News and Perspective

Beyond Waiting: How Patients Are Reshaping Digital Health

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Key Takeaways

- Patient innovators like Michael Seres and Nanea Reeves demonstrate what's possible when lived experience drives solution-building, but successful innovation requires resources, skills, and networks that not all patients have.
- Digital health now faces an overabundance of innovations lacking evidence of meaningful outcomes, requiring better frameworks to evaluate which innovations genuinely deliver value.
- Health care systems should support promising patient-led innovations while addressing the underlying gaps that force patients to solve their own problems through entrepreneurship.

This piece was inspired by a JMIR Publications webinar presentation [1] on patient engagement and innovation, which was led by Denise Silber, MBA. Silber—founder of the Doctors 2.0 & You conference series and recipient of France's Legion of Honor, the highest civilian award—has long documented patient-initiated innovations across Europe and North America. She has worked directly with many of the patient innovators featured herein. This article includes an interview with Silber, and her insights informed both the topic and the analysis.

By age 42, Michael Seres had already been through more than 25 surgeries for Crohn disease [2]. In October 2011, he woke up from an intestinal transplant to find an ileostomy bag attached to his abdomen. Monitoring the bag's output would shape his recovery. Too much output meant dehydration and possible kidney damage. Too little output signaled blockage. Yet, the system for managing the ileostomy was surprisingly low-tech: nurses poured the contents into plastic jugs and eyeballed the volume.

During recovery, Seres started looking for something better. Using parts he found on eBay, including a flex sensor originally meant for a Nintendo Wii glove, he built a rough prototype that could detect and alert him when his pouch was filling.

That improvised prototype eventually became the *alfred: SmartBag*—a device that tracked ostomy output in real time and sent alerts to both patients and clinicians. Clinical data showed a 30-day readmission rate of 15.1% among SmartBag users, compared to 24.7% with standard care [3]. By 2016, Seres' idea had grown into 11Health—a company serving thousands of ostomy patients and named for his status as the 11th intestinal transplant recipient in the United Kingdom.

Seres' story illustrates an emerging pattern in digital health: patients building what the health care system has not [4].

A Movement Shaped by Need

Over the past decade, patient-led innovations have multiplied across digital health. In 2012, Fredrik Debong and Frank Westermann, who were living with diabetes, created mySugr—an app that gamified glucose tracking [5]. Around the same time, Ida Tin launched Clue after finding that existing period-tracking tools unduly pathologized menstruation [6].

These innovations span diagnoses, demographics, and continents but share a common starting point: a problem that could be felt by a patient in their daily life but lacked a meaningful solution.

Several societal shifts made this possible. The opening of PubMed in the mid-1990s made medical literature accessible to the public for the first time, giving patients unprecedented insight into their own conditions [7]. New technologies lowered the barrier to creating apps and prototypes, enabling experimentation outside traditional institutions [8]. Meanwhile, cultural changes in health care encouraged shared decision-making, making patients feel increasingly empowered to participate actively in their own care [9].

As patient-led innovation has flourished, it prompts a deeper question: who becomes an innovator, and what allows them to succeed?

Understanding Patient-Led Innovation: A Conversation With Denise Silber

I spoke with Silber to explore what distinguishes patient innovators, the equity implications of this movement, and what health care systems should learn from it.

What distinguishes a frustrated patient from one who becomes an active innovator?

DS: It varies, but the common starting point is a strong internal drive. Frustration becomes innovation when the patient has the motivation to act rather than accept the status quo. From there, their personal experience—communication skills, education, health literacy, a technical problem-solving profession such as engineering, business, science—can help them access the right resources and move faster.

Still, no patient innovator succeeds alone. Even the founders of major tech companies relied on support. Patient innovators combine determination with a supportive community around them: family, peer networks, health care professionals, a start-up accelerator.

The early patient innovators helped patients communicate with one another and with professionals through blogs and social media platforms. As eHealth matured, patients went further, raising money for research, developing devices and start-ups.

In the end, it's the blend of personal drive, relevant skills, and a supportive environment that turns frustration into innovation.

You've talked about health care's "two-tier system" of lucky and unlucky patients. How does patient-led innovation fit into this?

DS: We are all lucky if we're born in perfect health and in an environment where we can maintain that health. But that's true for a minority. For most patients, especially before the internet, it was luck whether they happened upon the right health care professional in their location. There was no way to look up a surgeon's success rate or compare treatment options. It was word of mouth. Many patients had no choice at all. Patient innovators often emerge from this "unlucky" category. They didn't have someone who could navigate the system for them, or the system simply didn't have a solution for their problem. But they had something else: the ability, motivation, and resources to take action.

How did information access through tools like PubMed lay the groundwork for patient-led innovation?

DS: The opening of PubMed in the mid-1990s brought extraordinary potential. Before that, access to the latest medical research publications was limited to institutional subscriptions used only by professionals. Suddenly, the lay person could type in a disease or the name of a medicine and see research results that likely no one around them knew about. This was crucial for patient empowerment. But it didn't start there. Before PubMed, there were already grassroots movements, for HIV and women's health, for cancer, using bulletin boards and early internet tools to share information. PubMed democratized that access on a much larger scale.

You mentioned that not everyone should innovate. Can you explain?

DS: We often hear that only 1 in 10,000 molecules becomes a successful medicine, because the low-potential ones are eliminated early. In digital health, the barriers to entry are lower. As a result, too many low-potential or me-too products give birth to a start-up. We're almost drowning in innovations that don't demonstrate meaningful outcomes, have little clinician uptake, or lack a viable business model.

So, not every patient needs to become an innovator, and realistically, not every patient can. What we need are clear packages of best practices: guidance for health care professionals on how to use digital tools effectively, and guidance for patients about these packages, regarding which communities to join, which apps are worth their time, and how to navigate the health system.

Right now, the pace of product creation is faster than our ability to evaluate what works. The priority should be strengthening communication among patients and professionals and ensuring that clinicians and patients can access the innovations that genuinely deliver value.

Beyond Traditional Diagnoses

Not all patient innovators emerge from clearly defined medical diagnoses. After her husband died, Nanea Reeves struggled with grief and anxiety that didn't fit neatly into health care pathways [10]. There was no diagnosis, no protocol, and little structured support.

Drawing on her background in technology, Reeves created TRIPP—a virtual reality meditation platform now used by millions to manage stress, anxiety, and pain. Her story illustrates how patient-led innovation is increasingly expanding beyond disease-specific challenges.

Yet, it also reinforces the equity questions that Silber raises. Reeves had skills, financial resources, and industry connections; many people facing similar challenges do not.

Implications

For health care systems, these innovation stories serve as a prompt for reflection. Which unmet needs push patients to invent their own solutions? How can systems identify and address these needs earlier and support promising patient-led innovations without expecting every patient to become an entrepreneur?

For researchers and policymakers, they raise questions about access, evidence, and regulation. Traditional frameworks for medical devices were not built with patient-led prototypes in mind [4,11], nor are evaluation standards keeping pace with rapid product creation [12]. Better guidance, clearer pathways, and stronger collaboration between clinicians and patients could help ensure that meaningful innovations rise above the noise.

Patient-led innovation reveals both remarkable individual resourcefulness and creativity, as well as persistent institutional gaps. Progress means closing those gaps or bridging them together.

Keywords: patient innovation; digital health; health equity; patient empowerment; medical devices; participatory medicine

Conflicts of Interest

None declared.

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