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Author manuscript

*Acad Emerg Med.* Author manuscript; available in PMC 2016 June 01.

Published in final edited form as:

*Acad Emerg Med.* 2015 June ; 22(6): 754–756. doi:10.1111/acem.12692.

## Patient engagement and the design of digital health

Faith Birnbaum, BSc<sup>1</sup>, Dana M. Lewis, BA<sup>2</sup>, Rochelle Rosen, PhD<sup>3</sup>, and Megan L. Ranney, MD MPH<sup>1</sup>

<sup>1</sup>Emergency Digital Health Innovation program, Department of Emergency Medicine, Rhode Island Hospital/Alpert Medical School, Brown University

<sup>2</sup>#DIYPS, Seattle, WA

<sup>3</sup>Center for Behavioral and Preventive Medicine, Department of Psychiatry & Behavioral Health, The Miriam Hospital/Alpert Medical School, Brown University

### Abstract

Digital health is an area of growing interest for physicians, patients, and technology companies alike. It promises the ability to engage patients in their care, before, during, and after an emergency department visit. Current efforts to create, study, and disseminate digital health have been limited by lack of user engagement. In this commentary, we outline the imperative for engaging end-users in each phase of digital health design, as well as a few techniques to facilitate better digital health design and implementation.

### Keywords

Digital health; mHealth; patient engagement; design; qualitative

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Patient engagement is a term used to refer to enhancing patients' ability to fully participate in healthcare, helping them to be “equipped, enabled, and empowered” regarding their own health.<sup>1,2</sup> Patient engagement has been repeatedly linked to better health outcomes.<sup>3,4</sup>

Digital health, such as wearable technology and mobile phone applications (“apps”), is increasingly promoted as a means of facilitating patient engagement.<sup>5,6</sup> Digital health may, for instance, help patients self-monitor; encourage behavior change; improve comprehension of diagnoses and discharge plans; and permit dynamic interchanges between patients, their healthcare data, and clinicians. Digital health tools have been hailed as easily disseminated, low-resource solutions to help patients take ownership of their healthcare journey.<sup>7–9</sup>

Despite the rhetoric and hope for digital health, however, patients are not using the tools as much as they could. Typical medical or fitness apps have a 90-day user retention rate of only 27–30%,<sup>10</sup> and 50% of apps are downloaded less than 500 times.<sup>11</sup> The low usage of current digital health tools is not, interestingly, due to a lack of demand. Research in the emergency department (ED) shows that 90% of patients are interested in a technology-based intervention for their health.<sup>12</sup> Recent national surveys show that up to 66% of Americans are interested in specifically using apps and wearable monitors (like FitBit and the AppleWatch) to improve their healthcare.<sup>13</sup>

If not due to lack of interest, then what explains the low use of digital health by patients? There are multiple competing explanations, including lack of evidence of effectiveness, concerns about privacy and security, and resistance from physicians. Ultimately, many experts feel that the lack of uptake may be explained by a lack of attention to users' perspectives during the design of digital health.<sup>3,14</sup> Prior research has shown that patients will only use new technologies if the tools are felt to be relevant to their own health care problems; are engaging and easy-to-use; and are effective at achieving behavior change.<sup>17</sup> Existing digital health tools by-and-large fail to address the issues that matter to patients<sup>15</sup> (and doctors<sup>16</sup>), and fail to feel relatable.<sup>11</sup> To create relevant, usable, and effective digital health, it is critical to increase patients' involvement in the design of technological tools.<sup>18</sup>

“User-centered design” is the term used to refer to the broad category of methods through which end-users – including patients—can have an impact on technology design. Patient-centered design methods can occur at any point during the digital health development process. Patients may be incorporated as equal partners with the designers at the beginning of a project, when a technology is first conceived; at the other end of the design spectrum, patient input may be obtained via usability testing only during the final stages of design.<sup>19</sup> The design process can also explore the needs of those who are peripherally affected by its use (e.g. family members) or who are expected to pay for it (e.g., insurance companies).

