

# Bridging Medical and Lay Health Languages: the Role of Terms and Concepts

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National Library of Medicine, NIH

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# Participatory Medicine

My Personal Health Record  
**Medical Information**  
 Albert B Cunningham  
 Shelby A. Turner, September 18, 2009

Birthdate: 12/01/1959 Height: 5'8" Weight: 180

Primary Insurance: Medicare Primary Ins. Phone: 1-800-455-1930  
 Other Insurance: United Health Care Other Ins. Phone: 1-800-455-1930

Primary Physician: Dr. Alan Jones Phone: 1-800-455-1930 Fax: 1-800-455-1930  
 Physician Two: Dr. Martin Kelly Phone: 1-800-455-1930 Fax: 1-800-455-1930  
 Specialty: Walgreen Phone: 1-800-455-1930

Emergency Contact: John Cunningham Relationship: Son Phone: 1-800-455-1930  
 Medical Conditions: Arthritis, Asthma  
 Allergies/Reactions: Penicillin/Sulfonamide, Shellfish/Fish

Major Illness 1: Lymphoma Date Entered: 04/01/04 Major Illness 2: Lung Cancer Date Entered: 04/01/04  
 Major Illness 3: Lung Replacement Date Entered: 09/01/00 Major Illness 4: Kidney Stones Date Entered: 04/01/04

LAST RECORD 11-11-09 VIEW MENU PRINT



**MedlinePlus**  
 THE WEBSITE YOUR DOCTOR PRESCRIBES

Redesign Overview | Homepage Preview | Health Topic Preview | Drugs & Supplements Preview | Vision & Cool Tools Preview | Homepage Comparison

### Homepage Preview

We've redesigned the MedlinePlus homepage to give it a vibrant look and feel and to make it easier to find the content you're looking for.

**Highlights:**

- At the top, the new health boxes link you to frequently visited MedlinePlus topic pages.
- Rotating image feature at the top of the page displays current interest topics and new MedlinePlus features.
- Simplified navigation to Health Topics, Drugs & Supplements, and Vision & Cool Tools.
- Spotlighting popular features such as the Medical Dictionary, Popular Searches, and useful film database.
- Quick links to the mobile version and updates via email, RSS, and Twitter on every page.

Next: Health Topic Preview

**MEDICAL AUTHORIZATION FORM**

We, the undersigned, parent of SALLY SMITH and JOHN SMITH, hereby authorize BETTY SMITH or WILLIAM SMITH, natural grandparents of SALLY and JOHN SMITH, to authorize any and all medical treatment for SALLY and JOHN SMITH in their discretion as fit. This includes, but is not limited to, treatment or referral to any.

A photocopy of this authorization shall be deemed effective as if it were an original. This authorization shall remain in effect until January 1, 2008.

MEDICAL INSURANCE COMPANY: BLUE CROSS  
 MEDICAL INSURANCE ID or GROUP #: ABC1234  
 MEDICAL INSURANCE CO. PHONE #: 913-555-0000  
 PEDIATRICIAN: Dr. Jones  
 PEDIATRICIAN PHONE #: 913-555-0000

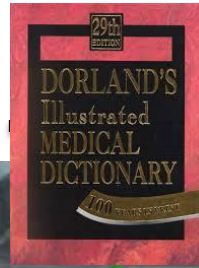
BY: SALLY SMITH DATE: \_\_\_\_\_  
 BY: JOHN SMITH DATE: \_\_\_\_\_

# Minding the Language Gap



“My feet are swollen”

