

Attitudes Towards Sharing Personal Genomic and Health Information for Advances in Medicine

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Background

- P4 Medicine (predictive, preventative, personalized, and participatory medicine) is a project that aims to improve the prevention and early detection of disease by using reliable predictive and diagnostic tools/software.
- However, to develop such tools scientists require large amounts of medically-relevant data from diverse individuals in the population. Specifically, participants will be required to 1) have their DNA analyzed 2) provide regular blood samples and 3) report any illnesses or disease they develop.
- This study explores people's attitudes towards sharing personal genomic and health information for the research and development of P4 medicine tools/software.

Research Questions

- How willing are people to share personal genomic and health information for research and development in P4 medicine tools/software?
- How concerned are people about privacy when sharing personal genomic and health information for research and development of P4 medicine tools/software?
- Does explicit education on a) the costs and benefits of genomics research for public good and b) privacy and security protocols of handling genomic and health data affect:
 - People's willingness to share this data
 - People's level of privacy concern

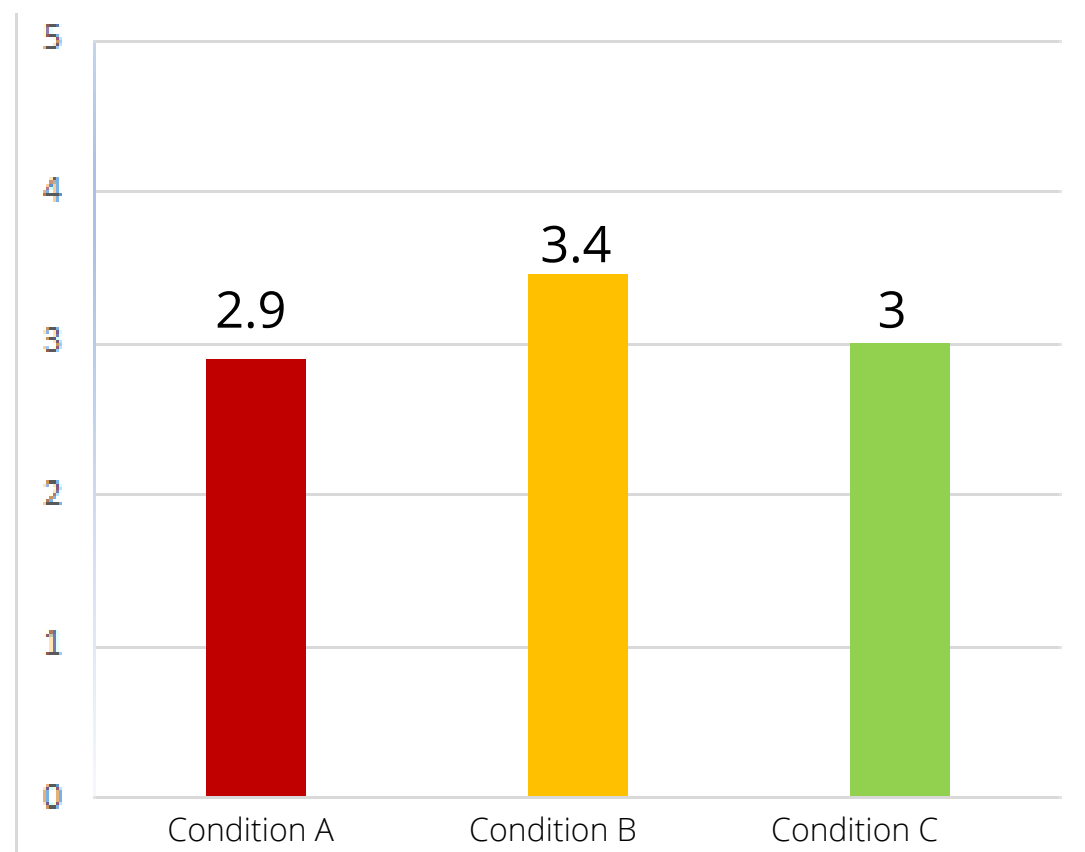
Method

- Survey (N=11)
- Participants: Female (82%); Male (28%); Students
- Experimental Design: Within Group
- Dependent variables:
 - Willingness to share genomic and health information data
 - Privacy concern associated with sharing of genomic and health information data
- Independent Variables
 - Condition A: No educational prompts
 - Condition B: Educational prompt on Privacy and Security Protocols
 - Condition C: Educational prompt on Future Benefits of P4 Medicine

