Building Digital Literacy in Health: About a Hen, an Egg and Why Usage is Not Understanding

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DOI: 10.25929/9fsk1677

ABSTRACT

Digital transformation in healthcare is often equated with the widespread use of digital tools such as apps, wearables, electronic health records, and artificial intelligence–based systems. In this narrative, patients and citizens are frequently framed as users of technology rather than as competent actors whose understanding, confidence, and judgment ultimately determine whether digital health solutions are trusted and effective. However, usage alone does not constitute digital literacy. This short commentary argues that meaningful participation in digital health requires a broader understanding that integrates health literacy, data literacy, and digital literacy into a coherent framework, explicitly centered on patients and citizens and their ability to act competently in digital health contexts. Drawing on insights from a session at the DigiHealthDayS-2025, this paper explores why awareness, trust, and a shared language are currently the weakest links in digital health transformation. Using the metaphor of the "hen and the egg", we describe how patient- and citizen-led initiatives can close the circle from understanding data to building digital competence and confidently using digital tools. Reflections from audience discussions highlight persistent gaps in awareness and trust, despite high levels of access and usage. The commentary concludes that digital literacy must be understood as a shared societal responsibility and a prerequisite for sustainable digital health innovation, rather than as an optional add-on or individual skill.

KEYWORDS

Digital literacy, health literacy, data literacy, patient participation, digital health, digital competence

Introduction

Digital health is advancing rapidly, and with it the assumption that populations are ready to participate simply because digital tools are widely available. Smartphones, health apps, wearables, and artificial intelligence-(AI-)supported services have become part of everyday life for many patients and citizens. Yet this visibility of technology masks a deeper problem: widespread usage is often mistaken for understanding, and patients and citizens are assumed to be digitally competent simply because they interact with digital systems on a daily basis. At the DigiHealthDayS-2025 in Pfarrkirchen, the session "Building Digital Literacy – Patients and Citizens Leading the Way" addressed this disconnect. The

[*] *SESSION – Building Digital Literacy – Patients and Citizens Leading the Way. Host: Birgit Bauer (Data Saves Lives Germany).*

discussion was grounded in a simple but powerful metaphor: the relationship between the hen and the egg. Data literacy initiatives may start as the egg, but without a broader digital and health literacy ecosystem—the hen—the circle remains incomplete. This commentary reflects on that session and argues that digital literacy in health must be built around patients and citizens—their competencies, questions, and lived experiences—rather than around tools, if digital transformation is to be trusted and sustained.

Key Considerations

Digital Literacy is not Access, but Awareness

A recurring theme during the session was the misconception that being "online" or using multiple health apps equates to being digitally literate. Many patients and citizens described themselves as digital simply because they used technology, while simultaneously expressing uncertainty, misconceptions, or blind trust in digital outputs. Participants openly acknowledged relying on apps, smartwatches, or AI tools without understanding how these technologies work, what their limitations are, or how data are processed and reused. Digital literacy therefore goes beyond technical access. It requires awareness of why, when, and how digital tools should be used, as well as an understanding of their potential risks and benefits.

Participation Fails without a Shared Language and Trust

Another critical issue is the gap between expert discourse and public understanding. Digital health discussions are often conducted in highly technical language that excludes large parts of the population. As several participants noted, this mirrors long-standing challenges in medicine, where professional jargon can prevent meaningful patient engagement. Without clear, accessible explanations and transparency about intentions and consequences, trust cannot develop. Digital transformation fails when people feel left behind or overwhelmed by complexity.

Patients and Citizens as Co-Creators, not Target Groups

From the perspective of Data Saves Lives Germany (DSL DE), patient and citizen involvement must be understood in the context of real-world behavior and capabilities. Patients and citizens are highly curious and actively use digital health tools, often experimenting with apps, wearables, and AI-based systems on their own initiative. However, this use frequently occurs with limited digital and data competence. As a result, misinterpretations, unrealistic expectations, and, over time, mistrust toward digital health solutions can emerge.

At the same time, patients and citizens are still insufficiently involved in the development, evaluation, and decision-making processes surrounding digital health technologies. Co-creation is often discussed rhetorically, but in practice remains limited or symbolic. This gap is reinforced by a lack of accessible, transparent, and understandable information that would enable people to form informed opinions and judgments. Without deliberate efforts to explain how digital health solutions work, why data are used, and what this means for individuals, meaningful co-creation cannot occur.

Patient-driven initiatives such as Data Saves Lives Germany (DSL DE) and educational formats developed within the european digital health academy (edha) illustrate how building competence and providing clear, human-centered explanations can reduce misinterpretation, foster trust, and enable patients and citizens to contribute as informed partners rather than passive recipients.

Future Directions

Future digital health strategies should prioritize building patient and citizen competence before formal participation mechanisms are introduced. Rather than introducing involvement mechanisms prematurely, stakeholders should invest in education and dialogue that enable people to understand data use, digital tools, and health information in context. This includes developing plain-language resources, fostering cross-sector learning environments, and embedding literacy as a form of infrastructure within digital health systems.

In response to these needs, the european digital health academy (edha) is currently developing digital learning modules designed to create accessible learning opportunities for patients and citizens. Emerging directly from discussions such as those at the DigiHealthDayS-2025, these lessons aim to translate complex digital health concepts into understandable, practical knowledge. As a grassroots initiative supported by an advisory board that includes people living with chronic diseases, the edha seeks to strengthen competence, build trust, and encourage active engagement with emerging digital health formats.

Policy makers, developers, researchers, and educators all share responsibility for creating conditions in which digital literacy can grow. At the same time, patients and citizens must be supported to engage responsibly and critically with digital tools. Only through this shared responsibility can digital health innovation become both inclusive and sustainable.

Conclusion

The discussion in this special session at the DigiHealthDayS-2025 highlighted a clear message: patient and citizen digital literacy is not a luxury, but a prerequisite for trust, meaningful participation, and innovation. High levels of tool usage coexist with significant gaps in awareness, understanding, and confidence. Addressing these gaps requires moving beyond a narrow focus on technology toward a people-centered approach that integrates health, data, and digital literacy.

The hen-and-egg metaphor captures this challenge succinctly. Data literacy initiatives may start the process, but without a broader ecosystem that enables people to use digital tools consciously and confidently, the circle remains open. Building digital literacy together—through explanation, empowerment, and engagement—means investing in patient and citizen competence as the foundation for trust. This is essential if digital health is to fulfill its promise for patients, citizens, and society as a whole.

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* *Disclosure: The author is involved in the development of the cited white paper on data sovereignty..*