Consumer Health Vocabulary

Soo Kyoung Lee, RN, MPH
Contents

- Introduction
- Issues
- Previous Studies
- Research Topics
Introduction

- Consumer health informatics (CHI)
  - The branch of medical informatics
  - Analyses consumers’ needs for information
  - Studies and implements methods of making information accessible to consumers
  - Integrates consumers’ preferences into medical information system

Introduction

- Consumer health informatics
  - The study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumer
  - Consumer health information helps people to understand their health and make health-related decisions

Ref. Tom Ferguson, 2001
Ref. Conceptual framework for consumer health informatics (Logan, 2007)
Ref. The Growing Demand for Health Information (MedlinePlus, 2005)
Welcome to the Town
An introduction to toxic chemicals and environmental health risks you might encounter in everyday life, in everyday places.

- **Neighborhoods**
  Select a view of the Town City, US-Mexico Border, or Farm to learn about urban, suburban, farm and border town health risks.

- **Locations**
  Click on a location in the neighborhood, like the school, and find out more about the chemicals that could be in that location. Also learn about health risks that might be in that location.

- **Chemicals**
  Roll your mouse over a chemical name to see where it might be found in the neighborhood. Then click the button for selected Internet information on that chemical.

- **Are these chemicals in MY community?**

Introduction

MedlinePlus.gov
THE WEB SITE YOUR DOCTOR PRESCRIBES

Information Rx

Hypertension = High Blood Pressure

Dr. Karl Rössle 4/15/08

Ref. Information Prescription ( http://www.informationrx.org )
Introduction

Ref. Multimedia Healthcare Information system (www.hichart.net)
Introduction
Issues

- Issues in consumer health
  - Patient–physician communication
    - information flow from physician to patient, for example, in the context of obtaining informed consent
  - Patient interpretation of print and media
    - the information itself observed in transit
  - Consumer health vocabulary
    - information flow from consumer to information retrieval system and back again in the context of information seeking

Ref. Consumer Health Informatics (Deborah Lewis et al, 2005)
Issues

- CHV Definition

  - Consumer health vocabularies link everyday words and phrases about health to technical terms or jargon used by health care professionals

Ref. Consumer Health Vocabulary Initiative (www.consumerhealthvocab.org)
CHV Aim

• Consumer health vocabularies help bridge the communication gap between consumers and health care professionals

• Using such vocabularies, technical terms may be "translated" into lay language

Ref. Consumer Health Vocabulary Initiative (www.consumerhealthvocab.org)
Issues

- CHV Problems
  - Patients often have difficulty understanding information provided to them by health care professionals.
  - Health-related computer applications and sometimes even health care professionals have difficulty interpreting expressions used by lay people.
  - Not understanding medical concepts could have significant consequences for patients and their health care providers.

Ref. Consumer Health Vocabulary Initiative (www.consumerhealthvocab.org)
Previous Studies

- **Characteristics of Consumer Terminology for Health Information Retrieval** (Q. Zeng et al, 2002)
  
  - Study focused on consumer queries that were used on a consumer health service Web site and a consumer health information Web site.
  - Analyzed data from the site-usage logs and conducted interviews with patients.
  - Findings show that consumers’ information retrieval performance is very poor.
  - There are significant mismatches at all levels (lexical, semantic and mental models) between the consumer terminology and both the information source terminology and standard medical vocabularies.
## Previous Studies

Classification of mismatches between consumer terms and UMLS

<table>
<thead>
<tr>
<th>Type</th>
<th>Subtype</th>
<th>Example</th>
<th>Query Term</th>
<th>UML Name</th>
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<tbody>
<tr>
<td>Lexical</td>
<td>Spelling Error</td>
<td>Rhumetology</td>
<td>Rheumatology</td>
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<tr>
<td></td>
<td>Morphology</td>
<td>Addictions</td>
<td>Addiction</td>
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<tr>
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<td>Concatenation</td>
<td>Anti phospholipid</td>
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<td>Sequence</td>
<td>Headache migraine</td>
<td>Migraine Headache</td>
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<tr>
<td>Semantic</td>
<td>Abbreviations and Acronyms</td>
<td>Adhd</td>
<td>Attention Deficit Disorder</td>
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<tr>
<td></td>
<td>Synonym</td>
<td>Bone spur s</td>
<td>External extoses</td>
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</tr>
<tr>
<td></td>
<td>Redundancy</td>
<td>Cardiac arrhythmia</td>
<td>Arrhythmia</td>
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<tr>
<td></td>
<td>Generalization / Specialization</td>
<td>Diabetic leg ulcers</td>
<td>Leg ulcer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other Semantic Relationship</td>
<td>Retinal surgery</td>
<td>Retinal disease</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>Valid term, but not in UMLS</td>
<td>Genomics</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Non-medical term, not in UMLS</td>
<td>Mass General Hospital</td>
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<tr>
<td></td>
<td>Unclear meaning of consumer term</td>
<td>Scc</td>
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</tr>
</tbody>
</table>
Previous Studies

