DIGITAL TRANSFORMATIONS FOR HEALTH LAB

GOVERNING HEALTH FUTURES 2030

Trust in Digital Health

Exploring Barriers and Enablers Among Youth

Rupal Jain, January 2025

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CONTENTS

ABSTRACT

Digital health ecosystems are transforming healthcare delivery and accessibility, particularly through innovations such as mobile health, telemedicine, and Artificial Intelligence interventions. However, trust remains a significant barrier to adoption, particularly among youth who are otherwise technologically adept. This paper explores the factors influencing trust in digital health systems, focusing on personal (trustor and trustee-related), technological, and institutional factors. Using the conceptual framework of Mayer et al.'s trust model, this study highlights the importance of transparency, security, and perceived competence in fostering trust. It also examines how trust varies across age groups, education levels, and the nature of digital interactions. Key findings suggest that while younger users are more concerned with privacy and data security, older adults face challenges with usability. Policy recommendations emphasize robust data protection, transparency in AI applications, and targeted efforts to enhance trust in Digital Health ecosystems, especially in low- and middle-income countries.

1. INTRODUCTION

With an ever-growing global population of approximately 7.9 billion and continuous technology advancements, digital transformation in health offers a solution to providing universal health coverage (World Bank, 2022). The Lancet and Financial Times Commission report defines digital transformations "as the multifaceted processes of integration of digital technologies and platforms into all areas of life, including health, are central to understanding — and shaping — many of these disruptive dynamics" (Kickbusch et al., 2021). Particularly, digital health (DH) encompasses the use of technology to deliver healthcare services and manage health-related data.

At the micro level, Digital Health (DH) encompasses mobile health (mHealth), telemedicine, precision medicine, and precision public health, through the usage of Artificial Intelligence (AI) to provide better, more personalized information for patients. At the macro level, it can improve population health through data-driven public health interventions (Landers et al., 2024). It provides an essential tool for reaching underserved and difficult-to-reach areas, thereby addressing gaps in healthcare accessibility (Landers et al., 2024). For instance, telemedicine facilitates remote medical consultations, eliminating the need for patients to travel great distances for care, while the usage of digital technology for health data in countries with large population sizes can help manage health data with more efficiency (Ferretti et al., 2024). Despite the numerous benefits of DH identified, there is notable hesitancy observed in the usage of such technologies, acting as a barrier to the widespread adoption, alongside major issues of digital access in low and middle-income countries (LMICs), (Adjekum et al., 2018). The adoption of digital technologies in health relies on trust from patients, healthcare professionals and other stakeholders (Vayena et al., 2018). Wherein, trust is dependent on various personal, technological, and institutional factors (Adjekum et al., 2018).

Given the pervasive engagement of youth with digital technologies in today's world, the Lancet and Financial Times Commission prioritized them as a key focus in digital health initiatives (Kickbusch et al., 2021). On the basis of which, the United Nations Children's Fund (UNICEF) conducted a U-Report survey in order to understand the challenges faced by youth in trusting digital health (Governing Health Futures 2030 Commission, 2021). The study found that inaccurate health information and concerns about privacy are two major barriers to the trust in the adoption of such technologies. Many respondents expressed that they do not trust the

information provided on digital health platforms, while others were reluctant to share personal health information due to fears of data breaches and misuse (Digital Transformations for Health Lab, 2024). To overcome these challenges and fully leverage the potential of digital health, it is essential to understand trust as a concept and identify the factors enhancing and undermining trust among youth. Only then can the challenges of trust in digital health be realized, and policies would be more focused and evidence-based.

1.1. Conceptualizing Trust

Trust is a complicated construct that is challenging to define in operational terms. According to the theorists, trust can be built between various entities: these entities could be individuals, organizations, and institutions (Ferretti et al., 2023). Some have explained this relationship as involving two parties, i.e. trust between a trustor (the entity placing trust) and a trustee (the entity being trusted). On the contrary, others, like Guinnane (2005), suggest that trust is always a three-part relationship involving at least two actors and one act. By this, Guinnane implies that if the act changes there is a possibility that trust might not hold for this new act, even while the actors may remain the same. Understanding and maintaining trust is not just a theoretical concept, but a practical necessity for all entities involved in the digital health ecosystem.

