

Engaging Patients and Citizens in Digital Health – Opportunity or Challenge?*

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ABSTRACT

Digital health innovations thrive when patient involvement is integrated from the outset. This commentary highlights insights from the DigiHealthDayS-2024 Scientific Congress, emphasizing the pivotal role of patient engagement in shaping digital health solutions. Drawing on recent presentations, it is evident that early collaboration with patients—not merely as end users, but as co-creators and experts—yields solutions that are more user-centered, effective, and sustainable. The WHO has been strongly recommending patient engagement in primary care ever since 2016, underscoring its importance in improving care quality and fostering trust. Key innovations include the structured use of advisory boards, focus groups, real-world evidence platforms, agile development processes, and the acknowledgment of patient diversity. Furthermore, the session calls for embedding patient collaboration modules into digital health curricula, ensuring that future practitioners are well-versed in participatory design and ethical compensation. This commentary discusses these findings, identifies critical considerations for effective patient involvement, and outlines future directions for research and policy in digital health innovation.

KEYWORDS

Digital Health, patient involvement, patient engagement, co-creation, healthcare innovation

1. Introduction

Digital Health is rapidly transforming healthcare delivery, and patient involvement has emerged as a critical success factor. This commentary explores the importance of integrating patient perspectives into digital health development and highlights key insights from the DigiHealthDayS-2024 Scientific Congress. With increasing demands for personalized and effective care, engaging patients from the early stages of design is essential. The session underscored how patient co-creation and adherence to WHO recommendations can bridge the gap between technology and patient needs.

**WORKSHOP @ Data Saves Lives (DSL) Germany: Patient Involvement – Burden or Unknown Resource? Hosts: Birgit Bauer & Dr. Benjamin Friedrich (DSL, Germany).*

2. Key Considerations

1. **Early Patient Engagement**
Involving patients early in the development process enhances the relevance and usability of digital solutions. Patients' lived experiences provide unique insights that drive patient-centered innovation and improve treatment outcomes.
2. **Integration into Curricula**
There is a pressing call to incorporate patient collaboration modules into every digital health curriculum. This ensures that future healthcare professionals are equipped to engage patients meaningfully and ethically in technology design.
3. **Ethical and Structured Involvement**
Structured frameworks such as advisory boards and focus groups are essential for effective patient engagement. Recognizing patient expertise through fair compensation reinforces their role as critical contributors to co-creation.
4. **Leveraging Real-World Evidence and Agile Development**
Integrating robust patient-reported data and agile methodologies—like the Build-Measure-Learn cycle—enables continuous refinement of digital health solutions based on real-world evidence, ultimately enhancing patient-provider interactions.
5. **Embracing Patient Diversity and Inclusiveness**
Patients represent a diverse group—from general end users to expert advocates and caregivers. Tailoring engagement strategies to accommodate varied experiences ensures all voices are heard, leading to more inclusive and effective digital solutions.
6. **Digital-First Approach and Agile Methodology**
A digital-first strategy, supported by agile development and early involvement of key opinion leaders, ensures that tools are state-of-the-art, continuously refined, and seamlessly integrated into daily life for both patients and healthy individuals.
7. **Addressing Data Privacy and Investment Concerns**
Community discussions at the DigiHealthDayS-2024 raised concerns about data privacy and the resources required for tool development. Bauer and Friedrich emphasized that strategic investments in secure, patient-centered development yield strong returns on investment (ROI), foster early community engagement, and enhance trust and communication, ultimately supporting a robust market reputation.

3. Future Directions

Future research should explore scalable models for patient engagement and investigate long-term impacts on treatment adherence and system efficiency. Patient participation, along with the involvement of caring persons, is a must for the future. Such collaboration not only empowers developers to create valuable tools that support patients in daily life and disease management but also enhances the quality and quantity of health data, offering deeper insights into diseases. These approaches must be implemented transparently throughout the development process, ensuring that stakeholders are informed and involved in shaping ethical and effective digital health innovations.

4. Conclusion

Integrating patient involvement from the outset is essential for advancing digital health. The insights presented at the DigiHealthDayS-2024 reinforce that early, structured, and ethically managed patient engagement leads to superior healthcare solutions that extend beyond clinical benefits, transforming digital health into a true lifestyle component for both patients and healthy individuals. It is crucial to ensure fair conditions for all participants, recognizing patients as valuable partners who deserve compensation through improved data access, information, and knowledge sharing, rather than being exploited as free resources. Embracing a digital-first, agile approach empowers developers to create responsive, state-of-

the-art tools that adapt continuously to real-world needs. Furthermore, addressing community concerns about data privacy and the necessary investment through secure, patient-centered development builds trust and fosters early community engagement, ultimately enhancing market reputation. Embedding these practices into academic and professional curricula will have a transformative impact on digital health innovation, ensuring a sustainable ecosystem that is both effective and widely trusted.

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