

Developing a Web Site to Support the Implementation of Medical Home

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Abstract

The MedHome Portal is a web site aimed at providing information and resources to primary care physicians and families to improve care of children with special health care needs and support the Medical Home model of comprehensive care. Its development is a collaborative effort among a University's Department of Pediatrics and its Health Sciences Library, the state Department of Health, a family advocacy organization, and others. The Portal's development to date, unique features, results in terms of content and utilization, lessons learned, and future directions are detailed.

Introduction

Comprising 12.8% of US children¹, children with special health care needs (CSHCN) are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Among the more common of these chronic conditions are asthma, attention deficit-hyperactive disorder, and seizures, but the definition subsumes well over one hundred congenital and acquired conditions, most of which are very uncommon.² A typical pediatric practice will have 200-300 CSHCN, but will have only one or two patients each with any of the less common diagnoses.

Primary care physicians (PCPs) caring for CSHCN are challenged by the need to maintain knowledge of the many chronic and complex conditions that affect them. They must also be familiar with relevant subspecialty and community services and other key resources. The Medical Home model, promoted by the American Academy of Pediatrics (AAP), expands on these responsibilities to include coordination of care and partnership with the family.³

Parents of CSHCN and other family members desire knowledge about their children's conditions and about available resources.⁴ Parents' priorities for information and resources differ from what physicians believe them to be,⁵ making it harder to develop effective partnerships.

While much of the information needed by both PCPs and families about CSHCN is available on the web, it is neither organized around their needs nor easy to find. Most medical knowledge resources focus on etiology and diagnosis, with relatively little attention to management or to chronic care and collaboration with community services. Consumer health information sites may be unreliable, confusing, or overwhelming for families. Nevertheless, families are often highly motivated and find valuable information of which their physicians may be unaware.

The MedHome Portal, www.medhomeportal.org, (Portal – see Figure 1) is being developed to provide reliable and useful information and simplified access to resources for physicians and families to help them in caring and advocating for CSHCN. Goals of the Portal include improving the care of CSHCN and fostering a collaborative approach to providing health care for them, know as “Medical Home.”

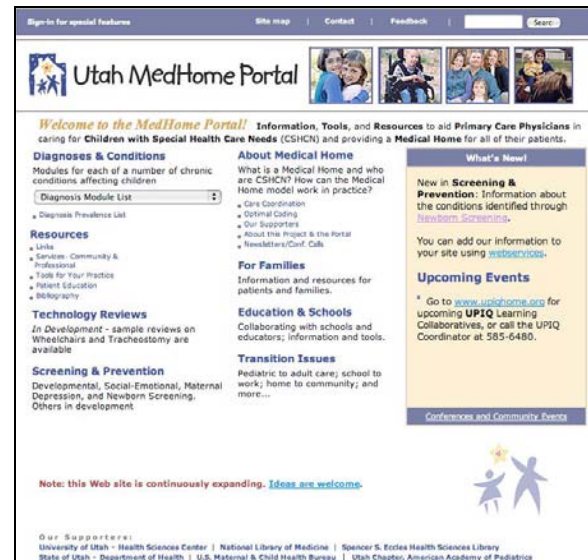


Figure 1 – MedHome Portal home page.

Methods

Development of the Portal began in 2001 as a collaboration among the University of Utah's Department of Pediatrics and Spencer S. Eccles Health Sciences Library (Eccles Library), with

consultation from the Department of Biomedical Informatics, the Utah Department of Health (UDOH), Utah Family Voices, and the Utah chapter, American Academy of Pediatrics. Utah's 211 Info Bank and the Utah GoLocal project, funded by the National Library of Medicine (NLM) and based at the Eccles Library, provide access to information about local resources. Prompted by interest from several states, the AAP is currently coordinating development of a national collaboration to share the Portal's infrastructure and content and develop a network of authors and peer reviewers. After several years of funding from small grants and a UDOH contract, in 2006 the Portal received a 3-year NLM Information Systems grant.