- Patients’ and physicians’ understanding of health and biomedical concepts (Patel et al, 2002)
  - Physicians explained the patient problems in terms of causal pathophysiological knowledge underlying the disease (disease model)
  - Patients explained them in terms of narrative structures of illness (illness model)
  - The physician–patient interview allows physicians to capture crucial aspects of the patient’s illness model, which are necessary for understanding the problem from the patients’ perspective
**Previous Studies**

- **A Web Application to Support Consumer Health Vocabulary Development** (Jon Crowell, 2005)
  - They designed a Web application, *VocabTool*, to support the analysis of term- and concept-related information by geographically distributed reviewers.
  - In a recent study [1], six reviewers used *VocabTool* to review 2,193 candidate CHV terms from a corpus of 12.5 million MedlinePlus queries.
  - An XML DTD for storing vocabulary terms and modules for reporting voting statistics are being developed.

## Previous Studies

VocabTool: Module for Creating new CHV Concepts and Relations

![Image of VocabTool interface](image)

### Table 1: VocabTool Concept List

<table>
<thead>
<tr>
<th>Concept ID</th>
<th>Term</th>
<th>Concept Type</th>
<th>Spelling</th>
<th>Variant</th>
<th>Concept ID</th>
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</thead>
<tbody>
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<td>Bulging Disc</td>
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<td>DC000060</td>
<td>Internal Bleeding</td>
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<td>DC000059</td>
<td>Vitamin B12</td>
<td></td>
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<tr>
<td>DC000058</td>
<td>Vitamin B12 Deficiency</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>DC000057</td>
<td>Mayo Clinic</td>
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<td></td>
</tr>
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<td>DC000056</td>
<td>Shoulder Injuries</td>
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<tr>
<td>DC000055</td>
<td>Research Articles</td>
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<td>DC000053</td>
<td>Auto Immune Disorder</td>
<td></td>
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<td></td>
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<tr>
<td>DC000068</td>
<td>Upper Gastrointestinal Tract</td>
<td></td>
<td></td>
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<td>DC000051</td>
<td>Laboratory Test Results</td>
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<td>DC000065</td>
<td>Fungal Nail Infection</td>
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<td></td>
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<tr>
<td>DC000063</td>
<td>Tylenol 3</td>
<td></td>
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<td>DC000013</td>
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<td></td>
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<tr>
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<td>Obese children</td>
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<td></td>
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<tr>
<td>DC000003</td>
<td>Abdominal Trauma</td>
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</tbody>
</table>

### Table 2: VocabTool Relation List

<table>
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<th>Concept One</th>
<th>Relation</th>
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<td>can_refer_to</td>
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<td>DC000210</td>
<td>synonymous</td>
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<td>Delete</td>
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<tr>
<td>DC000209</td>
<td>can_refer_to</td>
<td>C0282473</td>
<td>Delete</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concept One</th>
<th>Relation</th>
<th>Concept Two</th>
<th>Delete</th>
</tr>
</thead>
<tbody>
<tr>
<td>DC000254</td>
<td>is_a</td>
<td>C0452264</td>
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<td>DC000213</td>
<td>can_refer_to</td>
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<td>DC000211</td>
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<td>DC000211</td>
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<td>DC000210</td>
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<td>DC000209</td>
<td>can_refer_to</td>
<td>C0282473</td>
<td>Delete</td>
</tr>
</tbody>
</table>

### Insert Concept Relation

- issue_in
- can_refer_to
- contains
- has_subject
- has_location
- has_function
- is_treatment_for
- with_health_condition
- with_temporal_constraint
- has_child
- is_a
- synonymous
Previous Studies

- A Study for Building a System of Consumer Vocabulary for Health Information (Shin, 2009)
  - The rate of mapping between the consumer vocabulary for health information and the medical vocabulary was not high.
  - The number of “unmapped terms” was decreased by linking terms having similar forms to “preferred terms” and by extending synonyms (1st rate of mapping 30.7%, final mapping 46.3%).
  - The terms that consumers use are essential to further be researched in order to understand their morphology and features; hence, increasing consumer accessibility to the medical field.
Previous Studies

Mapping process between consumer vocabulary and medical vocabulary
The Development of Ontology-Based Dialogue System for Efficient Cancer Information Supply
(My master’s thesis, 2005)

- In this study, an ontology dialog system was built with the Protégé.
- This ontology system was linked with the Dialogue Agent.
- To assess performance of the ontology system, searching capability and usability was measured.
- The ontology system was found to be more effective for the provision of specialized knowledge to non-experts than to experts.
CancerQ System

http://cancerq.ezzin.com

System Architecture
CanceQ System added to NCIC (Expectation)
Research Topics

..... There is a cutaneous eruption on the lower extremity.....

..... There is a rash on the legs and feet....

I have water on the knee, Is this serious?

Knee joint effusion
Q & A
Thank you!