Developer's deep understanding of the diverse patient needs is critical to patient engagement with digital health technology

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Abstract

In recent years, patient engagement has emerged as a cornerstone in clinical decision-making, medical research, and health policy development, with its multifaceted value widely recognized by stakeholders across the healthcare continuum. However, digital health technologies, which are designed to enhance patient engagement, often fall short of their full potential due to developers' limited understanding of patients' needs and preferences. This perspective paper argues for adopting a patient-centered approach, emphasizing the critical importance of developers immersing themselves in patient communities to gain richer insights into patients' lived experiences. Such an approach can lead to improved usability of digital health tools, enhanced user experience, and increased patient motivation, ultimately fostering more effective patient engagement in medical practice. Although challenges persist in the effective collection, analysis, and implementation of user feedback, prioritizing patient engagement remains crucial for optimizing health outcomes and enhancing the overall patient experience. By embracing this approach, developers can bridge the gap between technological innovation and patient needs, promoting more meaningful interactions and ultimately contributing to the advancement of healthcare systems and improved population health.

Keywords

Patient engagement, digital health tools, product development, patient-centeredness, patient experience

In recent years, patient engagement has assumed an increasingly pivotal role in clinical decision-making, medical research, and policy development. To date, no universally accepted definition of patient engagement exists. For the purposes of this paper, it is defined as "the active collaboration of patients, families, their representatives, and healthcare professionals at all levels of the healthcare system (including direct care, organizational design and management, and policy development) to enhance health and healthcare quality" [1]. Extensive evidence underscores the substantial value of patient engagement in advancing both health outcomes and the quality of healthcare delivery. For instance, patient engagement

introduces a vital patient perspective into healthcare decision-making, which is essential for achieving truly patient-centered care. Research has demonstrated that patient involvement fosters transparency and trust within the healthcare decision-making process, resulting in heightened patient satisfaction and improved adherence to treatment regimens [2]. Patient engagement has the potential to decrease hospitalizations while enhancing the effectiveness, efficiency, quality, and responsiveness of healthcare, as well as improving patients' quality of life [2]. Moreover, patient engagement plays a crucial role in drug development. It can assist in identifying unmet clinical needs and provide essential feedback throughout the drug development process. This not only improves the quality and relevance of research but also offers researchers deeper insights into topics and outcomes of interest, thereby optimizing recruitment rates and study designs [3]. Additionally, patient organizations are pivotal in policy development, particularly in health technology assessments and drug reimbursement decisions. Patient input enables policymakers to gain a more comprehensive understanding of patients' needs and priorities [4].

Since its inception, digital health technology has been conceptualized as a transformative tool for enhancing patient engagement in medical practice [5]. This is supported by extensive research demonstrating the potential of digital health technologies to facilitate patient engagement and improve outcomes across various medical contexts [6]. However, despite the promise of well-designed digital health tools, it is evident that their implementation does not consistently lead to the desired enhancement of patient engagement [7]. A striking example highlights that providing patients with access to health data does not necessarily ensure increased engagement. A 2019 survey evaluating patient access initiatives for electronic health records across 27 European Union Member States revealed that fewer than 10% of patients regularly reviewed their medical records or test results [8]. Therefore, for digital health technologies to effectively enhance patient engagement, it is imperative that patient-centered design principles are prioritized during the development phase. This gap between technology and genuine patient involvement has emerged as a critical area of focus for researchers aiming to elucidate its underlying mechanisms [9]. Several factors have been identified as influential in shaping patient engagement, including sociodemographic characteristics, patient empowerment dynamics, motivational drivers, healthcare professionals' attitudes and competencies, structural elements of the health system, techno-functional attributes, and policy frameworks [10, 11]. Nevertheless, a key aspect often overlooked in this discourse is the necessity for developers of digital health tools to possess a deep and nuanced understanding of patient needs and preferences. Such comprehension can serve as a foundational element in bridging the divide and enhancing the efficacy of digital health interventions.

