

## If We Build It, They Will Come: Standardized Consumer Vocabularies

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Consumer retrieval of healthcare information may soon dominate all other uses of the Web, but even when consumers reach a site that is relevant for them, they are not always able to find the exact information they need. This is due, in part, to the mismatch between the words they use in expressing their queries and the way in which the information is represented on the Web site(s) they have found.

### **A Standardized Consumer Vocabulary: The Challenges**

Consumers bring culture and cognition to potentially high-stress healthcare situations. Language for them serves many purposes: e.g., to convey meaning and interest in health topics, to express fear and hope regarding one's health status, and to establish a link with a care provider. Although there is merit as well as the need to comprehend the meaning of the language of consumers, to presume that it contains a knowable, stable vocabulary and grammar similar in structure to that of the formal languages of health care imposes a professional structure on a very personal experience. In order to be effective, a standardized consumer health vocabulary will need to consist of "normal standard ways of expressing things" (in every day life), and will also likely need to contain "informal" terminology. What is also needed are strategies that enhance the conveyance of meaning, and strategies that are sufficiently robust to encompass the many, and sometimes confusing, meanings found in the language of consumers.

### **A Standardized Consumer Vocabulary: The Technical Perspective**

As a "translation mechanism," a standardized consumer health vocabulary could serve to match consumers' health information needs and their ways of expressing those needs within information resources. The healthcare consumer then would not need to know the language of the healthcare provider in order to effectively find relevant information resources, and he/she could search for resources in his/her own language and on the basis of his/her own interests and knowledge structures. The maintenance and enhancement of connections based on a standard vocabulary are reusable, and reuse supports scale. The challenge is how to start the "forward feedback" loop that takes what already exists and ends up with a process that sustains a high-quality standard

consumer vocabulary. This "process challenge" is the same as that being faced by the UMLS Metathesaurus, SNOMED/RT, LOINC, HL7 version 3, Metadata, and other attempts to "normalize meaning" at Web scale. At present, the only way we know how to create the desired "self-organizing" result is to put existing vocabulary into a formal infrastructure, so that, on the outside, consumers see familiar language and behavior, while on the inside structure and meaning are predictable and standard.

### **A Standardized Consumer Vocabulary: Research and Implementation**

The development of a Consumer vocabulary should be based on research that includes consumer information needs and consumers' ways of talking about and expressing those needs. The National Library of Medicine has taken a lead role in research and implementation in this area. Analyses have been done on user queries to Web sites at the National Library of Medicine (NLM), including their newest site "ClinicalTrials.gov", which is a system designed specifically for healthcare consumers. This research has led to development of methods to assist users as they search, and also to improve consumer access to health information. Another research effort, SchoolhealthLink, is a comprehensive Web-based health information resource for use by children and school health nurses in Missouri. SchoolhealthLink, provides decision-making assistance, communication support, and access-to-care information, including research databases and health information resources. These resources are intended to extend and enhance school nursing practice. Using the Dublin Core metadata elements, subject and keywords, the SchoolhealthLink team is providing vocabulary for the subject as well as keywords by using select terms from the Medical Subject Headers (MeSH). The pages are stored in an Access<sup>®</sup> database and published dynamically for easy retrieval by the school nurses using a keyword. As the project evolves, the challenge for the SchoolhealthLink team is to map children's' and parents' terms to the controlled vocabulary, thus allowing children and their family's meaningful access to health resources.

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