

Direct to Consumer Genetic Testing: Methods & Tools Used to Share Direct-to-Consumer Genetic Test Results

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Background

- Direct to Consumer (DTC) genetic tests are becoming a lot more popular as they allow one to find out many new details about their genetic makeup on their own without the need for references from health care providers.
- However, once the genetic test results are obtained it is not clear what tools and methods are used by people to share the genetic information with others and why.

Research Questions

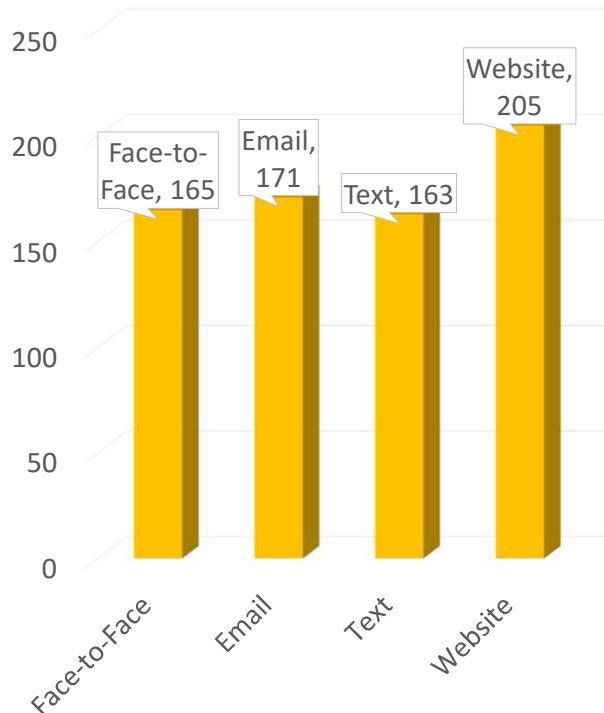
- This study aims to understand the use of various methods and tools to share genetic information among DTC genetic test consumers.
- What methods & tools do people use to share DTC genetic test results?
 - What motivates people's choice of method & tools for sharing test results?

Method

- Survey (N=384)
- Participants:
 - 63% Female, 29% Male
 - 281 (73%) took a DTC genetic test
- Data Collected [Open-ended Questions]
 - In sharing your DNA information with others what method do you think is appropriate?
 - Explain why you chose or did not choose the method(s) above as being appropriate for sharing your genetic/DNA information. Consider both technological and non-technological factors.

Findings

Preferred Methods & Tools



Preferred Attributes

- Tools/methods that provide convenience (e.g Eliminate the need for travel)
"Face-to-face would be great, but not always practical. E-mail is readily accessible."
- Tools/methods that enable rich face to face communication
"Face to face for someone I am wanting to help further my research is best, because I can show them how it works and answer questions."
- Tools/methods that provide security and Privacy Controls
"I wouldn't want to have the website directly share my information. I would rather do it myself."
- Tools/methods that allow for flexibility to match the nature of sharing task
"I think any method can be fine depending on the situation. With people that I see frequently I might discuss face to face. In most instances I would probably do email or internal messaging at the website (such as at Ancestry)."

Discussion

- Due to the sensitive nature of the data that individuals receive, there seems to be a lot of thought that goes into the ways in which people desire to share data.
- While sharing tools within DTC genetic testing websites provide some level of privacy it appears that sharing with people who don't use the website requires greater privacy and security mechanisms.
- These findings have implications for designing tools within DTC genetic testing websites that provide 1) communication richness 2) convenience and flexibility to switch between tool features depending on the nature of information shared and with whom.