Johnson-George and Swap (1982) proposed that: "willingness to take risks may be one of the few characteristics common to all trust situations." Furthermore, Mayer, R.C., Davis, J. H., dan Schoorman (1995) conceptualized “trust as the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party.”

This brings the theorists to argue that building trust cannot be a one-way relationship; instead, it involves the characteristics of the trustee as well as the trustor, in addition to the contextual and environmental factors. (Mayer, R.C., Davis, J. H., dan Schoorman, 1995). Figure 1 describes the characteristics of a trustee that are important to the trustor in order to make the decision of risk-taking as ability, benevolence, and integrity. The trustor’s propensity is noted on an individual level, as some may have more risk-taking behaviour than others.

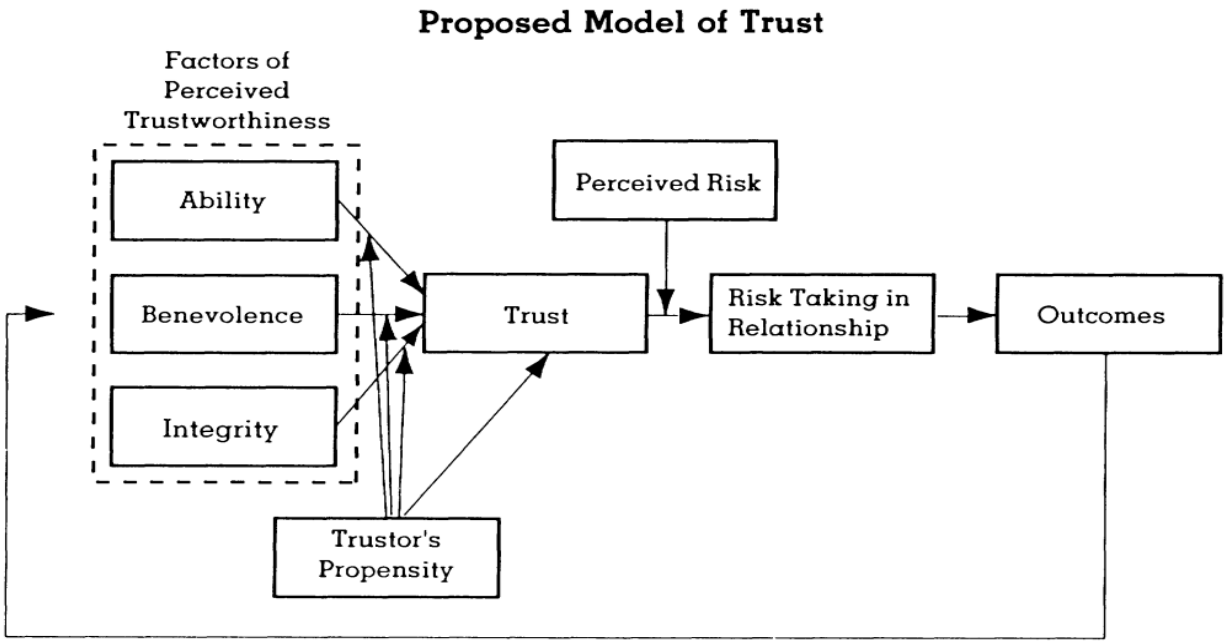

Figure 1: Model of Trust by Mayer et al, 1995

2. MATERIALS AND METHODS

A search for literature was conducted on two databases, The US National Library of Medicine's PubMed and Google Scholar, during the period from August to November of 2024. Search terms included: "digital health," "mHealth," "telemedicine," "precision medicine," "precision public health," "barriers," and "adoption," in combination with keywords like "youth," "age," and "trust". The search included studies from high-income countries as well as low and middle-income countries to get a comprehensive understanding of both scenarios. With this the time cap was also kept open to observe the evolution of barriers in digital health. The findings employed a conceptual analysis approach using Mayer et al.'s (1995) trust model as a theoretical framework.

