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

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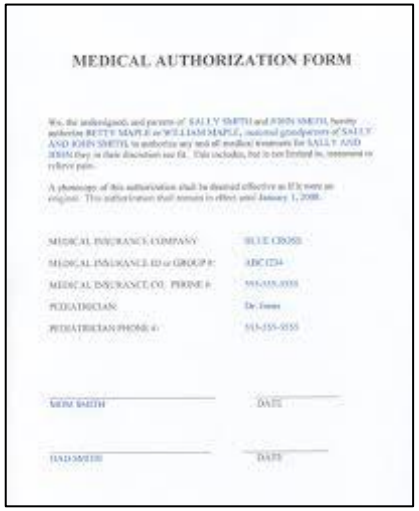
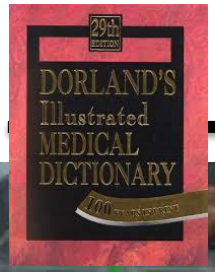
Participatory Medicine



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

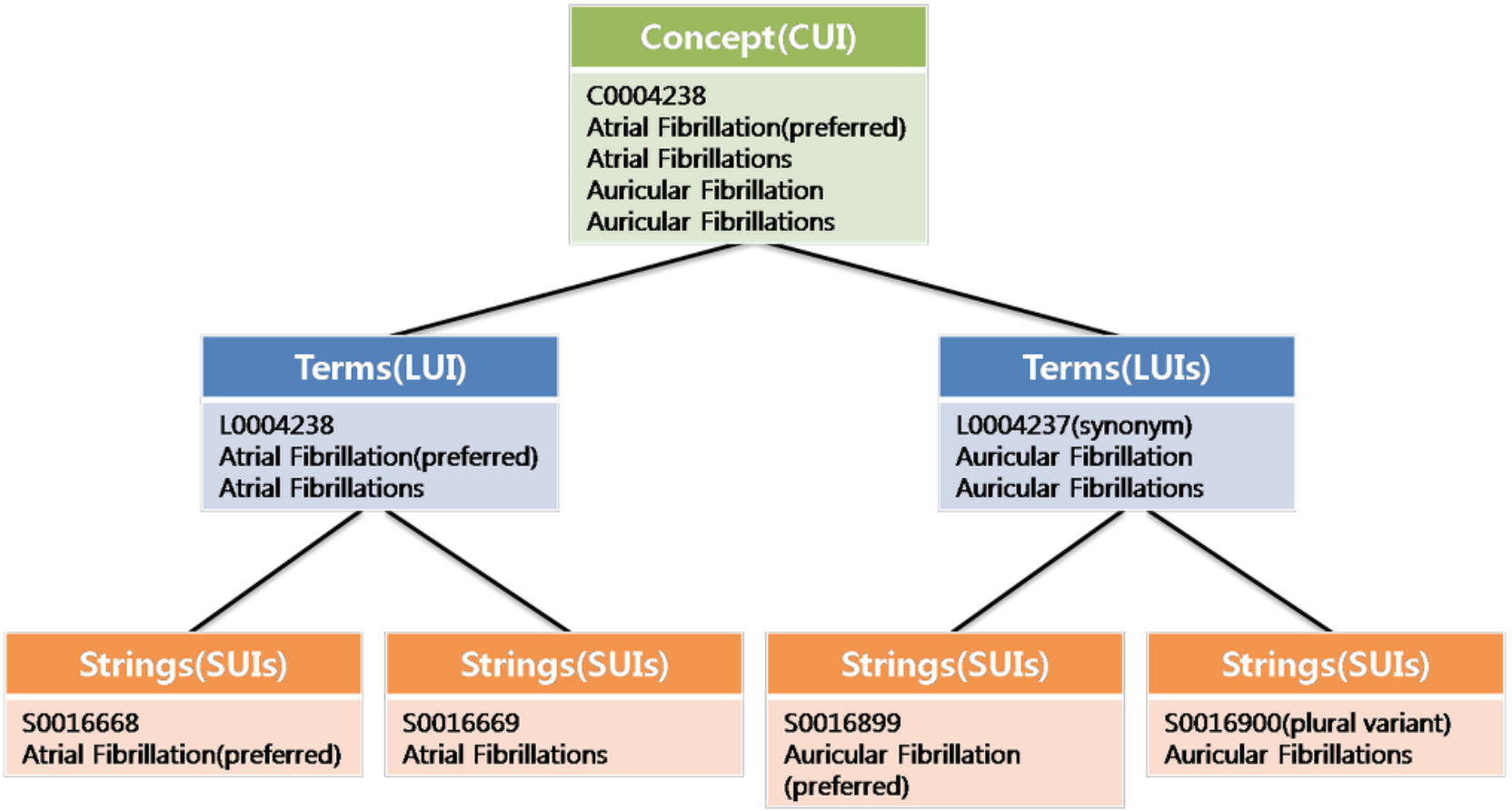
"Patient has 1+ pedal edema"

