Using Clinical Questions to Structure the Content of a Web-based Information Resource for Primary Care Physicians

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Abstract

The Medical Home Portal is a web site aimed at supporting physicians and families in improving the care and outcomes for children with special health care needs (CSHCN) in the Medical Home model. To optimize access to its information and resources, the content has been structured using XML schemas that incorporate relevant clinical questions. This approach guides authors as they develop content and informs the organization of the site, aimed at assuring that users can readily locate needed information and resources. It will also enable direct access to relevant content via "infobuttons" or a questions-based interface, and extraction of content for use in electronic health records or other electronic media.

Introduction

Children with special health care needs (CSHCN), comprising 13.9% of US children,[1] 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."[2] This group includes those with common chronic conditions (e.g., asthma and attention deficit-hyperactive disorder), as well as those with any of numerous uncommon or rare congenital and acquired conditions.[3] Pediatricians generally care for 200-300 CSHCN, many of whom will share their diagnosis with only one or two other patients in the practice.

Maintaining up-to-date knowledge about managing chronic conditions and about important subspecialty and community services is a major challenge for primary care physicians (PCPs). The Medical Home model, promoted by the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and the American Osteopathic Association, describes an optimal approach to caring for patients with chronic conditions, that includes coordination of care and partnership with the patient/family.[4]

The Medical Home Portal

We previously outlined the development of a web-based tool for meeting the information and resource needs of both PCPs and parents in support of the Medical Home model.[5] The Medical Home Portal (www.medicalhomeportal.org) (Portal) aims to provide reliable, useful information and simplified access to resources for physicians and families to help them care and advocate for CSHCN. Key features of the Portal include "diagnosis modules" and "newborn disorder modules" that provide information, aimed at PCPs, about specific diagnoses affecting CYSHCN. With support from the National Library of Medicine, a new version of the Medical Home Portal (known from 2001-2009 as "MedHome Portal") is being developed[6] to enhance the site's infrastructure, improve its utility and usability, and augment its content and impact. We are "refactoring" the site's content, aiming to assure its usefulness in clinical settings.

Content Refactoring

The requirements/aims guiding the refactoring of the Medical Home Portal content include:

1. Guide content authors and facilitate:
   a. focusing on practical, clinically relevant information,
   b. following a standardized content organization,
   c. integrating links to supporting evidence and tools for use in clinical practice,
   d. integrating information about local and national services and resources for patients and families.
2. Ensure that users of the Portal can find answers to their questions by:
   a. presenting content in a structure consistent with common clinical thought processes,
   b. enabling presentation of information in question-answer format,
   c. enabling content retrieval via "infobuttons",
   d. allowing searches formulated as questions.

Additional requirements/aims, that are not the focus of this paper, are to:

A. Improve content development and editorial and peer review through standardization of content structure, creating reusable elements within an XML-based online content management system.
B. Separate content from presentation by using XML mark up with minimal formatting, and using XSLTs to describe the transformation to HTML.
C. Support multiple states/regions in sharing the Portal's content and platform by allowing for substitution of Utah's services with those from other states/regions, following categorization of the services into the Portal's taxonomy.

Methods

Development of schemas

Development of the schema for Diagnosis Modules was accomplished in concert with the development of clinical questions relevant to each content module sub-section. Analysis of the content and structure that had evolved over 8 years for the legacy site identified 72 paragraph-level content elements, representing specific topics relevant to each diagnosis, and 14 metadata elements. These were then organized and modified based on feedback received from users and through informal user testing. Several iterations of the schema resulted in a structure that now elicits few critiques when presented for evaluation to new users or authors.

The schema began as a word processor document that was refined through numerous iterations by the Medical Home Portal development team, including two pediatricians (CN and LMK), a nurse/doctorate in health promotion with expertise in care coordination and working with medical homes, a medical informatics consultant (RAR), and a software engineer, who provided ongoing feedback regarding the practicality and programmability of the various topics and their associated characteristics (e.g., cardinality, data types, presentation).