Can't wear shoes  
Feet hurt  
Ice pack does not help  
Can't walk to the store



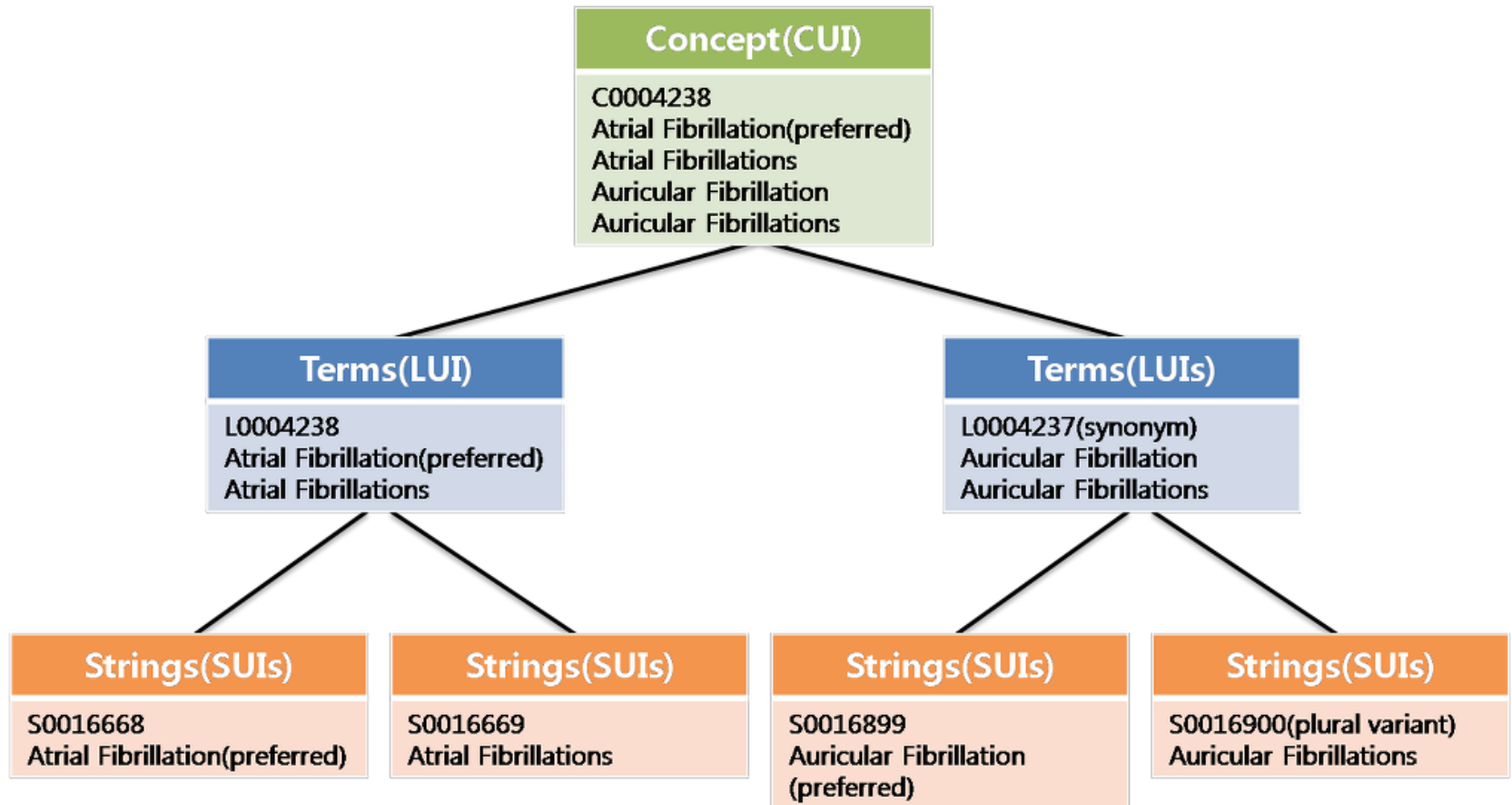
“Patient has 1+ pedal edema”

Ischemic heart disease  
Severe LV systolic dysfunction  
Diabetes mellitus  
Fasting blood glucose 140