3. RESULTS

3.1. Analysis of the Different Factors that Increase or Undermine Young People's Trust in Digital Health Ecosystems

3.1.1. Factors Related to Trustor:

1. Age and Trust Dynamics in Digital Health

Trust in digital health (DH) systems varies significantly across different age groups, with younger individuals, generally more comfortable with technology, facing distinct barriers compared to older adults (van der Vaart et al., 2019). Studies have suggested the complexity of digital services, perceived ease of use, and inexperience with technology are key barriers preventing people from middle and late adulthood from using DH services (Zulman et al., 2011). One of the distinct responses included, "I am afraid of it. It chickens me out" (Zulman et al., 2011). This highlights that older users often struggle with the operational and navigational aspects of digital platforms. As the complexity of digital services can be daunting for older adults, they rely instead on more traditional, face-to-face healthcare interactions.

However, for the older adults who are comfortable using digital services, issues of trust were not found prominent. One such study in Spain observed that people found digital health communication completely trustworthy. Some of them even referred to Google as "Mr Google", or "Doctor." Yet, this trust was often conditional, as many believed that information sourced on the Internet can complement the in-person physician's visits, but cannot replace them (Sanders et al., 2015). A few of them also mentioned that one should check the information from multiple sources before blindly trusting it (Sanders et al., 2015).

On the contrary, perceived ease of use was not found to influence intentions to use digital health services among the young generation (Sawrikar & Mote, 2022). Instead, younger users encounter issues rooted in trust rather than usability, given they are better aware of technology and its potential. Research indicates that the youth, despite their fluency with technology, can be wary of adopting digital health services due to concerns about privacy, data security, and the credibility of

online health information (Governing Health Futures 2030 Commission, 2021; Sawrikar & Mote, 2022).

2. Education and Occupation

As discussed in the Mayer et al. (1995) trust theory, the relationship of trust does not exclusively depend on the trustee's characteristics but also on the trustors'. One such study highlighted that people from rural areas, or with lower education, had lower concern for data privacy and security, while those with an undergraduate or graduate degree had a higher level of concern. This could be due to greater awareness among educated people and their ability, therefore, to make informed decisions (Care et al., 2023). Similarly, people who have professions related to medical data, healthcare, or administration are the most critical of health-related data (Lupton, 2019), as they are more aware of potential breaches and thus better equipped to make informed choices. In addition to this, people with chronic diseases and caregivers who were seeking care for their children had increased levels of concern regarding data security and privacy (Care et al., 2023)

3. Nature of the Act

As Guinnane (2005) suggests, trust is dynamic and can change based on the nature of the act or interaction. In this context, trust in digital health services may also vary depending on the specific type of consultation and the sensitivity of the topic. An interesting study found that according to healthcare providers, young people would prefer digital services to face-to-face consultations, specifically for sensitive topics like sexual health, due to patient privacy. Youth, on the other hand, stated that while they might feel more at ease in an online setting, they still would not trust online services because they cannot check the credibility of the person behind the screen, and they are also not sure if anonymity would be properly preserved (Bennett et al., 2023).

3.1.2. Factors related to Trustee:

4. Data Usage and Privacy Concerns

The use of personal data by digital health service providers is a significant concern for young people. The integrity and security of health data, particularly in the context of government-managed health records, have been subjects of skepticism (Lupton, 2019). Interestingly, one of the studies highlighted that patients with chronic illness were more willing to share their personal health information with not-for-profit organizations for research than with clinics. (Care et al., 2023). People have also raised questions regarding anonymity in the process, thus, techniques like data anonymization, where personal identifiers are removed, can help maintain privacy while still allowing for data analysis (Bennett et al., 2023).

There is a need for the state to introduce and implement comprehensive and clear privacy policies that are easy to understand, and focus on transparency about the purpose of data collection and its usage, especially wherein health-related data is categorized explicitly as highly sensitive data. When users are assured that their data is handled in compliance with strict privacy regulations, they are more likely to engage with digital health services. Robust data protection measures, such as encryption and secure storage, help to build confidence in the system's ability to safeguard sensitive health information (Brost & Hoffmann, 2015).

