

Direct to Consumer Genetic Testing: Privacy and Security Implications

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Background

- Although Direct to Consumer (DTC) genetic testing services such as 23andme and Ancestry.com are widely used, people are concerned about the privacy and security of personal genomics data.



- This study explores people's privacy and security concerns in the context of DTC companies.

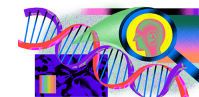


Research Questions

- To what extent are people concerned about privacy and security of their genomics data?
- What is the nature of privacy and security concerns?
- Are there differences in privacy and security concerns between those who have taken a DTC genetic test and those who have not?

Method

- Survey (N=384)
- Participants:
 - 63% Female, 29% Male
 - 281 (73%) took a DTC genetic test
 - 103 (27%) did not take a DTC genetic test
- Quantitative and Qualitative Data
- Data not normally distributed, Mann Whitney U and Kolmogorov Smirnov Tests performed

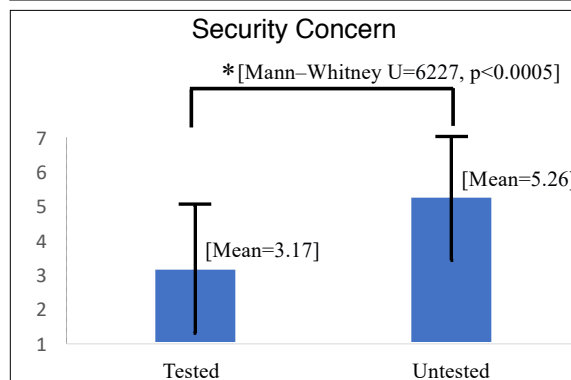
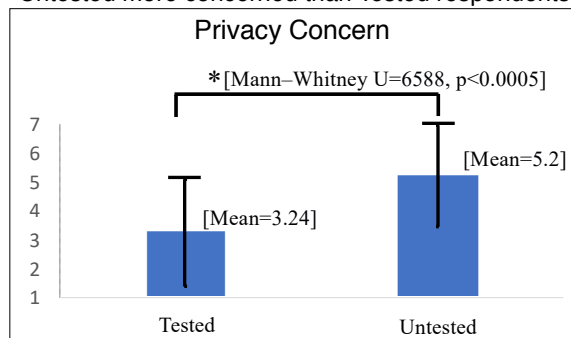


Results: Quantitative and Qualitative

Extent of Concern

1-Not at all concerned; 7-Extremely concerned
7-point scale

- Untested more concerned than Tested respondents



Nature of Privacy & Security Concerns

(Qualitative responses to open ended questions)

Key Common Concerns

- Unauthorized sharing of data by
 - DTC companies
 - Law Enforcement
- Inappropriate and unethical use of data by
 - Insurance companies
 - Government
 - Malicious hackers



"Police use of my data at Gedmatch [an online genetic genealogy company]. Even though I have indicated to Gedmatch that I wanted nothing to do with the police, they allowed my data to be used once a subpoena was issued by a judge for a VERY OLD CASE." (Tested respondent)

"Strangers, law enforcement, insurance companies, advertising agencies all could misuse or leak my DNA/genetic information for profit or power" (Untested respondent)

Key Differences in Concerns

- Untested respondents concerned about
 - social judgment/ prejudice
 - other organizations taking advantage of their data for profit

"People, even relatives, will judge you if you have certain risk factors (Alzheimer's, addiction, violence, etc.) People might judge lifestyle choices. (You have an increased risk for heart disease, you shouldn't eat that). GINA only prevents health insurers from discriminating against you (in theory), not other companies like life insurers."

- Many tested respondents not concerned and believe
 - there is no such thing as privacy in this world
 - they have nothing to hide
 - that fears of privacy with DNA are misplaced or ill understood

"No such thing as privacy on the internet"