What are patient perspectives on privacy and trust in digital genomic tools? A qualitative study

Vedika Jha, Saumeh Saeedi, Marc Clausen, Yvonne Bombard

Introduction

Digital tools have emerged as a promising solution to increase efficiency and capacity of genomic services. Patient facing digital tools can improve access, decrease wait times, and boost patient engagement. However, accessing medical records, especially genomic records, through the internet raises concern about privacy and security risks. As patient facing digital genomic tools continue to develop, it is important to understand and incorporate patients' perspectives on privacy and security.

This analysis will help inform the design of future digital genomic platforms, which can incorporate the features that will build trust and security according to patients.

Methods: qualitative study using semi-structured interviews

Interviews:

- Semi structured interviews with 30 participants who had previous experience with genetic testing
- ↓
- Ask participants what would make them trust a genetics platform and feel like it was secure
- ↓
- Review transcripts and participants complete demographics survey

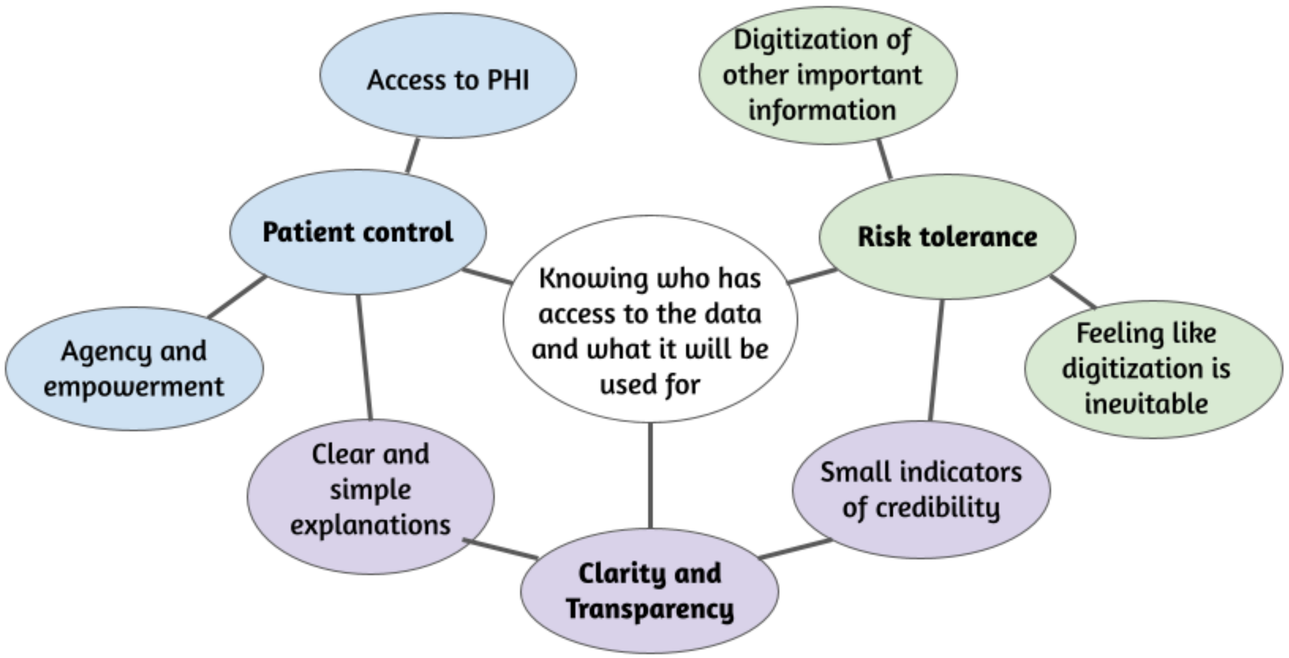
Analysis:

- Use thematic analysis employing interpretive description to create coding scheme
- ↓
- Consult with larger study team to refine coding framework, test out preliminary coding scheme
- ↓
- Code and analyze all transcripts to extract key themes

Results

Overall, participants were willing to store and access genomics personal health information (PHI) in a patient-facing digital platform.

- Participants expressed that the benefits of digital genomics services, such as patient empowerment and personalized care, outweighed the perceived risks, such as potential data leaks.
- Participants discussed factors that may minimize the risks of a digital platform, such as an emphasis on transparency about what security measures are in place and who has access to their PHI.
- The main benefit identified by participants was the ability to access and control their own PHI. Participants emphasized that a digital genomics platform should prioritize patient control of information to give patients more agency and increase efficiency in their care



Conclusion

Patients are willing to access their genomic information digitally as long as security measures are clearly explained and patients are able to access and control their own information. These findings inform the design of digital genomic platforms to enhance patients' sense of security, which is critical for any platforms' uptake and usage.

Acknowledgements: Thank you to the Hayeems lab at Sick Kids Hospital and the Genetics Navigator Study Team.