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

Background: 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.

Aim: To assess patient perspectives on privacy and security in digital genomic tools.

Methods: A qualitative study was conducted using semi-structured interviews with patients or parents of patients who underwent genetic testing. Participants were either recruited from the Canadian Organization of Rare Disorders or had previously participated in a Toronto-based cancer genetics study. Interviews focused on features that would make a digital genomics platform feel secure and trustworthy. Interview transcripts were analyzed using thematic analysis and interpretive description.

Results: Thirty participants who previously received genetic testing for themselves (n = 17) or their child (n = 13) were interviewed (n=20 females, n=15 above 50 years old). 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 described factors that increased their risk tolerance, including the digitization of other sensitive matters such as banking information. In order to minimize risks, participants emphasized the importance of transparency about what security measures are in place and who has access to their PHI. Participants described this information as a prerequisite, which should be easily found on a consent form or a page on a digital platform. 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.

Conclusions: 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.

Background

Digital health tools increasingly being used in many medical disciplines as a way to monitor health, improve access to health information, and increase efficiency of the healthcare system[1][2]. Within this shift to increasing digital care, digital genomics tools have emerged as a promising solution to increase efficiency and capacity of genomic services[1]. Such tools, including online decision aids or patient portals, can alleviate wait times for genetic services while providing patients with more control over their care[3]. Along with digital healthcare comes a radical change in the storage and security of personal health information (PHI). Both patients and providers have expressed concerns regarding this change and the new security risks that it poses.

Digital genomics platforms can include software used by researchers to manage patient information or can include patient facing tools for pretest and post test counseling, which can include intake of family history, health history, education, and return of results[4][5][6][7]. Different tools contain different kinds of sensitive health information and with varying degrees of anonymity of the data. For example, digital tools used by labs and sequencing facilities may contain information about a patients' DNA sequence but no other identifiers of the patient. On the other hand, a patient facing tool may not contain genetic information but may contain personal health history and family history or results from genetic tests, while remaining connected to the patient's identity. In this paper, we will be focusing largely on patient facing tools that encompass both pretest and post test, such as the Genomics ADvISER tool and Colour Health's genetic consultation software, which have been used to collect health history, conduct

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risk assessment, and deliver genetic test results in health settings and have been well received by both healthcare providers and patients[231].

However, a large issue for digital genomics platforms is privacy and security of information, as the success of any digital health tool is dependent on patients trusting the platform enough to access and store their health information on the platform. A 2016 review exploring the factors that affect recruitment to digital health interventions identified privacy and security concerns as a key deterrent[8]. Such concerns may be heightened due to the sensitive nature of genomic information that, if stolen could affect not only the patient but the patient's relatives as well[9]. Privacy, security, and credibility must be prioritized when designing patient-facing genomic services, both to protect personal health information (PHI) and to ensure the patient trusts the platform and feels comfortable using it.

Most of the current literature on privacy and security of digital genomics tools focuses on the concerns of healthcare providers and recommendations on how to improve privacy and security. There is a lack of literature of patient perspectives on the privacy and security of digital genomics tools. Existing literature on patient perspectives explores genomic data sharing for research purposes[1011], which largely involves sharing DNA sequence information between researchers and does not provide the patient with direct benefits. As patient facing digital genomic tools continue to develop, it is important to understand the patient's perspective on privacy and security.

In this study, we aim to assess patient perspectives on privacy and security in digital genomic tools.. 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. The ability for patients to trust a digital health platform is critical for its uptake and usage.

Methods

Design:

In order to assess the preferences of adult patients and parents of pediatric patients regarding privacy, security, and trust, we conducted a qualitative study using semi-structured interviews. We employed thematic analysis in order to capture key ideas from the interviews while

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accounting for flexibility and variety in the experiences of research participants. Research ethics approval was obtained through the St. Michael's Hospital.

Sample and Recruitment:
Potential participants were recruited either through an invitation and reminder email by the Canadian Organization of Rare Disorders (CORD), or were previous participants in a Toronto-based cancer genetics study and had agreed to be recontacted for future research. We chose to sample nationally to increase the geographic diversity of participants. Recruitment criteria included English proficiency and previous experience with genetic testing of any type for a presenting condition for the participant or their child. Participants were offered a gift card of $20 to thank them for participating.