Patient-centered design is often a multi-stage process. Many digital health developers hold initial focus groups or interviews, modify their designs and content based on qualitative findings, then iteratively re-test the product with additional groups of patients.<sup>20</sup> These methods can also be used to help define the focus of a project. For example, we have engaged panels of patients, using rigorous qualitative methods, in the development and refinement of both the message content and the day-to-day structure of text-messaging interventions and apps.<sup>20–22</sup> This kind of interactive and flexible design process differs from traditional intervention development efforts, which rely on expert opinion and only solicit patients' viewpoints after the technology has been created.<sup>23</sup>

Patient-centered design for digital health can be accomplished using both traditional research funding and industry support. Projects funded by the Patient Centered Outcomes Research Institute (PCORI) use patients as advisors and co-investigators throughout the design process. Numerous investigators within emergency medicine have obtained grants from the National Institutes of Health to use patient-centered design methods. And a growing number of clinicians are partnering with businesses, ranging from start-up companies to technology giants like Apple, to facilitate the creation of patient-centered digital health tools.

Traditional approaches to patient-centered design can, however, take months to years. In the world of digital health, a more dynamic process is needed to match pace with evolving technology. Some emergency medical researchers have used crowd-sourcing – in which content is curated from groups of people similar to the target population — to develop and rate intervention content.<sup>24</sup> Others use shorter trials with strategic qualitative components, to uncover flaws in design more quickly than larger controlled trials. For instance, interviews can be used to explore the perceived effectiveness of intervention strategies, rather than

focusing on quantitative measures of end-user behavior change.<sup>25</sup> A third time-saving option is to utilize existing patient organizations and communication networks to provide repeated feedback on each new version of a project. Finally, some researchers suggest using the tools of the tech industry, such as “A/B testing” (in which two versions of a product are tested simultaneously with groups of users).<sup>26</sup>

A still more radical transformation of the development of digital health is patient-led design. In patient-led design, it is patients themselves who determine the focus of an intervention: what a digital health tool should focus on, and how it should do so. There are multiple examples of patient innovators creating new tools that address real problems in truly usable ways. For instance, the #WeAreNotWaiting movement aims to improve digital health tools for monitoring and treating Type 1 Diabetes Mellitus.<sup>27</sup> In these movements, patient innovators self-organize and connect with independent researchers (who are often patients themselves) and medical device companies using social media. They use free, open-source software to draw on their collective expertise to re-design and launch numerous products, such as Nightscout and #DIYPS. These patient-led products have novel features, such as remote monitoring of continuous glucose levels, augmented low blood glucose alerts, and predictive alerts of future glucose highs or lows. They thereby reflect patient needs and result in ways that had not been identified by standard medical device development processes. Patient-led design efforts also provide input to less-well-funded technology ventures and medical researchers, who may not be able to take on a thorough user-centered design process. The highly motivated e-patients and caregivers in these movements use Twitter, Facebook, and other forms of social media, rather than academic journals and peer conferences, to disseminate ideas and facilitate faster innovation outside of the traditional product development framework.

Clinicians and researchers can be involved in patient-led and patient-centered digital health design. For instance, we can encourage patients to share their efforts with us. We can learn about patient online networks ourselves and educate our patients, thereby connecting them and strengthening the network. We can join online efforts and contribute knowledge about clinician workflow. We can help facilitate grants and formal efficacy testing.

Lastly, we would urge clinicians to be considered part of the patient-centered design team. After all, physicians are end-users as well. As we have seen with electronic health records, if clinicians’ needs are not taken into account, products will be difficult to use, and patient engagement will be more difficult to achieve.

Although time, economic resources and access to diverse skill sets are barriers to bridging the divide between technology companies, patients, and clinicians regarding effective development and use of digital health,<sup>28</sup> a way forward exists. In our experience, participatory, patient-centered design is worth the investment, as it results in higher quality digital health tools. We urge future developers of digital health tools to include patients in the development process, from start to finish. Patient-designed, patient-centered digital health tools are more likely to be bridge the gap between existing products and populations who would most benefit, and to realize the promise of digital health.

## Acknowledgments

**Disclosures:** Dr. Ranney is partially supported by NIMH K23 MH 095866 and PCORI.

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