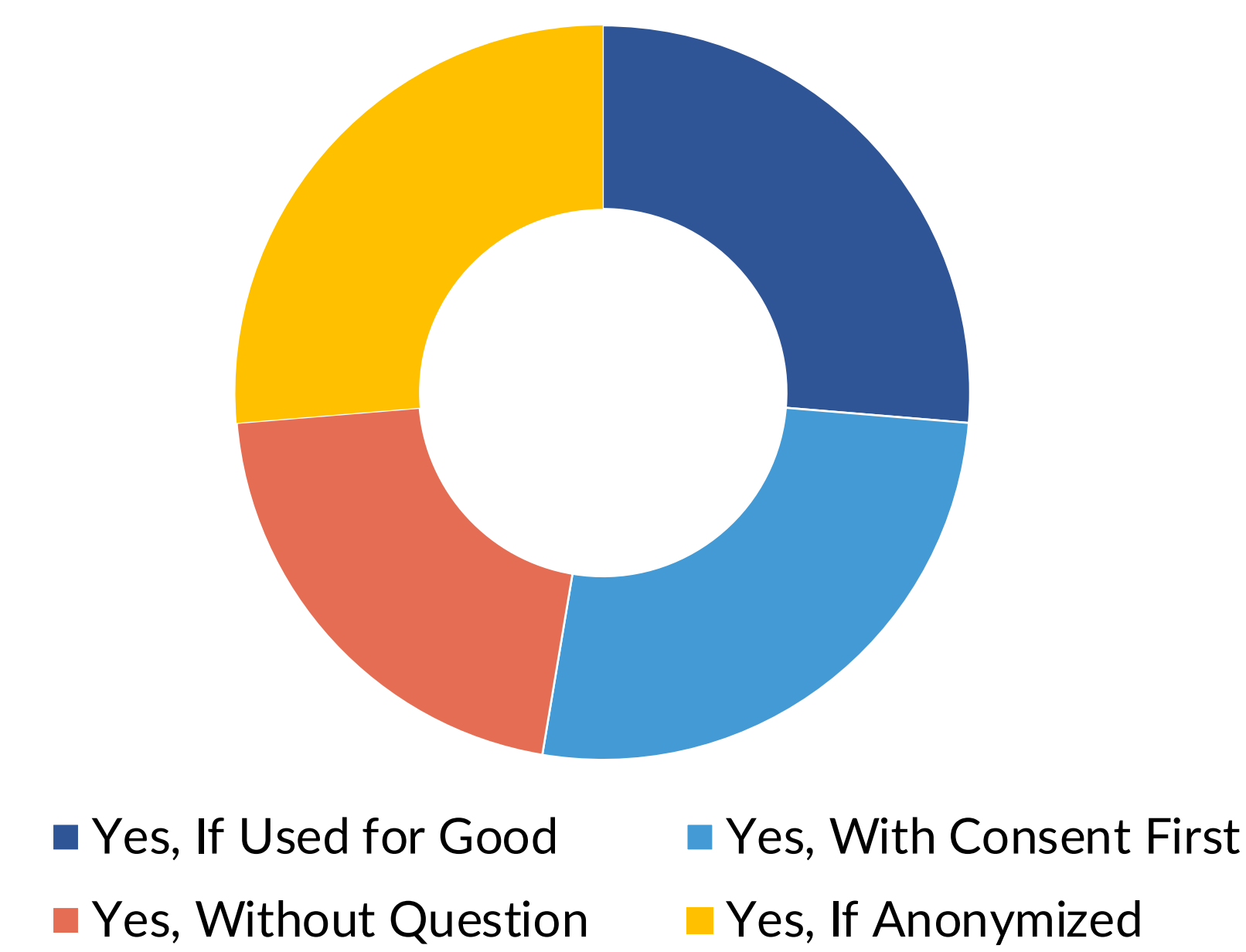
(B) Did Participants Read The Contract



(C) Who Should Own The Data



(D) Participant's Views About DTCG Companies Using Their Genetic Data



Participant's Comments

“I was looking through privacy policies and things and when they send stuff back to you, your names aren't used on the files... I'm just not worried about it the way it is and I would hope that they would do more good with it then bad. I know that sounds horrible, but it's just like, well, it's not my social security number.”
[Related to Figures A, B & D]

“I don't think it's significant because I don't know. It's just life. It's not my address or my social security number. I don't feel like I could have a monetary loss on this one so I can affect my health. I mean I don't understand how my DNA being in the hands of somebody is going to hurt me.”
[Related to Figures A & D]

“I would say me, but I'm not sure who does legally.... Like I don't know if in the fine print it signed off my DNA to them as, as the data to them as owners, but if they are assuming that ownership, I would want a more explicit and clear right to give that to them... I'd be fine with that. I would just hope that they would ask permission, but I'd be more than happy for them to use it if it could help other people or help research.”
[Related to Figures B, C & D]

The Insights

The patterns that emerged from the data demonstrated low genetic literacy where the majority of the participants:

1. Had an unjustifiably high perception of safety in providing their genetic data. [Figure A]
2. Only skimmed or did not fully read the contracts and the implications for sharing the data. [Figure B]
3. In turn felt that they should own the data despite what was stated in the contract terms. [Figure C]
4. Were comfortable with the data being used by the companies, despite their ownership views. [Figure D]

Conclusion

Adults in the US appear to be ill-equipped to understand the complexity of genetic testing, and likewise, we contend that:

- **Separated Minors** who likely have little genetic literacy would not be able to provide appropriate informed consent, potentially even with adult supervision.
- **No Human** should be coerced into a genetic test for purposes of reunification under such a state of duress.

References

1. ACLU. 2018. “ACLU MS L v. ICE Joint Status Report”
2. Phillips, Andelka. 2015. “From the Lab to the Market.” *GeneWatch* 28 (3): n.d.
3. Artz, Matt. 2018. “An Ethnography Of Direct-To-Consumer Genomics (DTCG)”