Those who were interested in the study contacted the study team and were then screened to ensure they met the eligibility criteria. Recruitment occurred between January and July of 2021. Participants were recruited as part of a broader needs assessment project guiding the development of the Genetics Navigator: a digital patient-facing genetics platform.

Data Collection:
We conducted semi-structured interviews with 30 participants. During interviews, participants were asked what would make them trust a genetics platform and feel like it was secure. Specifically, participants were asked to share what would make them feel like a digital genomics platform was secure, what features would make them trust the information on the platform, and what features would allow them to trust the platform to hold their personal health information. Personal health information was not explicitly defined to participants, but previously in the interview participants were asked about storing their personal health and family health history on a digital platform, and receiving results of genetics testing through a digital platform. Participants were not asked about their perspectives on storing their DNA sequence on a digital genetics platform.

Four researchers, all experienced in qualitative interviewing, conducted the interviews. All interviewers were previously unknown to the interviewee. For each researcher, the first two interviews were conducted with another member of the research team to maximize consistency. Guided by the first few interviews, the interview guide was tweaked to improve clarity, precision, and build upon emerging themes. Interviews were conducted either over the telephone or through video conferencing software, and were digitally recorded and transcribed verbatim. Additionally, participants completed a short demographics survey. After the interviews, participants were offered an opportunity to review their transcript if requested and provide additional feedback.

Analysis:
Thematic analysis employing interpretive description was used to analyze interview transcripts. The primary researcher (VJ) developed the coding scheme by reading the interview transcripts and consulting with the larger study team about key themes in the data. The coding structure was fine tuned and reviewed by a second researcher (SS). Both researchers independently

coded the first four interviews using Dedoose software (Version 9.0.54, Los Angeles) and compared their coding in order to ensure intercoder reliability and mutual understanding of the codes. The rest of the coding was completed by the primary researcher and reviewed by the secondary researcher, and any disagreements were resolved through discussion.

Results

Demographic characteristics

In total, 30 participants who previously received genetic testing for themselves (n = 17) or their child (n = 13) were interviewed. Of these, 20 (67%) identified as female and 10 (33%) identified as male. Among all participants, 20 (67%) had at minimum a university or college degree. All participants were 30 years of age or older and exactly half were above 50 years of age. Almost three-quarters (n = 22) lived in an urban centre (Table 1). Interviews ranged from 34m58s to 68m15s in length, with an average interview time of 53m16s. (from chatbot)

Overview of results

Overall, participants were willing to store PHI in a digital genomics platform, but acknowledged that doing so comes with risks. Participants identified several factors that contribute to their increasing risk tolerance, such as a broader shift to digital platform use in other aspects of their life, especially banking. Some participants viewed the digitization of genetic services as inevitable, while others worried that digitized information could never truly be secure. However, participants expressed that the benefits of digital genomics services outweighed the perceived risks. Participants voiced aspects of a genomics platform that would minimize the privacy and security risks and maximize its benefits. In order to minimize risks, participants emphasized the importance of clarity and transparency about what security measures are in place, who is responsible for the platform, and who has access to their PHI. Participants discussed how this information should be easily retrievable on a consent form or a page on a digital platform. The main benefit identified by participants was the ability to access and control their own PHI in order to gain more agency and increase efficiency in their care, and emphasized that a digital genomics platform should prioritize this feature.

Risk Tolerance

When asked about privacy, security and trust, many participants showed low levels of concern and high risk tolerance. Many participants could not identify any serious risks of accessing and storing their genetic results on a digital platform. Those who expressed concern worried about insurance companies accessing their PHI, or that their personal data could be sold to third parties and used for commercial purposes.

"To be honest, like at the end of the day, like I'm not, I'm not too worried about the data, like it's there, you know like if somebody else, like if there was a breach of that and, you know like I just don't know how it could be used nefariously…I'm not too worried about that piece, to be honest, cause it's a tool that we use to help care for our son."