**omnis traductor traditor = every translator is a traitor**

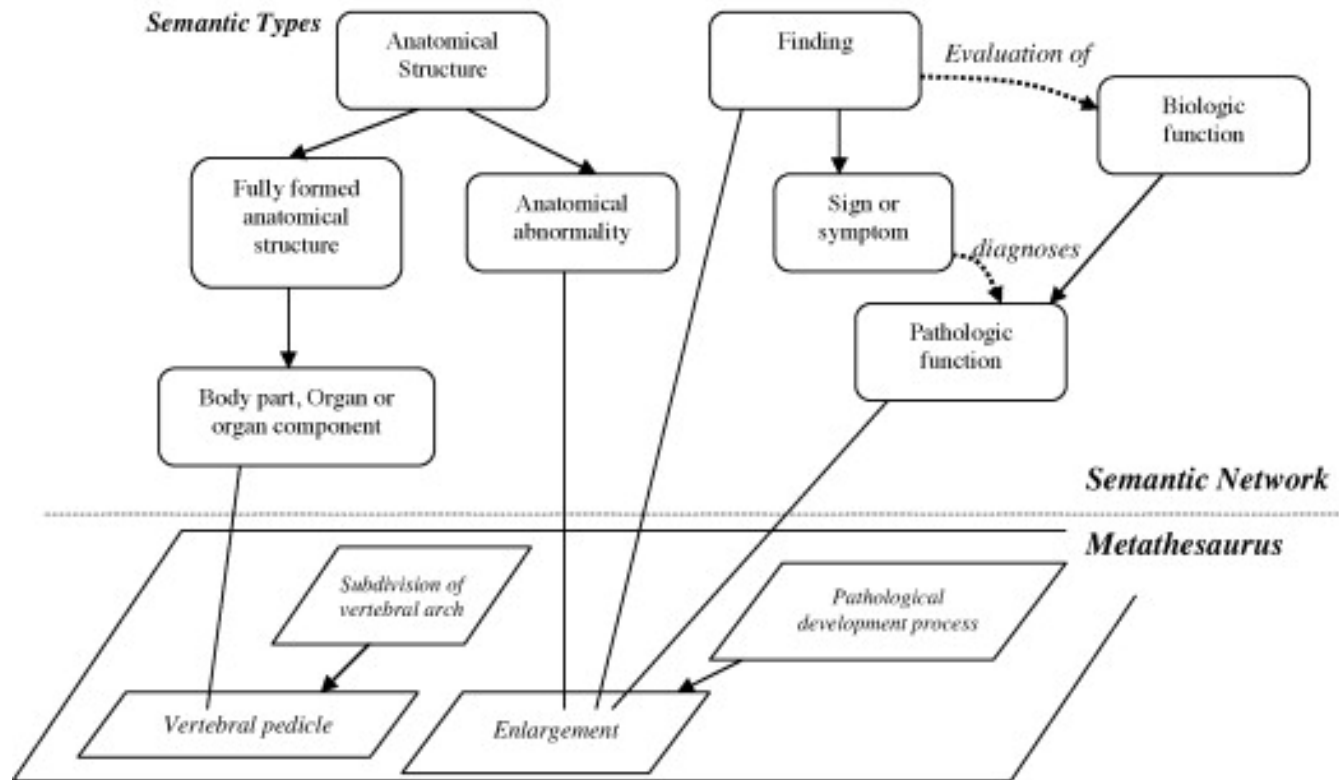
# Medical Language from the Informatics' Perspective

UMLS: Unified Medical Language System – Metathesaurus



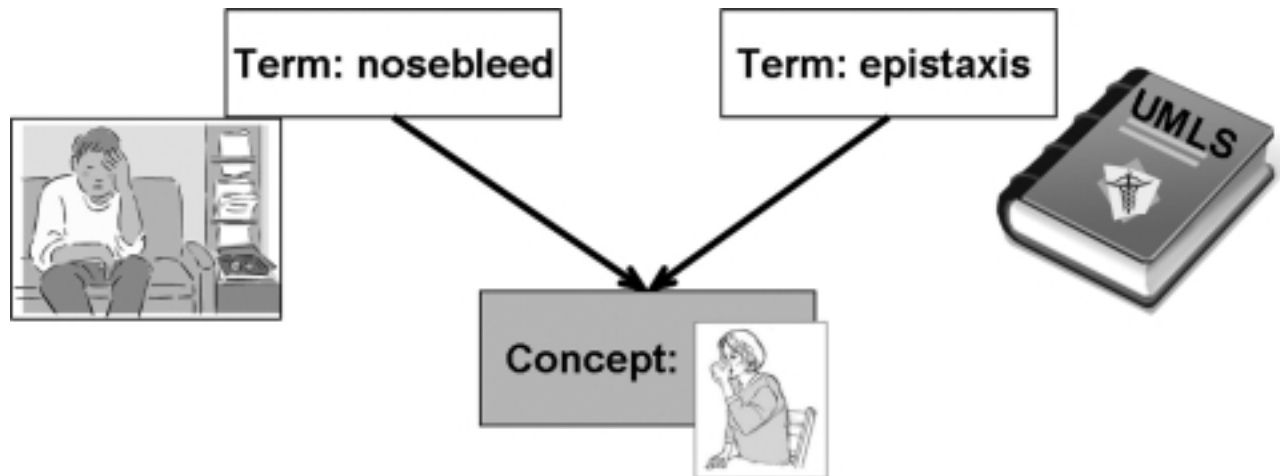
# Medical Language from the Informatics' Perspective

UMLS: Unified Medical Language System – Semantic Network



# Typology of Misunderstandings

# Synonyms



## Lay to professional

1. Identify them – consumer queries; language on patient forums
2. “Translate” them
3. Link to professional concepts

## Professional to lay

1. Rate difficulty
2. Suggest lay synonyms for difficult terms

## Challenges

- A lot of labor
- No single “lay language”

# Uniquely Lay Concepts

Term: aura

Concept:



These are rare!!