The initial scope of the project was to provide information to primary care providers in Utah about chronic conditions in children, local resources, and the Medical Home model. With input from the collaborators and the community, the scope has steadily expanded to include assuring access to this information for families of CSHCN and providing information about other aspects of Medical Home (including screening and prevention, cultural competency, transition of CSHCN to adult-care systems, etc.). Recognizing the broad appeal of the focus and content of the Portal, but the limited geographic relevance of the resource information offered (listing only Utah and national services), we are reprogramming the site to allow substitution of resource listings from other states to permit customized sites for users in those locations.

The Portal's knowledge repository is implemented as a relational database using MySQL 4.0.16 and the presentation is programmed with ColdFusion. It is housed in a server at the Eccles Library and maintained by dedicated Portal staff with support from library information technology personnel.

The Portal development staff currently includes a director/editor, a manager, a software developer, a web designer and usability manager, a library associate, an outreach librarian, and an administrative assistant, all of whom are part-time. Content management, medical informatics, and librarian consultants assist the Portal staff.

Medical content is developed by staff and faculty of the University of Utah, with pediatric subspecialty fellows, a nurse/medical informaticist, or other specialist (e.g., psychologist, physical therapist) in collaboration with pediatric faculty mentors. Content for the other sections (e.g., Transition Issues, For Families, Screening & Prevention, About Medical

Home) has been written by authors from the UDOH, the University of Utah, Utah State University, a contracted free-lance writer, and the Portal staff. As with the medical content, these have generally been prepared collaboratively and the Portal Editor has provided final approval.

Engaging content authors has been challenging due to the time commitment needed for developing and revising content with a non-traditional focus. The Portal's Diagnosis Modules are organized to follow the work/thought flow of a primary care physician looking for information about a condition and managing a child with that condition. This differs from traditional textbook approaches which focus on pathophysiology and diagnosis.

Successful strategies for engaging authors have included in-house writing sessions for multiple authors to facilitate the development of content and frequent follow-up (harassment) for support and editing. Recently, a pediatric neurologist who works part-time has taken a much larger role in content development, with a commensurate increase in new content being developed. Final editing and approval has been the responsibility of the Portal Editor (one of the authors of this paper, CN).

Information on community non-profit services has been obtained from the "211 Info Bank" (www.informationandreferral.org/), which operates the state's information & referral service through the 211 information line. From their listing of over 3700 services, about 2000 have been selected as relevant to CSHCN and their families. A collaboration with the MedLine Plus GoLocal project for Utah (<http://apps.nlm.nih.gov/medlineplus/local/utah/homepage.cfm?areaid=21>) has offered enhanced updating of selected services. The Info Bank data is categorized by the Association of Information and Referral Services (AIRS) Taxonomy of Human Services (<http://www.211taxonomy.org/>), which is used by many similar services throughout the country and has existing "crosswalks" matching categories to three other taxonomies (National Taxonomy of Exempt Entities, Nonprofit Program Classification System, and United Way of America Services Identification System II).

Utilization of the site is tracked and reported using Google Analytics (www.google.com/analytics). Reports are compiled and analyzed on a bi-monthly basis to assist in driving ongoing site and navigation improvement.

Outreach and promotion to physicians have included presentations at local, regional and national meetings, supplemented by Medical Home newsletters that are distributed to all Utah pediatricians. The meetings include training for physicians and their staffs during two prolonged Medical Home Learning Collaboratives that have involved 20 primary care practices over the past 5 years. Other presentations have included poster sessions at regional and national conferences, local grand rounds, and academic detailing in PCP offices. Of the various promotional materials we've distributed, bookmarks that are easily posted near a workstation and handed out to families have proven the most popular.