Results

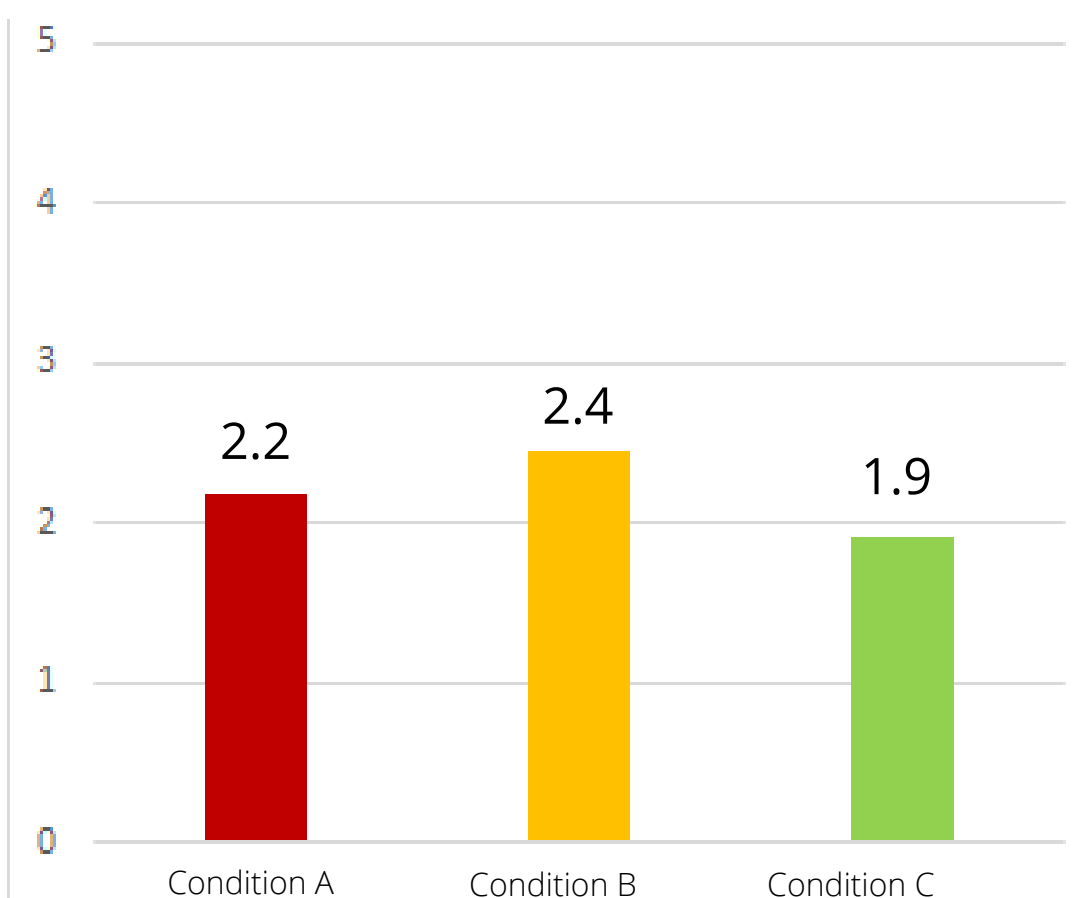
Willingness to Participate

Scale: 1- Not at all willing to participate 5-Extremely willing to participate



Privacy Concern

Scale: 1- Not at all concerned 5-Extremely concerned



Discussion

Privacy concerns seem to decrease (as expected) when participants were educated on the future benefits of P4 medicine. Below is a quote from a participant illustrating this change:

- Participant A: *"It helped to know that even if the information does get "hacked" that it will not be connected to my information. Like mentioned about, information on the internet gets hacked all the time and usually that is information that is always connected to our name so having this extra measure that it will not be connected to our identity is very reassuring"*.

Willingness to participate seem to increase (as expected) when participants were educated about privacy and security protocols as well as future benefits of P4 medicine. Participants reported that explanations helped them understand the benefits better as illustrated below:

- Participant B: *"I think this explanation [future benefits of P4 medicine] makes me more willing to participate"*.

Privacy concerns seem to increase (not as expected) when participants were educated about privacy and security protocols, however, examination of the qualitative data suggests that this increase was due to an error in the rating data provided by one participant. In fact, this participant expressed that they were actually less concerned.

- Participant A:
 - Concern for privacy in Condition A: 1
 - Concern for privacy in Condition B: 5
 - Concern for privacy in Condition C: 1
- Participant A: *"I was already fully willing to participate. However, this [privacy and security protocols] made me feel more secure in my decision and thoughts towards my privacy concerns"*.

Future Work

- There is a need to redesign the scale question on "privacy concern" so that participants do not misinterpret the scale.
- Study needs to be run with a larger sample size to test for statistical significant differences.
- Insights from this study have implications for developing narratives to educate public about data privacy and sharing of genomic and health data for research.