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

omnis traductor traditor = every translator is a traitor

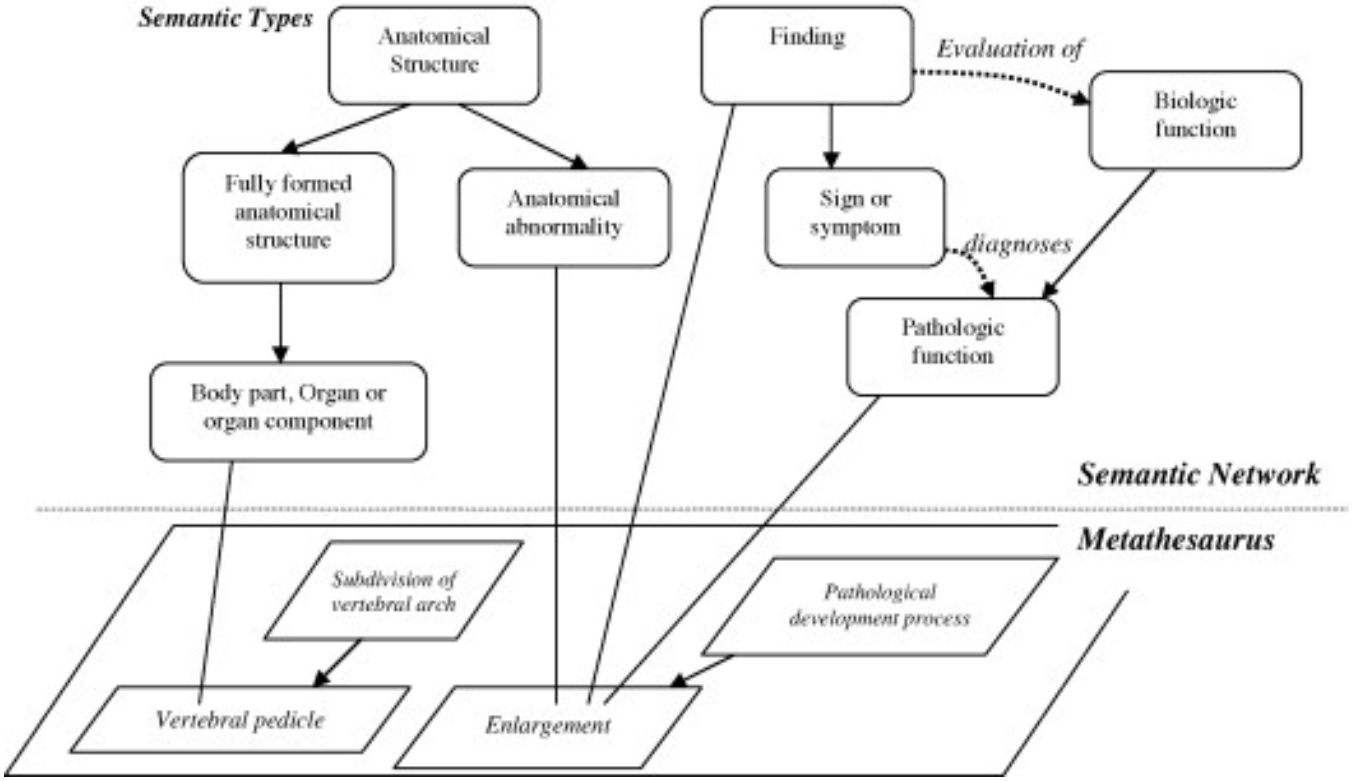
Medical Language from the Informatics' Perspective