The development process for digital health tools significantly diverges from that of many other consumer products. For everyday commodities such as food, clothing, and beverages, developers often adopt a user-centered approach during the design phase because they are frequently also end-users of these products. This self-usage enables a more intuitive understanding of consumer needs, thereby facilitating product refinement and optimization. In contrast, digital health tools are designed for patients—a population whose experiences are inherently heterogeneous and multifaceted. It can be challenging for developers to fully empathize with the specific needs, pain points, and dissatisfaction that patients encounter while interacting with digital health solutions. An insightful article in the New England Journal of Medicine [12] highlights how an oncologist's personal experience with cancer provided her with a profound appreciation of her patients' fears, helplessness, and desire for medical support. These were personal insights she could not have gained while solely in the role of a physician. This narrative underscores the challenges that even medical professionals encounter in understanding the patient experience. Consequently, it is not surprising that developers, who may have limited exposure to or interaction with patients, struggle to fully grasp the patient's perspective. This exemplifies the importance of incorporating real-world patient perspectives into the development of digital health tools to ensure they are both effective and compassionate in addressing user requirements. To achieve a truly patient-centered approach in the development of digital health tools, developers should be actively engaged with and immersed in the patient community. This involvement can foster deeper empathy and insight into the nuances of patient needs, ultimately enhancing the design and functionality of these tools.

It is recommended that developers engage in participatory action research [13], a methodology wherein they actively immerse themselves in the daily lives of patients. This approach typically involves an iterative cycle of "observe and listen", "reflect and discuss", and "collaboratively take action" [14]. The key advantage of this method is its dual engagement: it not only integrates researchers into patients' lives but also fosters co-creation of research with patients as active participants. In a sense, this mirrors the work of anthropologists conducting ethnographic research [15]. Such efforts might include accompanying patients to medical appointments, spending time in their homes to observe daily routines, dietary patterns, and overall lifestyle, thereby facilitating a comprehensive understanding of the contexts in which digital health tools are utilized. This holistic approach ensures that interventions are more closely aligned with real-world patient experiences and needs. Here, I would like to present a success story that elucidates the value of the aforementioned concepts and methods. SloMo is a digitally-enhanced therapeutic intervention specifically designed to address psychotic paranoia, aiming to improve the accessibility, quality, and efficacy of psychological treatments for psychosis. The therapy utilizes an integrated platform that supports synchronous, therapist-guided sessions (conducted either in-person or remotely) as well as a mobile application intended for daily use to facilitate self-management of symptoms in real-world settings. Developed over more than a decade through a rigorous, human-centered inclusive design process by an interdisciplinary team (including individuals with lived experience, professional designers, clinical therapists, training specialists, academic researchers, regulatory advisors, and software engineers) SloMo exemplifies a collaborative approach to mental health innovation. This comprehensive methodology ensures that the intervention is both user-centered and evidence-based, enhancing its applicability and effectiveness in diverse clinical contexts. Empirical evidence demonstrates that SloMo achieves high levels of user engagement and consistently provides positive user experiences, regardless of participants' digital literacy, age, or ethnic background [16, 17]. These findings highlight the successful incorporation of inclusivity principles into the therapy's design, thereby enhancing its broad applicability and efficacy across diverse populations. The typical processes involved in SloMo include (a) therapy development through clinical studies, (b) co-design initiatives outside of healthcare settings, and (c) evidence-based co-design methodologies. For more detailed information on the design process, refer to the latest research from the SloMo design team [18]. Despite the numerous benefits of these methods, it is essential to recognize the inherent challenges of this methodology. These include concerns regarding patient privacy, as well as the considerable time and financial resources required for such initiatives. Nevertheless, one fact remains indisputable: prioritizing patient engagement in the design and development of digital health tools is crucial for enhancing patient health, well-being, and overall experience [19].

In conclusion, while the path toward achieving optimal patient engagement through digital health tools is beset with challenges, the potential benefits for patient outcomes are substantial. By prioritizing patient needs, fostering a deeper understanding of their experiences, and incorporating their feedback into the development process, we can move closer to realizing the full potential of digital health technology in improving patient care.

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HY: Conceptualization, Writing—original draft, Writing—review & editing.

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The author declares that there are no conflicts of interest.

