AboutKidsHealth Online Resource Centres: Innovation in Family Health Education

Ross Hetherington PhD, CPsych,1,2,3 Andrew James MB, FRACP, FRCPC,1,4 Eric Bouffet, MD,4 Denis Daneman, MB, BCh, FRCPC,4 & Joel Kirsh, MD, FRCPC4

AboutKidsHealth, The Hospital for Sick Children1, and Departments of Psychology2, Public Health Sciences3, and Paediatrics4, University of Toronto, Toronto, Canada

Abstract
We conducted initial proof-of-concept and needs assessment qualitative research with families and clinicians concerning the online information needs of families of children with complex conditions. Subsequently, we used wireframes to assess the proposed information architecture and content of resource centres with families and clinicians. In collaboration with clinical programs, we developed resource centres for Brain Tumour, Diabetes, and Heart Conditions. We describe the initial research and development of the centres, and usability testing conducted after launch.

Family health information needs
Families of children with complex conditions frequently have unmet needs for trusted health information. A large gift to The Hospital for Sick Children from TD Securities, a Canadian investment bank, made possible a unique initiative in consumer health informatics that would strive to meet the information needs of these families.

In recognition of families’ concern with psychosocial and adult outcomes of complex paediatric conditions in addition to their needs for reliable medical information concerning diagnosis and evidence-based treatment, we hypothesized that a determinants of health model would best meet their needs. We tested this model and an information architecture based on the concept of a family journey.

Initial qualitative research
1. We conducted unstructured interviews with clinicians, observed families interacting with caregivers in clinic, and conducted unstructured interviews with families.
2. A series of initial proof-of-concept, semi-structured interviews with site schematics was performed with parents of children with complex conditions in Toronto, and parents with typically developing children in Toronto, Atlanta, and Portland, Oregon.
3. A second set of semi-structured interviews with wireframe schematics of resource centres for brain tumour, diabetes, and heart conditions was conducted with families and clinicians.

Results of the initial qualitative research supported the utility of a determinants of health model for meeting families’ health information needs. Furthermore, an information architecture for resource centres based on the family journey from the time a child was diagnosed with a complex condition through adult outcomes was seen as appropriate and useful by both parents and clinicians.

Development of the initial three resource centres
The resource centres were built with five main sections: About (Condition), Understanding Diagnosis, Treatment, At Home, and Looking Ahead. Creating each resource centre represented an 18- to 24-month collaborative effort among the medical writers, medical illustrators, designers and developers of the AboutKidsHealth team and the health professionals of The Hospital for Sick Children clinical programs.

Centre Words Medical Illustrations
Brain Tumour 139,000 38
Diabetes 60,000 24
Heart Conditions 330,000 52

As part of the development process, original narrated animations concerning anatomy, disease knowledge and management, and health for children and youth were created to support each resource centre.

Usability testing
Usability testing of the initial three resource centres was conducted with 12 families. Following an initial interview with a questionnaire to gather demographic information and patterns of internet use, parents completed a 1.5 hour, task-based, think-aloud protocol in a usability laboratory followed by a 24-item evaluative questionnaire containing questions with a 7-point Likert scale. The overall mean response (6.1/7) to the questionnaire and analysis of qualitative responses indicated a very positive response to the design and utility of the Resource Centres and AboutKidsHealth.ca overall.

www.aboutkidshealth.ca