POSTER ABSTRACT

It's all in the App! Co-design approach in the development of the MyHealthMemory app for families caring for children with complex and chronic conditions

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Introduction: Carers are the constant in their child's medical journey and many have a much greater understanding of their child's condition and medical needs than is evident in the medical records. Faced with limited coordination and communication among different health services and health care providers parents are often the conduit of information across these health service "silos". Resourceful families typically carry their child's medical records including discharge summaries, lists of medications and answers to questions commonly asked by the triage team in the emergency department. They ask questions and act as strong advocates and "project managers" for their child's care. Vulnerable families with psychosocial disadvantage or limited English language are less able to take on the role of coordinator. MyHealthMemory is a smart phone app intended to assist families to navigate the systems and to overcome roadblocks to access by supporting appointments coordination and mobile medical records management.

Methods: A co-design approach was employed, involving families from the outset. Stage 1: 10 families representing a number of different profiles, ranging from those who were capable service navigators to the more vulnerable, were interviewed to understand their challenges. They were also "shadowed" by a researcher through their interactions with the health and social care systems. Stage 2: additional 7 families were interviewed representing those with teens, with psychosocial challenges and from non-English speaking backgrounds (NESB). De-identified transcripts of the interviews and filed notes from the "shadowing" project were analysed using NVivo to identify key themes.

Results: Six main themes were identified by families (stage 1 and 2):

Free-up my time for what really matters

Simplify my records and data management

Support me and show me I'm on the right track

See me as a person and recognise what matters most for me

Connect the dots and catch loose ends

Empower me without overloading me

Priority features for inclusion of further development of the app:

Automated, pre-populated data entry

Text entry in multiple languages

Dedicated children's proxy accounts independent of carers account

Integration with supporting resources – e.g. Medicare, CenterLink, NDIS; links to trusted databases of healthcare providers

Non-medical reminders – pre and post appointment reminders and automated links to concessions (e.g. for travel or parking)

In App communication and document sharing with non-SCHN providers (e.g. GPs)

Referral and reminder tracking – integration with supporting resources; alerts when actions tied to a consultation are missed.

Discussion and Lessons Learned: The co-design approach which included families from the very beginning has been highly successful in developing the prototype app and to identify specific needs of different types of families likely to rely on the app to navigate the health system.

Limitations: We did not canvas opinions of health care providers about the usefulness of the app, and the time frame for obtaining feedback from parents was relatively short.

Suggestions for future research: On-going evaluation to track the utility of the app, and the experiences of patients and of providers is needed to inform further development to meet specific needs.