Once the schema was fully represented in XML Schema, an authoring interface was implemented using Altova's Authentic®.[7] Clinicians subsequently began developing content modules, resulting in new insights that continue to drive incremental improvements in the schema and the authoring interface.

Development of questions

Assuring that clinicians' questions will be answered requires understanding the nature and breadth of those questions. Ely, et al. compiled questions generated by PCPs while caring for patients into a taxonomy of generic clinical questions.[8] Another study found that questions generated while caring for CSHCN differ from those that arise in the care of children without special needs.[9]

The Medical Home Portal's content is being indexed by the questions it answers, using Ely's taxonomy, to guide authors as they develop content. The questions will allow answers to be found by alternative means, such as via "infobuttons"[10,11] or a list, accessed from an electronic health record's "dashboard," of questions for which answers are available within the Portal. Table 1 offers examples of questions from the taxonomy and their extension to the Portal's schema.

To ensure that the questions will reflect the needs of providers caring for CSHCN, generic questions were posed by two experienced clinicians for each content module section/sub-section and then validated through informal review by other clinicians. These are further validated by content experts as they author or revise each content module, and questions specific to the diagnosis are added.

Each paragraph-level XML tag ('leaf' section) is assigned one or more required questions. Required questions must be answered by the content of their respective tags. Optional questions (0 to many) may also be associated with each tag. The questions that are answered, both required and optional, will form the basis for auto-generating a questions-based interface to the content in the future.

Figures 1-5 demonstrate instances of the Initial schema development in MS Word®; XML Schema; authoring interface in Authentic®; native XML representation of the document; and Web page display of the same document.

Ely's classification	**code**	**primary**	**secondary**	**tertiary**	**quaternary**
	1.2.1.1	diagnosis	criteria/manifestations		
Ely's question(s)	… What are the criteria for diagnosis of condition y? OR How do I diagnose condition y (based on information I have or could get)? OR How do I distinguish between conditions y1, y2, …yn (based on info I have or could get)?...				
Section/Subsection Portal Question	**Ongoing Assessment / Diagnostic Criteria** How is this diagnosis best established, so I can be certain of it for this patient and can rethink the diagnosis periodically?				
Ely's classification	2.2.1.1	treatment	not limited to but may include prescribing	efficacy/indications	treatment
Ely's question(s) *(imprecise match with Portal question)*	… What is the efficacy of treatment/procedure x (for condition y)? OR Does procedure/treatment x work (for condition y)? OR … What is the goal of treatment of condition y?...				
Section/Subsection Portal Question	**Treatment** What specific findings/measures should be followed to assess response to treatment?				

Table 1. Examples of Ely's classification, the "generic clinical questions" assigned to the specified codes, and their extension to questions used in the Medical Home Portal schema.

Description
What is this condition/diagnosis – how do you define or describe it (briefly, in 1-3 paragraphs)? [1.2.1.1]
What subsets or related conditions are important to distinguish before I read further? [1.2.1.1]
Genetics
What genetic factors are associated with this diagnosis (brief explanation; can link to genetics Issue page for more detail)? [4.2.1.2]

Figure 1. Author schema section – subsection headings (in blue), associated clinical questions and taxonomy classification (in brackets). Schemas were initially developed and presented to authors as a MS Word® document

```
<xs:element name="Description" type="mh:BasicFormattedTextValueType" />
<xs:element name="Genetics" type="mh:BasicFormattedTextValueType" />
```

Figure 2. XML Schema section corresponding to Figure 1.