Outreach and promotion to families have focused on parents of CSHCN accessed through meetings of advocacy and support groups, participation of parents in the Medical Home Learning Collaboratives, and individually by personnel at the Utah Parent Center (one of the advocacy groups). Librarians from the Eccles Library have provided training for their own staff as well as for community public librarians through UtaHealthNet (<http://utahealthnet.org>), a statewide consumer health information infrastructure project funded by the NLM. The public librarians in turn assist parents, family members and patients in accessing information on the site.

Results

The Portal comprises 8 content sections: About Medical Home, For Families, Resources, Diagnoses & Conditions, Technology Reviews, Education & Schools, Screening & Prevention, and Transition Issues. Each has multiple sub-sections and there are currently 10 Diagnosis Modules within Diagnoses & Conditions, with another 3 nearing completion. The Portal currently includes over 680 pages of content, over 800 links to other sites, and more than 600 citations of scientific articles to allow users to delve deeper into topics of interest. It provides information on over 2000 community services and resources. These are searchable or browsable by category (see Figure 2 for a partial category list).

Content is structured and accessed using five document types, outlined in Table 1. Four of these are programmed as site-specific, repurposeable links that can be used multiple times in any section of the site. Their structure is standardized and format for presentation can be altered as needed from default.

The Portal averages about 3,300 visits per month, with an average of about 3.2 page views per visit. Of those visits, about 2760 are unique visitors, about

1.8% of whom are return visitors. Of the 742 return visitors in February, 450 had visited the site more than 8 times in the past 12 months.

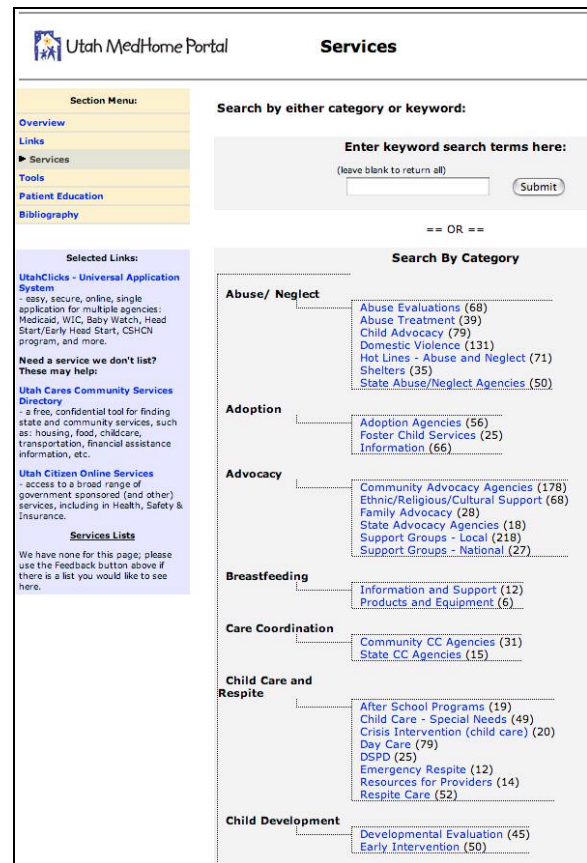


Figure 2 – Services search/browse page.

Table 1 – Document types.

Document type	Description
Content page	standard page presented as html, may contain tables, images, links, citations, etc.
Issue	focused content page that may be referenced from multiple other pages
Service	information about a community or professional service
Citation	formatted as a citation [<i>last name:year</i>] within the content; each triggers a bibliography entry with annotation at the bottom of the page and in the site bibliography
Applink	internal and external links, format {applink id=' __ '}, each with option for annotation and several potential display formats

The majority of referrals (57%) to the Portal come from Google and those visits average 2.6 page views. Direct access comprises 16% of visits with page views averaging 3.6. Yahoo and MSN refer an additional 12% of visits.

The AAP is coordinating efforts to develop a collaboration among several states to expand the scope and geographic applicability of the Portal's content, standardization of categorization for listing community services, and development of a national network of authors and peer reviewers. These offer the potential for cost sharing for further development and maintenance, as well as opportunities to impact the care of CSHCN nationally and enhance the spread of the Medical Home model.

