Development of a Pilot Application for Children with Chronic Medical Conditions Using the Personal Health Library

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Objective

Caregivers are responsible for the in-home care of children with chronic medical conditions (CMCs) and may have care-related questions to support the child's higher quality of life.

We propose using a digital health platform, the personal health library (PHL) and mHealth app (1), to facilitate, organize, utilize, store, and retrieve health information.

The PHL will allow further development of the mHealth App to facilitate patient/caregiver engagement and self-care management of children with CMCs.

Methods

The PHL for the CMC mHealth app for children will contain: 1) Parent/caregiver-reported data; 2) Clinical data and; 3) Social determinants of health (SDoH) data; 4) Observations of Daily Living (ODL) data including the PedsQL Parent Questionnaire and the Functional Status Scale. The app will be customized to provide information regarding training in post-acute hospitalization management and deliver information on troubleshooting medical technology care, such as tracheostomy care.

Project Strategies

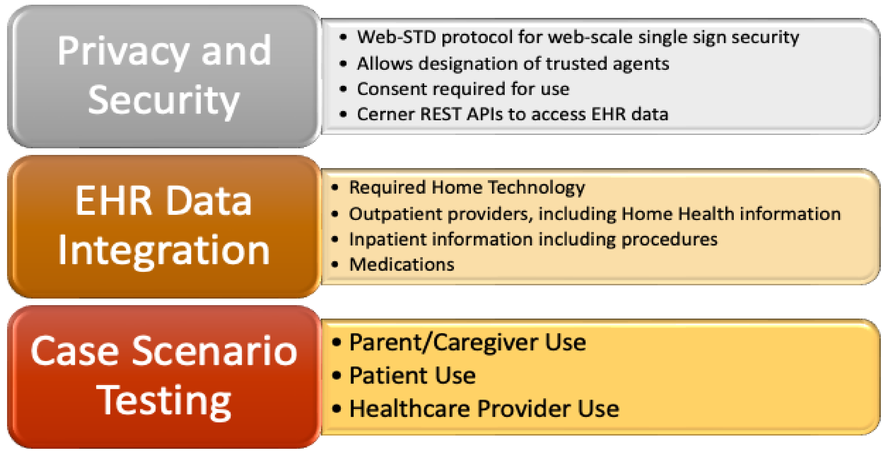

Figure 1. mHealth App testing

PHL Categories	Variables
Parent-Caregiver Reported Data	Demographics Socioeconomic Data Healthcare access data Transportation data Education level Home Monitoring of Patient Technology
EHR Clinical Data	Procedures Medications Discharge orders Home health records
Social Determinants of Health Data (Population-level neighborhood data)	Healthcare access Transportation data Socioeconomic data Child Opportunity Index
Observations of Daily Living	PedsQL Parent Questionnaire Functional Status Scale

Table 1. mHealth App Categories

Expected Outcomes

The mHealth app for the self-care management of pediatric CMC patients will integrate information from various sources to create an interface that can be used across devices (smartphone and smartwatches) (1).

The CMC mHealth app for children will interact with other applications i.e. calendar apps.

The CMC mHealth app for children end users will be providers and their parents/caregivers but accessible by organizations and will be successfully tested using case scenarios by the research team.

Implications for Practice

We expect that the design of the PHL application will ultimately provide a layer of support for parents and caregivers of children with CMCs for whom home health is not available following an acute hospitalization.

References

1. Ammar N, Bailey JE, Davis RL, Shaban-Nejad A. JMIR Form Res. 2021 Mar 16;5(3):e24738. doi: 10.2196/24738. PMID: 33724197

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