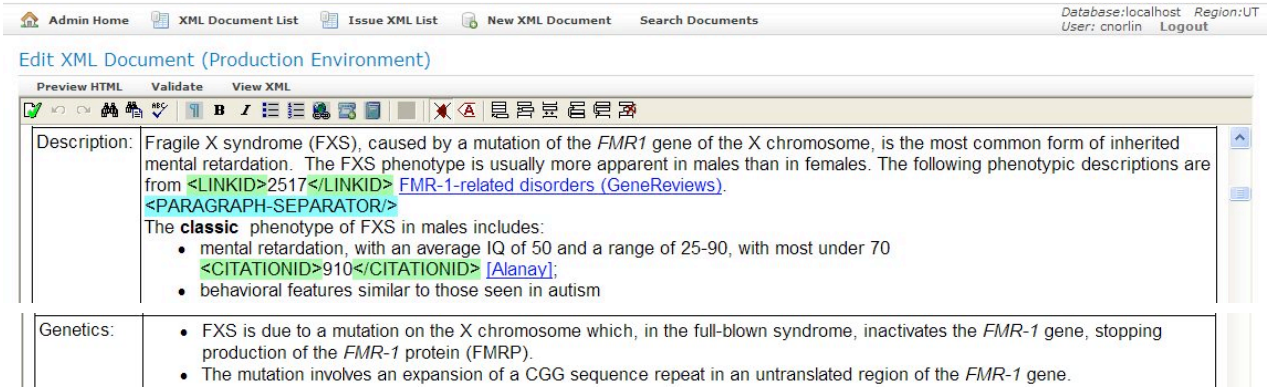

Figure 3. View of the Authentic® authoring interface, reflecting the schema in Figures 1 and 2 (text from the Fragile X syndrome diagnosis module; both sections truncated). Highlighted tags, e.g., <LINKID> </LINKID>, are added using the ID number or from search results of available documents within that type.

```
31: <diag:Description>Fragile X syndrome (FXS), caused by a mutation of the
    <mh:Italic>FMR1</mh:Italic> gene of the X chromosome, is the most common form
    of inherited mental retardation.  The FXS phenotype is usually more apparent in
    males than in females. The following phenotypic descriptions are from <mh:Link
    id="2517" label="FMR-1-related disorders
    (GeneReviews)"/>.<mh:ParagraphSeparator/>The <mh:Bold>classic</mh:Bold>
    phenotype of FXS in males includes:
32: <mh:BulletedList>
33:     <mh:BulletedListItem>mental retardation, with an average IQ of 50 and a
        range of 25-90, with most under 70 <mh:Citation id="910"
        label="Alanay"/>;</mh:BulletedListItem>
34:     <mh:BulletedListItem>behavioral features similar to those seen in
        autism</mh:BulletedListItem>
```

Figure 4. Native XML representation of the first part of the document displayed in Figure 3.

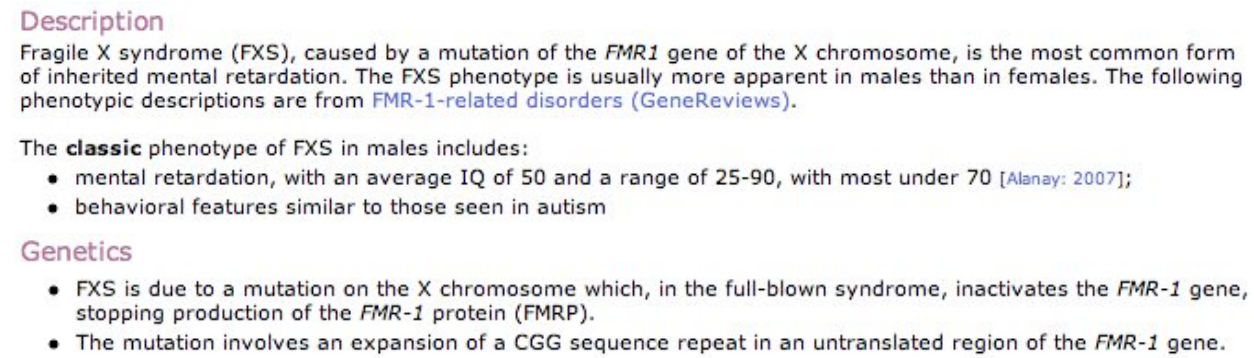

Figure 5. Web page display of the content described in Figure 4 (both sections truncated).

Results

The XML-based content management system is now operational, as are the schemas that provide the structure for the Medical Home Portal's content. We expect ongoing improvements to be made in both as more content is developed and user testing informs future development. Complex schemas have been developed for the two major types of "medical content" – Diagnosis Modules (nine are currently live and 15 are in varying stages of development) and Newborn Disorder Modules, addressing 31 disorders screened for in newborns in most states (all are live and one additional module is in development). See Table 2 for details on these schemas.