Patients identified that there has been a larger shift in how information is stored today. An increasing amount of sensitive information, such as banking information, is stored digitally, with similar user-facing platforms that allow electronic access to personal information. Multiple participants highlighted similarities specifically to banking and referenced the amount of trust needed in order to use digital banking services. In comparison, most participants expressed that storing genetic PHI digitally seems far less risky than storing financial information. As a result, participants were more willing to store PHI digitally with less of a concern for safety.

"You know, it's very funny how we take all our life savings and we put it into virtual platforms, in essence, but we really worry about some of our medical information, which I feel like is far less risky, obviously if it was disclosed."

Some participants discussed that they are overall more tolerant of risk due to a general sentiment that, as more and more services that were once conducted in person shift to online, it is inevitable for genetic services to shift on online platforms as well. This feeling of inevitability among participants made them less concerned about safety measures.

"Eventually everything's gonna be online. Eventually everything's gonna be done through electronic media."

The feeling of inevitability manifested in a different way among some participants, who doubted that anything kept online can ever be truly secure, and there will always be a risk of data breach. However, participants were willing to accept this risk as long as security measures were still explained clearly and transparently.

"But really, anything that's really secure, is really not really, you know, deep down in the rabbit hole, I mean, everyone has access to everything. But as long as you, as long as you can tell us where it's, how it's being secured, and what system we're using, and we can go and look that up, I would want to look it up."

Overall, participants were open to the idea of a digital genetics platform containing PHI. Their risk tolerance for accessing and storing sensitive information digitally has increased due to a broader shift to digital platforms in other aspects of their life, especially banking. Some participants viewed the digitization of genetic services as inevitable, while others worried that digitized information could never truly be secure. However, 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. Further discussions highlighted ways to minimize the risks associated with a digital genomics platform and ways to maximize its benefits.

Minimizing risks

Despite the generally high risk tolerance for using a digital genomics platform, participants still expected to have basic security measures in place, such as a username and password. Some participants took this expectation a step further, noting that the platform should be encrypted so that patient information would be incomprehensible to non-authorized parties. Other participants wanted to ensure all data is stored in Canada. However, within these discussions, many participants admitted to not understanding aspects of security and how information is protected, and thus being unsure about what security measures are adequate.

“So long as they’re saying they’re a secure website by whatever means they’re doing it, I mean, that’s good enough for me and a layperson” (Participant X)

Partly due to the lack of understanding technical details of security, participants voiced that they wanted the privacy and security measures to be clearly detailed in simple language somewhere on the platform. Participants want a clear explanation of who has access to the data, where the data is being kept, how the data is being secured, and how they could remove the data from the platform if they chose to. Some expressed that this should be done through a consent form, while others wanted to have an information page somewhere on the platform. Either way, participants clearly valued having as much transparency and clarity as possible about a platform’s privacy and security measures.

“I want page that tells me, you are entering a private and encrypted portal…we do not sell your data, your data is used only by your healthcare providers, you have the option of removing your data at any time, you know, like just a few points that shows me, I’m in control. Like you are getting my information because I allow it. OK, and I can remove that, I can revoke that back at any time, OK. So something that shows me that the element of control is really good.”

“I think having that information made really clear would be helpful and comforting to most people. And not in just some tiny little writing, but really upfront.”

When asked what would make them trust a platform’s credibility, most participants discussed measures such as including institutional logos of a hospital or university. A marker of an institution that they already trust with their healthcare and PHI makes them feel comfortable storing their PHI on the platform. Participants remarked how these kinds of indicators of credibility do not mean that the information is actually secure, but since participants already view these institutions as reputable and trustworthy, they assume that adequate security measures will be in place.

“If it comes from the hospital, I’m gonna assume the hospital knows what they’re doing. Like I see the same report that the doctor sees online. It makes people secure and happy with that. Trust, so, that’s the trust being met, yes, definitely.”

Participants also mentioned other indicators of credibility such as citations from peer reviewed journals for any general health information on the platform, or including the names of the healthcare providers working on the other end of the platform. Once again, participants stressed the importance of transparency for the success of a digital platform – both in terms of who and where any information was coming from.

