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KOS Design for Healthcare Decision-making Based on Consumer Criteria and User Stories
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Much research has been done on subject matter expert research behavior (engineers, medical professionals, etc.), and many information retrieval applications have been developed to support this user scenario. Less research has been done on the behavior of non-subject matter experts, especially in the context of life event decision-making, for example, in the context of unanticipated medical emergencies, treatments and recovery options. This presentation summarizes and compares existing KOS work on specialist-focused schemes to what was found to be important to a consumer-focused scheme.

Based on extensive primary and secondary research, a set of consumer (as opposed to healthcare practitioner) criteria and user stories for making healthcare related decisions were identified. These criteria were used to inform the development of a knowledge organization system (KOS) to facilitate a unified consumer-oriented search experience across insurance provider enrollment structured databases and related Web-based health resources from public information sources such as Medline Plus[1]. The KOS developed to support this application includes 7 extensible taxonomies with 12 types of semantic relationships defined between concepts. This presentation will discuss briefly 1) how consumer criteria were identified from a variety of sources including query logs, application prototypes, literature reviews, interviews with health experts, and collections of consumer healthcare stories; 2) how use cases were defined in response to common types of consumer healthcare queries; and then focus on 3) the high level KOS design to facilitate searching heterogeneous health information resources that meet consumer criteria for making healthcare related decisions. The main findings are:

- Consumer healthcare related decision-making behavior is very different from those of healthcare practitioners. While there are some "detective" users, most decisions are being made during a period of personal crisis or stress.
- While there are many healthcare-related technical KOS available, consumer-friendly terminology is generally not available from authoritative sources. Thus, a lot of work is required to compile a useful KOS from many sources. Documentation of editorial guidelines is important to support this activity and make it scalable.
- A small set of extensible taxonomies and custom semantic relationships are sufficient to develop the domain model. The domain model consists of a concise set of subject predicate object relationships, e.g., Condition IsConcernOf Specialty_Area.
- A strategy to map from the general domain model to the Medicare.gov datasets controlled vocabularies provided flexibility and extensibility.
- KOS management tools are immature in their capacity to accurately and efficiently batch import and export KOS, interim taxonomies and semantic relationships.

We will demonstrate a browsable version of the KOS implemented in the PoolParty tool, and a proof of concept tool for searching across heterogeneous sets of U.S. national data from 6 different

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[1] *MedlinePlus: Health Information from the National Library of Medicine.*
https://www.nlm.nih.gov/medlineplus/. Last checked 6/14/2016.

types of healthcare provider settings – physicians, hospitals, nursing homes, home health agencies, dialysis centers and a medical supply directory.

Bios

Joseph Busch is the Founder and Principal Consultant of Taxonomy Strategies. Taxonomy Strategies guides global companies, government agencies, and NGO's such as Nike, the Center for Medicare and Medicaid Services, and the Robert Wood Johnson Foundation in developing metadata frameworks and taxonomy strategies to help information achieve its highest value. Before founding Taxonomy Strategies, Mr. Busch held management positions at Interwoven, Metacode Technologies, the Getty Information Institute, PriceWaterhouse and Hampshire College. He is a Past President of the Association for Information Science and Technology, and a member of the Dublin Core Metadata Initiative Executive Committee.