As the guiding clinical questions were developed, most were assigned to one of the 64 quaternary categories found in Ely's taxonomy.[8] The five primary categories include: "diagnosis," "treatment," "management," "epidemiology," and "non-clinical." There are 25 secondary and 55 tertiary categories. Only 22 of the 64 categories have been used to date. We were unable to assign a classification to the questions associated with three of the 72 paragraph-level elements within the diagnosis module schema, each of which were introduction questions relating to the content of subsequent elements.

In addition, several XML tags were developed to reference specific types of content, data, or external web pages (see Table 3). Authors and editors are able to access existing instances of each of these via search function within the content management system. Tags to allow limited formatting of content (including bold, italic, bulleted list, etc.) are also available to authors and editors.

We envision having 35 to 40 diagnosis modules when the Portal is mature, and another 25-30 single page modules that focus on information about local services and resources for rare disorders. The documents currently in the production XML database use 163 unique XML tags, including section and subsection tags and a small number of content formatting tags (e.g., bold, bulleted list).

Discussion

Conversion of the Medical Home Portal data structure to XML Schema and development of XML-based authoring and content management tools have allowed us to address the requirements listed in the Introduction. Key utilities include offering authors a structure for their documents, a question-based

	Description	XML tags	Questions*
Shared schemas			
Metadata	shared across all documents	9 required 4 optional	9 required
MedHomeCommon	12 elements shared across schemas	36 required 24 optional 7 shared	Includes 49 questions across 11 content sections, all required
General schemas			
GenericPage	used for content pages without structure that is repeated across other pages	4 required 2 shared	none assigned
Specific schemas			
DiagnosisModule	described in the text (several tags, and questions, are reused multiple times within a given module)	20 required 30 optional 7 shared	27 required 11 optional
NewbornDisorder	described in the text	19 required 3 optional 2 shared	23 required 11 optional
Screening	pages addressing a variety of screening types (e.g., "Developmental Screening," "Hearing Screening," or "Social-Emotional Screening")	21 required 8 optional 2 shared	22 required
Issue	pages focused on a topic that may be common to multiple diagnoses or apply to a single diagnosis (e.g., "Constipation" or "Genetics of Prader-Willi syndrome")	6 required 1 optional 2 shared	none assigned
Technology	pages focused on applications of technology to caring for CSHCN (e.g., "Wheelchairs", or "Tracheostomy")	using *Generic* schema	question development pending

Table 2 Description of XML schema elements (* required status of questions not yet implemented)

Tag type	Purpose/Content
Link	data about internal or external web pages, including an annotation intended to guide the user as to the potential value of the link or how to find the referenced information on the site
Citation	data about journal articles, books, web documents, etc., including an annotation, as above
Tool	charts, graphs, data forms, etc. for use in practice, often converted from published guidelines and generally downloadable as PDF files
PatientEducation	downloadable files, usually in PDF format, or links to external web pages with focused content aimed at educating patients and families
PracticeGuideline	links and/or downloadable files of full text of published practice guidelines
Registries/Studies	data about clinical registries or active research studies relevant to a given diagnosis that may offer opportunities for patients
ServiceCategory	one of 203 categories of services for CSHCN and their families (e.g., Physical Therapy, Pediatric Neurology, Parent Support Groups, etc.) to which individual services are assigned

Table 3 Description of *Medical Home Portal*-specific XML tags

approach within which to development content, and constraints on their formatting options.

The schema was developed collaboratively by the web developer and clinicians. The primary criteria for question selection was relevance to primary care and care coordination. Initially, authors find using the question schema daunting but adapt quickly and are rewarded when the end product is visible as a web page. A key result of schema use has been much more consistency in content modules across authors.

Another result is enhanced flexibility in repurposing the content for use in other parts of the Portal and presentation in other formats (print, PDA, etc). A question-based search is planned that will allow us to test and incrementally improve the utility of our questions, while enabling extraction of discrete, relevant content into other media (e.g., electronic health records) to answer questions at the point of service in clinical settings.

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