Maximizing benefits
Some participants recognize that accessing PHI online comes with risks, especially in the realm of genetics. All participants expected the platform developers to mitigate those risks through security measures. However, many participants expressed that overall, the benefits of a digital genomics platform can outweigh the risks if patients are able to access their own information and have more agency and control over their healthcare, including management of information and the ability to share past information with new healthcare providers.

Participants emphasized access, control, and efficiency as the main benefits to storing genomics PHI on a digital platform. Many participants want access to their full test results and want to get as much information as possible. Digital storage of PHI allows for easier and more efficient storage of health results, which is particularly useful for patients with complex genetic conditions who have had multiple rounds of genomic tests or other health assessments. It also means that patients could have the ability to easily share their information with future healthcare providers, making their care more efficient.

"As long as it's just the people that you have said could have access to your data, have, you know, are the ones that are doing that. I don't, certainly don't have huge issues with that. If that data is going to optimize your care, that's great, that's wonderful!"

Increased access and control over personal data is viewed not only as a benefit of digital care, but also as a benefit for security. Participants felt as though their data would be most secure if it was clear that the patient had control over the data and would be able to remove their personal information from the platform at any time.

"...A few points that shows me, I'm in control. Like you are getting my information because I allow it. OK, and I can remove that, I can revoke that back at any time, OK. So something that shows me that the element of control is really good."

Discussion

As digital health tools become embedded into genetic services and more PHI is stored on patient-facing digital platforms, it is important to consider patient perspectives on the privacy and security of their own information. This qualitative study provides an understanding of patient attitudes towards privacy and security of patient facing digital genomics platforms. Participants discussed the factors that contribute to their assessment of the safety of a platform, and how a broader shift to digital information storage has increased their willingness to store personal health information online as well. Participants voiced that the security measures of any digital genomics platform should be clearly explained in accessible language so users can know how their information is being protected. Participants also said that small indicators of credibility, such as institutional logos or citations of peer reviewed articles can bolster their trust in a digital platform. Lastly, participants emphasized the importance of patient access and control over their own PHI, and saw this enhanced level of agency as the main benefit to a patient facing platform. Thus, the development of patient facing digital genomics platforms should prioritize clarity, transparency, and patient access when developing both the platform and its security measures.

Our work adds to the growing literature surrounding patient perspectives on digital health tools. While few studies have been conducted on the topic, related papers, such as those exploring patient perspectives on sharing data electronically for research, have found similar key themes, such as increasing risk tolerance and prioritizing transparency. One study that asked patients about their perspectives on sharing electronic data for research purposes similarly found that patients valued transparency and noted a current lack of transparency in the use of data[12]. Additionally, this study found that 98% of participants believed that the benefits of sharing data electronically outweighed security risks, and this study also highlighted the importance of patient empowerment and agency[13]. Another study on the security of digital health platforms found that concern over security was not correlated to use of the digital platform – thus even when patients expressed concerns, they were willing to accept the security risks in order to reap the benefits of an online platform[14]. A study of parents of children with a genetic condition found that parents also valued transparency, accessible language, and credibility of an institution when it came to sharing their children's data for research[15].

One limitation of this study is that it is a hypothetical one – we asked participants broadly about their perspectives on security in digital health tools without having participants use a digital health tool and then comment on privacy. However, many participants were able to draw upon their previous experience using digital health tools, as well as their own opinions on the current model of care, in order to share their perspective. Furthermore, this hypothetical study was done to inform the design of a future digital health tool and to ensure the tool was incorporating features valued by patients. It is also important to note that, despite sampling from a wide array of patients with different genetic conditions, perspectives may further differ across disease populations, settings, and disease presentations. Perspectives may also vary in other countries with different healthcare systems and privacy laws, as this study was conducted across Canada only. Further research could expand our work to encompass a more diverse array of settings across the globe. Finally, as stated previously, this study does not pertain to the storage of DNA sequence information but instead the storage of genetic test results. Thus, our findings cannot be easily applied to digital genomics tools that store sequence information, as this kind of information comes with many more security risks and concerns, as discussed previously in the literature.

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