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References

1. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood). 2013;32:223–31. [DOI] [PubMed]

2. Forbat L, Cayless S, Knighting K, Cornwell J, Kearney N. Engaging patients in health care: an empirical study of the role of engagement on attitudes and action. Patient Educ Couns. 2009;74:84–90. [DOI] [PubMed]

3. Zvonareva, O. Patient engagement in drug development: configuring a new resource for generating innovation. Crit Public Health. 2003;33:506–17. [DOI]

4. Papadopoulos K, Ammenwerth E, Lame G, Stahl N, Struckmann V, von Wyl V, et al. Understanding public trust in national electronic health record systems: A multi-national qualitative research study. Digit Health. 2025;11:20552076251333576. [DOI] [PubMed] [PMC]

5. Arueyingho OV, Al-Taie A, McCallum C. Scoping review: Machine learning interventions in the management of healthcare systems. Digit Health. 2024;10:20552076221144095. [DOI] [PubMed] [PMC]

6. Periáñez Á, Fernández Del Río A, Nazarov I, Jané E, Hassan M, Rastogi A, et al. The Digital Transformation in Health: How AI Can Improve the Performance of Health Systems. Health Syst Reform. 2024;10:2387138. [DOI] [PubMed]

7. van Kessel R, Ranganathan S, Anderson M, McMillan B, Mossialos E. Exploring potential drivers of patient engagement with their health data through digital platforms: A scoping review. Int J Med Inform. 2024;189:105513. [DOI] [PubMed]

8. European Union. Benchmarking deployment of eHealth among general practitioners (2018) – Final report [Internet]. Publications Office of the European Union; c2018 [cited 2025 Mar 15]. Available from: https://data.europa.eu/doi/10.2759/511610

9. Bertelsen N, Dewulf L, Ferrè S, Vermeulen R, Schroeder K, Gatellier L, et al. Patient Engagement and Patient Experience Data in Regulatory Review and Health Technology Assessment: A Global Landscape Review. Ther Innov Regul Sci. 2024;58:63–78. [DOI] [PubMed] [PMC]

10. van Kessel R, Roman-Urrestarazu A, Anderson M, Kyriopoulos I, Field S, Monti G, et al. Mapping Factors That Affect the Uptake of Digital Therapeutics Within Health Systems: Scoping Review. J Med Internet Res. 2023;25:e48000. [DOI] [PubMed] [PMC]

11. van Kessel R, Srivastava D, Kyriopoulos I, Monti G, Novillo-Ortiz D, Milman R, et al. Digital Health Reimbursement Strategies of 8 European Countries and Israel: Scoping Review and Policy Mapping. JMIR Mhealth Uhealth. 2023;11:e49003. [DOI] [PubMed] [PMC]

12. Rabinowitz Steele NZ. The Patient Resident. N Engl J Med. 2022;386:1010–1. [DOI] [PubMed]

13. Javadizadeh E, Oudshoorn A, Letts L, Barbic S, Shanoff C, Marshall CA. Participatory Research with Persons who Experience Mental Illness in Occupational Therapy: A Scoping Review. Can J Occup Ther. 2024;91:203–21. [DOI] [PubMed] [PMC]

14. Cormick A, Graham A, Stevenson T, Owen K, O'Donnell K, Kelly J. Co-designing a Health Journey Mapping resource for culturally safe health care with and for First Nations people. Aust J Prim Health. 2024;30:PY23172. [DOI] [PubMed]

15. Moine S. Health professionals must be ethnographers. BMJ. 2016;355:i6323. [DOI] [PubMed]

16. Greenwood KE, Gurnani M, Ward T, Vogel E, Vella C, McGourty A, et al. The service user experience of SlowMo therapy: A co-produced thematic analysis of service users' subjective experience. Psychol Psychother. 2022;95:680–700. [DOI] [PubMed] [PMC]

17. Hardy A, Ward T, Emsley R, Greenwood K, Freeman D, Fowler D, et al. Bridging the Digital Divide in Psychological Therapies: Observational Study of Engagement With the SlowMo Mobile App for Paranoia in Psychosis. JMIR Hum Factors. 2022;9:e29725. [DOI] [PubMed] [PMC]

18. Hardy A, Taylor KM, Grant A, Christie L, Walsh L, Gant T, et al. Co-designing technology to improve psychological therapy for psychosis: SloMo, a blended digital therapy for fear of harm from others. Schizophr Res. 2024;274:526–34. [DOI] [PubMed]

19. Zvonareva O, Craveţ C, Richards DP. Practices of patient engagement in drug development: a systematic scoping review. Res Involv Engagem. 2022;8:29. [DOI] [PubMed] [PMC]