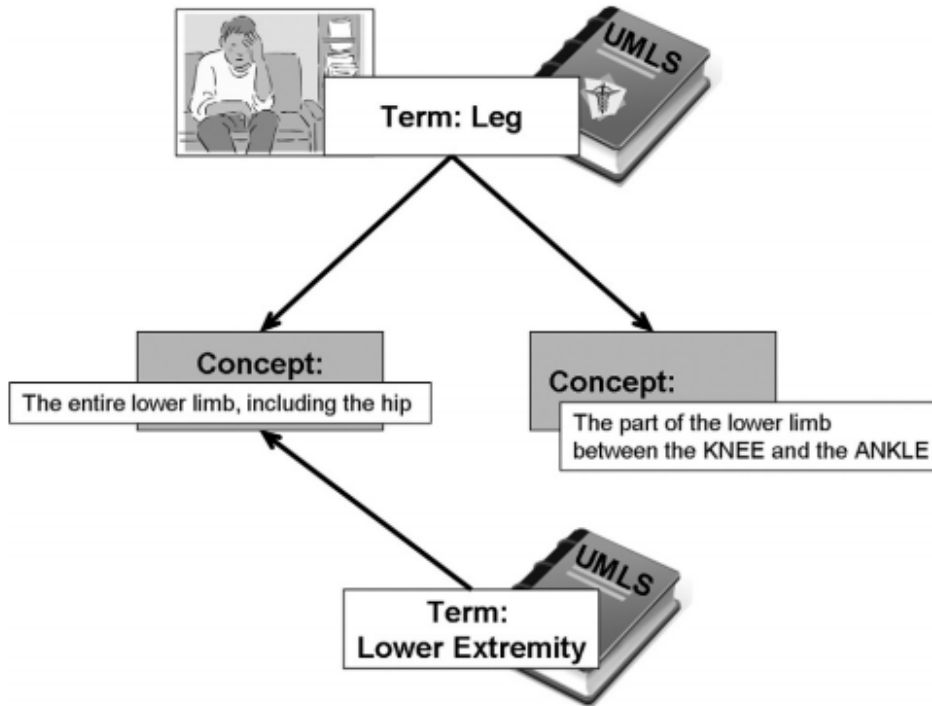
*Keselman, Arnott Smith, Divita, et al. Consumer Health Concepts That Do Not Map to the UMLS: Where Do They Fit? JAMIA 2008; 15: 496-505.*

- 12,000,000 MedlinePlus queries, free text from 25 health-focused message boards
- 1,046 terms that did not map to UMLS
- 64 non-mapping concepts
  - Most – 47 – could be expressed via existing UMLS concepts: e.g., childhood obesity, bone cancer treatment
  - 17 could not be expressed via UMLS concepts

The terms that could not be expressed via UMLS concepts: vaginal bacteria, privates, M-spot, G-spot, manhood, hairline, bangs, beauty marks, diet pills, cancer symptoms, coffin birth, eye genes, cure, lap, pelvic area, brown eyes



# Same Terms, Different Concepts



- Difficult to identify
- Likely to be ubiquitous
  - Due to difference in context, experience, education
- Difficult to remediate

Why is this a problem?

# Considering a Clinical Trial

Patients with **Type 1 diabetes** suffer from impaired **post-prandial hepatic glycogen** storage and breakdown, if they are under poor glycaemic control. Poor **glycogen** storage in the **liver** puts these patients at risk of **fasting hypoglycemia**. Amelioration of glycaemic control could improve these **abnormalities** and thereby reduce the risk of **hypoglycemia** in these patients. The “gold standard” technique for the assessment of hepatic glycogen metabolism in humans, **<sup>13</sup>C magnetic resonance spectroscopy** (**<sup>13</sup>C-MRS**), is expensive and limited to a few centers worldwide. Aim 1 of our project is to establish a new assessment method for **glycogen metabolism**. This new method is based on oral administration of **D<sub>2</sub>O** and **acetaminophen**.

# Attempts to Provide Vocab Support

## NCT00481598, Non Invasive Assessment of Liver Glycogen Kinetics in Type1 Diabetics

Patients with Type 1 diabetes suffer from impaired postprandial hepatic glycogen storage and breakdown, if they are under poor glycaemic control. Poor glycogen storage in the liver puts these patients at risk of fasting hypoglycemia. Amelioration of glycaemic control could improve these abnormalities and thereby reduce the risk of hypoglycemia in these patients. The "gold standard" technique for the assessment of hepatic glycogen metabolism in humans, 13 C magnetic resonance spectroscopy (13C-MRS), is expensive and limited to a few centers worldwide. The aim of our project is to establish a new assessment method for glycogen metabolism. This involves the oral administration of 2H2O and acetaminophen.

