

Accessibility and Beyond: Designing Consumer Health IT for Individuals with Disabilities



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As health care shifts to home- and community-based settings^{1,2} the roles of both providers and patients are transforming.^{3,4} There has been an increasing focus on consumer health IT (CHIT) (i.e., electronic technology used by laypeople to support health and health care management) to address this shift in health care.⁵⁻⁷ People living with physical, cognitive, and/or sensory disabilities face challenges engaging in CHIT and have not been a demographic focus of developers.⁸⁻¹⁰ Approximately one-fifth of the non-institutionalized U.S. population self-identifies as disabled.¹¹ With such a large portion of the population identifying as disabled it will be necessary to develop CHIT with this demographic in mind. This study aims to assess the needs of individuals with disabilities for CHIT focused on one technology platform (mHealth) and one self-management task (health information communication with social network members). This will be accomplished through a multi-method study that explicates individuals with disabilities' existing health information communication practices and the accessibility, usability, and usefulness of three existing mHealth solutions incorporating health information communication functionalities.

Methods: There are three phases in this two-year longitudinal study: (1) interview-based exploration of existing health information communication practices, (2) task analysis and journal-based exploration of challenges to using existing consumer health IT incorporating health information communication functionalities, and (3) design session-based exploration of potential design solutions. The study will involve 60 participants living with physical (n=20), sensory (n=20), and cognitive (n=20) disabilities. In Phase 1 participants are involved in a semi-structured interview about their personal network and health information sharing—including use of CHIT for health information communication. In Phase 2 participants interact with three existing mHealth apps focused on health information communication on either an iPad or iPhone: (1) Microsoft HealthVault (non-tethered PHR), (2) Epic's MyChart (tethered PHR), and (3) CaringBridge (social support). In Phase 3 participants attend group design sessions to discuss mHealth app design focused on health information communication as well as accessibility challenges of mHealth apps and how to overcome them in future design.

Results: To date we have screened 29 individuals, interviewed XX, and conducted task analysis with 4. Initial analysis of interviews has shown that most participants rarely use CHIT to communicate health information. Instead, they mainly use the telephone or communicate in person. Their networks tend to be small (range: n=3-47, mean: n=11, median: n=8). Many participants are not opposed to using CHIT, but have never learned how or do not have access. The pilot data from Phase 2 led to initial findings about the usability and accessibility of the three mHealth apps. HealthVault and MyChart do not have iPad versions. It is not possible to click the sign up button in HealthVault on the iPad, making it non-functional on the iPad. Additionally, there are limitations with the voiceover function's interface with the apps. For example, the terms and conditions text was not read out on the CaringBridge app, there was no voiceover indication when a pop-up appeared, and it was difficult for the user to tell what she had entered into the email text field. By the symposium we will have a more robust dataset and more results to present.

Discussion: The initial results show that there are still large gaps between CHIT developers and the needs of individuals with physical, cognitive, and/or sensory disabilities. After collecting and analyzing data from all 60 participants we will develop guidelines for app development that address this population's needs. Simple modifications, such as ensuring that alt text is available for photos and that the screen flips orientation to landscape, could reduce user burden. A limitation of the study is that the design guidance to be generated is anchored in one technology platform and three specific mHealth apps.

Conclusion: Engaging with people living with physical, cognitive, and/or sensory disabilities will allow us insight into user needs and preferences for CHIT. Through mixed methods we hope to use existing mHealth apps to inform design guidance and increase the accessibility and usability of future mHealth apps as health care shifts to home- and community-based settings.

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