5. Intention and Capability of the Trustee

As elucidated by Mayer et al. (1995), integrity and benevolence are key parameters that can highly influence the relationship of trust. One such study by Lupton (2019) highlights that the recent publicity of the Australian government's misuse of citizens' personal data has resulted in a low level of faith in the government's intention to protect the data. In addition to this, people mentioned not trusting the capability of the government to handle data breaches and security and, thus, not using digital health record services (Lupton, 2019). Overall, some of the participants pointed to the possibility of malicious activity, while others portrayed government authorities to be incompetent in regards to protecting data. Lupton (2019) and Care et al. (2023) highlight instances where people are more concerned about sharing their details with governmental agencies than with not-for-profit organizations. There could be many underlying reasons, like

political agenda and intentions associated with collecting health data and the capability of the government.

6. Artificial Intelligence, Algorithms and Trust

The integration of AI and algorithms in digital health services adds another layer of complexity to the trust equation. AI's ability to use individualization for diagnosis and personalized health recommendations offers promising advancements, but it also raises concerns about risks of privacy breaches (Esmaeilzadeh et al., 2021). Young users are particularly sensitive to the ethical implications of AI in healthcare, including potential biases in algorithms and the lack of human oversight in critical health decisions. AI characteristics such as "black box", self-learning, non-transparent, and autonomous characteristics pose a challenge to building trust in its implementation since these processes are not transparent to the user. (Steerling et al., 2023).

Furthermore, in cases of AI usage, people are also concerned about the technology's capability. Technical objectivity included characteristics such as accuracy, data-driven, lack of moral values, and lack of empathy (Steerling et al., 2023).

3.1.3. Design and Credibility

In the context of digital health information, the studies have also focussed on elements like the way that websites and applications are designed. Researchers have observed that people tend to trust sources that are appealing to the eyes: with good graphics, audio, and visual content. Knowing the source of information also increases trust: for example, when users are aware of whom they are talking to on the other side of a chat, or when the author of the health article is given on the website. Written assurances of privacy and credential information have also been identified as one of the trust factors. Zaini et al., (2013) and Care et al. (2023) also identified notifications of account activity, strong minimum password requirements, and using a trusted partner for sign-in could also add to the confidence of trustors in these companies.

The factors identified above that undermine trust, as well as the factors that enhance trust, are listed as follows:

Table 1: Summarizing factors that can undermine or increase trust in Digital Health systems

Factors undermining trust	Factors increasing trust
Privacy concerns	Transparency and accountability
Lack of security of data	Credibility of the source of information
Perceived incompetence and intentions of the trustee	Design of the website/application
Past history of malicious activity of the trustee	Capability of technology being used
Trustor occupation in the healthcare field (highly aware)	Trustor with low level of education (less aware)
Lack of anonymity	Strong security measures

4. DISCUSSION

The rapid adoption of digital health systems has marked a transformative shift in healthcare delivery, particularly with innovations like telemedicine, mobile health (mHealth), and AI-powered health interventions. While these advancements hold great promise, the concept of trust remains a critical barrier to widespread acceptance, especially among younger populations who are otherwise tech-savvy.

4.1. Trust and its Complex Nature in Digital Health Systems

Drawing on Mayer et al.'s (1995) conceptualization of trust, we find that trust in DH systems is contingent upon these critical elements: integrity, benevolence, and ability, as well as trustor characteristics and other contextual factors (Figure 1).

Integrity: Mayer et al., (1995) defined integrity as the trustor's perception that the trustee will adhere to a set of principles that the parties have agreed on (Mayer, R.C., Davis, J. H., dan Schoorman, 1995). Findings show that data usage, and privacy concerns regarding trustees can feed into perceived integrity. To cater to this, transparency and clear communication are necessary. Transparent communication about the treatment and the technology used can also alleviate fears and increase user-confidence in digital health technologies (Rodriguez-Villa & Torous, 2019). As also highlighted by Schmietow (2020), clear communication with patients about the treatment provided using precision medicine and AI gives them a stake in the decision-making process.

Benevolence: Users are more likely to trust platforms that market themselves as well-wishers. As highlighted in the findings, the perceived intentions of the trustee can help build trust. This could depend on various factors like demonstrating good intentions, providing a personalized experience, past success rate, hidden political agenda, or mere market reputation.