**HYPOLYCEMIA** (or abnormal decrease of sugar in the blood) expressed in the postabsorptive state, after prolonged FASTING, or an overnight fast.

## NCT00481598, Non Invasive Assessment of Liver Glycogen Kinetics in Type1 Diabetics

Patients with Type 1 diabetes suffer from impaired postprandial hepatic glycogen storage and breakdown, if they are under poor glycaemic control. Poor glycogen storage in the liver puts these patients at risk of fasting hypoglycemia. Amelioration of glycaemic control could improve these abnormalities and thereby reduce the risk of hypoglycemia in these patients. The "gold standard" technique for the assessment of hepatic glycogen metabolism in humans, 13 C magnetic resonance spectroscopy (13C-MRS), is expensive and limited to a few centers worldwide. The aim of our project is to establish a new assessment method for glycogen metabolism. This involves the oral administration of 2H2O and acetaminophen.

abnormal decrease of glucose in the blood, occurring after a prolonged - usually, overnight - period without food

- Retelling task, 80 participants, completeness and accuracy measures
- No significant improvement for either vocabulary support condition (also, none for office visit note)!!

Smith, Hetzel, Dalrymple, Keselman (2011). Beyond readability: Investigating coherence of clinical texts for consumers. JMIR, 13(4): e104

# Difficulties with Terms vs. Concepts

- Terminological challenges
  - “Neuropathy” vs. “nephropathy”
  - “Lasik” vs. “Lasix”
  - 20 ways to misspell “acetaminophen”
- Conceptual challenges
  - “Diabetes is a disease where the liver can’t produce a certain type of sugar”
  - “trouble breathing a green expectorant”
  - Clinical trials are always about testing treatment methods

*Keselman, Smith (2012). A classification of errors in lay comprehension of medical documents. JBI 45, 1151-1163.*

# Attempt to Improve Coherence

## **NCT00481598 Non Invasive Assessment of Liver Glycogen Kinetics in Type1 Diabetics**

This study tests a new technique for assessing liver glucose metabolism in individuals with type I diabetes.

Type I diabetes is the disease in which the body does not produce insulin, a hormone that helps the bloodstream glucose enter the cells of the body in order to be converted into energy. As a result, the levels of blood glucose get dangerously high (a condition called hyperglycemia). To prevent their blood glucose from getting too high, people with type I diabetes take insulin as a drug. Taking insulin as a drug may sometimes lead to situations when blood glucose gets dangerously low (a condition called hypoglycemia). As both hyperglycemia and hypoglycemia can lead to many serious health problems, the goal of diabetes management is maintaining good glycemic control, or proper blood glucose level.

As our cells need a constant energy supply between our mealtimes, our bodies have a mechanism for maintaining constant glucose concentration in the blood. When we have an oversupply of glucose after a meal, our body stores the excess in the liver and muscles by converting it into a substance called glycogen. When glucose is in short supply, the body produces it by breaking down this stored glycogen.

Patients with Type 1 diabetes suffer from impaired after-meal glycogen storage and breakdown in the liver, if they are under poor glycemic control. Poor glycogen storage in the liver puts these patients at risk of fasting hypoglycemia, or low blood glucose level, such as upon waking in the morning. Improvement of glycemic control could improve these glycogen storage and breakdown problems and thereby reduce the risk of hypoglycemia in these patients.

In order to better understand glucose metabolism and diabetes, researchers need to have good methods for assessing liver glycogen metabolism in humans. The "gold standard" technique for the assessment of liver glycogen metabolism in humans is magnetic resonance spectroscopy (13C-MRS), in which body tissues are stimulated by a magnet. The levels of different chemicals in these tissues can be identified, because these chemicals vibrate at different frequencies in response to the stimulation. Magnetic resonance spectroscopy is expensive and limited to a few centers worldwide, so a less expensive assessment method is desirable.

The aim of this project is to establish a new assessment method for glycogen metabolism. This new method is based on the administration of an oral drug, containing 2H<sub>2</sub>O and acetaminophen.

- Worked for Office Visit Note, but not Clinical Trial Description
- Small effect
- Very labor-intensive

# Conclusions

- Bridging synonyms is a good start
  - However, this is the tip of the iceberg
- Lowering readability scores of clinical texts is not sufficient to improve lay comprehension
- Coherence research has some promise
  - But we are far from automated text enhancers
- Tools for clinical intermediaries?
- Education



# Thank You!

- National Library of Medicine, NIH
- Qing Zeng-Treitler and OAC CHV Group
- Catherine Arnott Smith
- Prudence Dalrymple
- .....

