

CONFERENCE ABSTRACT

A View of the Whole Child - Patient Co-Design of a Communication and Information Tool to Support Complex Care

17th International Conference on Integrated Care, Dublin, 08-10 May 2017

Lisa Altman, Susan Woolfenden, Richard Knight

Sydney Children's Hospitals Network, Australia

Introduction: The Sydney Children's Hospitals Network (SCHN), in partnership with families, has designed a tool that supports families in navigating the health care system - the My Health Memory Integrated Care application (MHM). MHM provides all SCHN patients with a convenient app to access their SCHN information and communicate with clinicians. It further enables the families of children with complex and chronic conditions to manage the often overwhelming deluge of information and communication that they must coordinate within SCHN and across their local health services and community support agencies. Families are able to upload, tag, organise, search and store all documentation related to their child's care in every setting - SCHN, local health services, primary care, the community, school and home.

Practice Change Implemented: A co-design approach to the development of MHM was employed, involving families from the initial stages of the service design. They were interviewed to understand their challenges in accessing care for their children and then 'shadowed' through their interactions with the health and social care systems. After the initial round of consultation a 'pretotype' of MHM was developed, and families and were observed as they interacted with MHM.

Aim and Theory of Change: To facilitate partner and patient co-design in developing an integrated model of care that helps families feel safe and supported wherever they access care.

Targeted Population and Stakeholders: Children with complex and chronic conditions who are enrolled in the SCHN Care Coordination Service, where a care coordinator has helped to build a circle of coordination with the child at the centre, and a family, community and hospital lead who facilitate care in their setting. Stakeholders include - alongside our families and children - clinicians and management in the tertiary children's hospitals, local hospitals, primary care, education and community Services agencies, and non-governmental organisations.

Timeline: The prototype is currently under testing with the families initially engaged in the service design consultations. The app will be made available to the initial cohort in February 2017.

Highlights: The co-design approach has moved the app away from a vision of families being able to access and control hospital-generated information about their child to being the family controlled centralised repository of information from a vast number of sources, that has the room and the flexibility to store everything that families need for the daily care of their child.

Sustainability: The insights from the patient co-design have implications beyond the development of MHM. Understanding from this exercise will also influence the redesign of the network's Outpatients Services and the continued evolution of the Integrated Care strategy.

Transferability: There are significant similarities with the requirements for care for the frail elderly or adults with multiple chronic conditions, and the app will be easily transferable to these settings.

Conclusions: Every minute spent on an additional tool needs to prove its value in tangible impact for the child, the family and what genuinely matters to them. The app needs to provide a way to immediately access critical data, while providing a view of longer-term context and have the flexibility to represent the personal care needs of each child. It needs to recognise the child as a whole, in the context of their family and their environment, and illustrate for clinicians 'what matters to me', 'what's normal for me' and 'how to communicate with me'.

Keywords: patient co-design; complex care
