A novel mobile health application to support cancer surveillance needs of pediatric patients and families with cancer predisposition syndromes

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## Abstract

Background: At least 5-10% of malignancies occur secondary to an underlying cancer predisposition syndrome (CPS). For patients with a CPS, cancer surveillance is recommended with the goal of identifying malignancy earlier, in a presumably more curable form. Surveillance protocols, including imaging studies, lab work, and procedures, can be complex, differing based on age, gender, and syndrome, which may adversely affect adherence. Mobile health (mHealth) applications have been utilized in the oncology field and could help to facilitate adherence to cancer surveillance protocols. Methods: Applying a user-centered mobile app design approach, patients with a CPS and/or primary caregivers were interviewed to identify current methods for care management and barriers to compliance with recommended surveillance protocols. Broad themes from these interviews informed the design of the mobile app, HomeTown, subsequently evaluated by usability experts. The design was then converted into software code in phases, evaluated by patients and caregivers in an iterative fashion. User population growth and app usage data were assessed. Results: Common themes identified include general distress surrounding surveillance protocol scheduling and results, difficulty remembering medical history, assembling a care team, and seeking resources for self-education. These themes were translated into specific functional app features including push reminders, syndrome-specific surveillance recommendations, ability to annotate visits and results, storage of medical histories, and links to reliable educational resources. Conclusions: Families with CPS demonstrate a desire for mHealth tools to facilitate adherence to cancer surveillance protocols, reduce related distress, relay medical information, and provide educational resources. HomeTown may be a useful tool for engaging this patient population.

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