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AboutKidsHealth: A Unique Initiative in Pediatric Consumer Health Informatics

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Abstract

The Hospital for Sick Children, Toronto (SickKids), has launched AboutKidsHealth, a project that promotes and delivers evidence-based information and programs according to a determinants of health model arising from the understanding that health extends beyond the absence of disease. Accordingly, AboutKidsHealth takes an inclusive approach to the enhancement of quality of life that embraces the home, the greater community, the education system, and the health system. The project employs innovative communication strategies supported by state-of-the-art technology to deliver evidence-based information and programs in all major areas influencing child health and family quality of life. The web-based infrastructure is also used to provide enhanced communication for families of children with complex conditions and health professionals, and to develop web-based research projects in collaboration with SickKids scientists.

Keywords:

consumer health informatics, parents' health information needs, sources of health information, typically developing children

Introduction

Consumers of online health information are concerned with issues of quality and trust. No sites presently offer comprehensive child health information and tools for families seeking solutions to complex questions that may involve disease, lifestyle, behavioral, and educational issues. Parents of children with complex health issues, as well as parents of typically developing children, need a trusted, comprehensive online resource to inform and guide.

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.

Methods

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.

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 wire frames 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.

Initial qualitative research

We conducted unstructured interviews with clinicians, observed families interacting with caregivers in clinic, and conducted unstructured interviews with families.

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.

A second set of semi-structured interviews with wire frame schematics of resource centres for brain tumour, diabetes, and heart conditions was conducted with families and clinicians.

Development of the 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. 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.

In December 2003, the hospital launched the first phase of AboutKidsHealth. This phase included The Family Health Centre, a 1000 square foot site supporting families' health information and medical decision making needs. The site, staffed by trained health professionals and volunteers, includes a library of books, brochures, and multimedia resources, 12 computers, and two multimedia/counseling rooms equipped to handle telehealth consultations. A 50 inch plasma monitor and 10 foot pixel board facilitates coordination of messaging and campaigns with AboutKidsHealth.

In June 2004, three resource centres were published as the initial web component of the AboutKidsHealth: Brain Tumour, Heart Conditions, and Diabetes. Additional resource centres that have been published include Pain, Epilepsy, Pregnancy & Babies, Premature Babies, Attention Deficit Hyperactivity Disorder, and Learning Disorders. Other resources include the A-Z Health Library, News (Online magazine), How the Body Works (Child Physiology), and Just for Kids.

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.

Results

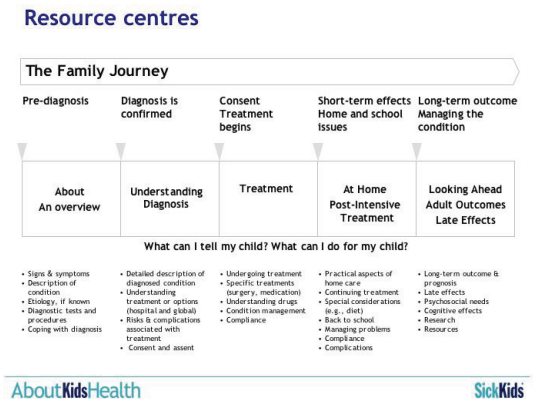
Initial qualitative research

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.

Resource centres

Each AboutKidsHealth resource centre consists of 45,000 to 325,000 words of level I content and 5000 to 1000 words of level II content. There are over 160 original medical illustrations, animations and other images. The material is comprehensive, incorporating not only medical information, but also addressing safety, nutrition, psychosocial, educational, and quality of life issues.

The resource centres are complemented with tools for families with typically developing children and



a range of articles on general child health issues. These articles focus on child and youth health from a determinants of health perspective and feature articles, expert columns, and series concerning healthy living and prevention, family living skills, understanding and managing common and complex conditions, safety, community-based systems and advocacy, and learning and education.

The A-Z Health Library contains 575 everyday health topics written at less than grade 7 reading level. This syndicated material has been reviewed by SickKids staff and complemented with original illustrations.

News comprises series, feature articles, news items and columns. Approximately 10,000 words are published each month.

How the Body Works contains interactive, animated illustrations that describe the brain, the heart and sexual development.

Just for Kids contains over 150 minutes of original narrated animations for children and youth. There are downloadable materials including games. Just for Kids supports all resource centres and provides general heatlth and safety information as well.

Usability testing

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.

Conclusion

AboutKidsHealth is an innovative and unique paediatric consumer health informatics initiative from several perspectives: utilization of a hybrid public/private business model within the Canadian health care system; integration of a physical site for families with a virtual child and youth

health site and telehealth capacity; development of programs in the context of a comprehensive, determinants of health model; and the use of offline, social marketing campaigns to increase traffic to the online site while promoting awareness of child and youth health issues.