Discussion

Analysis of site usage data suggests that the Portal has a loyal following of frequent users and feedback from primary care physicians and parents of CSHCN suggests that the Portal is reaching an increasing proportion of its intended audience. Utah has approximately 300 primary care pediatricians and 100,000 children that meet the broad criteria for being CSHCN. The number of first-time visitors reflects a much broader interest in Medical Home and the conditions and issues related to CSHCN, suggesting substantial potential for future growth in frequent users as the site offers local resource listings for other states.

Improvement Efforts

We are currently working on a series of enhancements to the Portal intended to make the Portal more useful to physicians, families, and educators of CSHCN and to help extend and disseminate its content through partnerships and collaborative efforts. These improvements can be grouped into three interrelated aims: (1) convert the existing portal content to XML and complete the development of authoring & content management tools, integrating content indexing with UMLS vocabulary and tools; (2) expand and optimize access to and utility of the Portal resources; and (3) work with partners to expand content, resources, integration, and impact of the Portal.

The conversion to XML will provide a more robust and flexible knowledge representation model and will simplify the Portal infrastructure.⁶ XML will also facilitate sharing of documents among collaborators, reviewers, and other organizations. An XML editor will be identified and integrated, enabling the

creation of documents that comply with the structure and semantics defined by the document models⁷.

The conversion to XML will also enable the implementation of more sophisticated information retrieval services, including the ability to properly respond to "infobutton" queries.⁸ Infobuttons are information retrieval applications that automatically generate queries to electronic health information sources, like the Portal, using patient data obtained from the electronic medical record. Infobuttons are designed to provide context-specific and evidence-based answers to clinicians (and parents) information needs at the point-of-care.⁹

Site administration and content management processes and tools will enable rigorous development, editing, and periodic review of all content. The upgraded tools will not only help assess the status and ongoing relevancy of hyperlinks, but also maintain currency of information on the ever-expanding number of services.

Indexing of the Portal's content using UMLS tools will allow improved searching and enable semantic navigation by providing much richer tagging of our content than can be done "by hand".^{10, 11} A challenge for any search methodology is accommodating users' use of the language, particularly for a resource like the Portal, which aims to serve medical professionals, families, and educators. UMLS indexing will offer comprehensive semantic linking among a myriad of both technical and common synonyms.^{10, 11}

In expanding and optimizing the Portal's resources, all improvements in presentation, features, and navigation will be driven by usability testing with physicians, other care providers, and parents. Content and presentation will meet criteria of the World Wide Web Consortium's (W3C) Web Accessibility Initiative. Personalizable features, including facilitated access to relevant published evidence, will be implemented for registered users.

User testing has demonstrated that, despite interest in the content and ability to understand it, parents of CSHCN do not readily sense that the site is for them. Testing with mock-ups of various approaches to the home page and subsequent navigation are underway. A proposed mock-up of the home page that has seemed to resonate with parents is shown in Figure 3, with an entrance for family members and one for professionals. Following entry into either, the user will find menus and headings customized to that user type, though the vast majority of the content will be the same in the two sections.

A key feature of the Portal is the integration of local and national resources and services information into relevant discussions within the content. This limits the value of the site to users in other states, but in our reprogramming we will enable the substitution of databases of services from other states/regions that have been categorized by the AIRS (Alliance of Information and Referral Systems) Taxonomy,¹² a human services taxonomy used by 211 information line agencies in many states.



Figure 3 – Draft mock-up of the future home page.

Conclusion

The MedHome Portal is currently a web site aiming to improve the care of CSHCN by providing information and resources to physicians and families that integrates Utah-specific resources and services into its content. It is being developed by a broad collaboration of experts and committed organizations. The site is being redesigned and reprogrammed to allow a national collaboration to enhance content development, provide peer review, share costs, and extend its impact by integrating information about local services into “mirror” sites customized for other states/regions.

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