Perceived ability: Ability can be divided into two segments — the capacity of the service providers and the technology being used. Our findings undermined the idea that service providers associated with reputable organizations and professionals might be perceived as better and more capable choices. Besides this, the technology that is being used for the service can also be a

deciding factor. The reliability and accuracy of digital health technologies can be achieved with continuous testing, validation, and updates to the technology (Vervier et al., 2018).

Trustor's characteristics: Age has been associated with different kinds of barriers. Youth have major issues with trust as they are usually more technologically adept and thus are more aware of the potential security breaches, compared to people in old age who struggle with usability more. As indicated, people who are more aware of the potential breaches, like those with higher education and occupation in the health sector, are more skeptical and do not trust the DH services easily. However, individuals with lower educational backgrounds or those outside the health sector may be more vulnerable to exploitation by companies that prioritize profit over privacy (Meier & Krämer, 2024). Interestingly, some individuals from lower-income groups may view digital health services as a necessary trade-off, where the convenience of healthcare access outweighs concerns about privacy. This highlights the need for ethical considerations when targeting vulnerable populations with digital health technologies.

4.2. The Role of Artificial Intelligence and Ethical Concerns

Artificial intelligence (AI) introduces another layer of complexity in healthcare platforms. It holds immense potential for personalized healthcare services but also raises ethical questions about algorithmic bias and decision-making transparency. Due to this, trust in such technologies is often undermined by the opaque nature of AI decision-making processes. Esmaeilzadeh et al. (2021) also observed that younger users expressed concerns about accountability and fairness due to the "black box" characteristic of AI, where the inner workings of algorithms are not visible.

A critical point of reflection here is whether the increasing role of AI in healthcare will enhance or detract from trust. While AI's personalized nature may appeal to users seeking customized health interventions, it can also exacerbate privacy and bias concerns. To build trust, it is crucial for digital health systems to not only integrate AI but also ensure that the systems are transparent, explainable, and regularly audited to avoid algorithmic biases (Steerling et al., 2023). One potential path forward is the development of AI-based systems that incorporate feedback loops from users, allowing them to understand, challenge, and modify AI recommendations, which could enhance user trust significantly.

4.3. Institutional Trust and Data Privacy

Institutional trust, particularly in the form of data protection policies, is another major factor influencing trust in digital health systems. While users are increasingly aware of the risks involved in sharing personal health data online, many digital health platforms continue to fall short when it comes to ensuring data privacy. The perceived risk of data misuse is compounded by historical inefficiencies in healthcare systems and governments that have failed to adequately protect personal information in the past (Lupton, 2019).

Moreover, the onus of safeguarding data privacy does not solely lie with healthcare providers. Digital health platforms must establish transparent and user-friendly privacy policies that clearly articulate how data will be collected, stored, and used.

5. CONCLUSION

Building trust in digital health systems will require targeted interventions from both governments and health organizations. From a policy perspective, the integration of digital health services should be accompanied by robust public education campaigns that focus on informing citizens, especially youth, about the benefits and risks of digital health technologies. These campaigns should not only address the technical aspects of using these services but also emphasize the ethical and privacy-related dimensions.

Governments should work towards standardizing digital health regulations and ensuring strict data protection laws. A global consensus on data privacy, perhaps through international frameworks, could enhance user-confidence across borders. Furthermore, collaboration between tech companies, healthcare providers, and policymakers will be essential to ensure that digital health systems are not only accessible but also trusted and secure. A comprehensive approach that combines technological innovation, ethical safeguards, and institutional transparency can help bridge the trust gap and unlock the potential of digital health systems globally.

Another point to be noted is that the studies based on trust in DH are primarily from high-income countries. Thus, there is a need to conduct such studies in low- and middle-income countries with high youth populations, where there have been tremendous recent increases in digital access.

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About DTH-Lab

DTH-Lab is a global consortium of partners working to drive implementation of The Lancet and Financial Times Commission on Governing Health Futures 2030's recommendations for value-based digital transformations for health co-created with young people. DTH-Lab operates through a distributive governance model, led by three core partners: Ashoka University (India), DTH-Lab (hosted by the University of Geneva, Switzerland) and PharmAccess (Nigeria).

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