UMLS: Unified Medical Language System – Metathesaurus



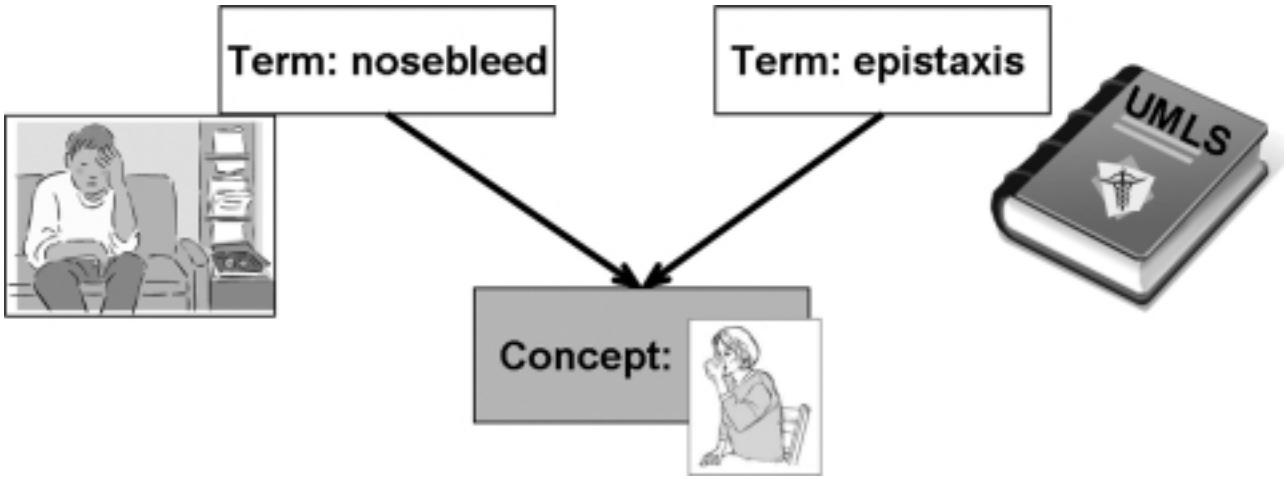
Medical Language from the Informatics' Perspective

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"

Qing Zeng-Treitler, OAC CHV

Uniquely Lay Concepts

Term: aura

Concept:

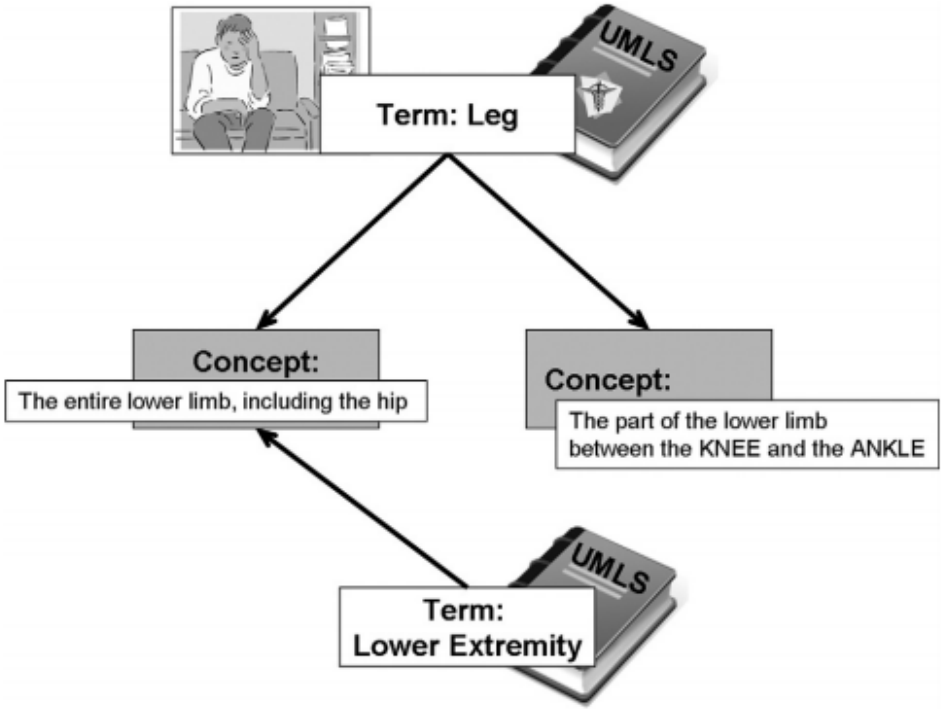
These are rare!!

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 exhisting 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



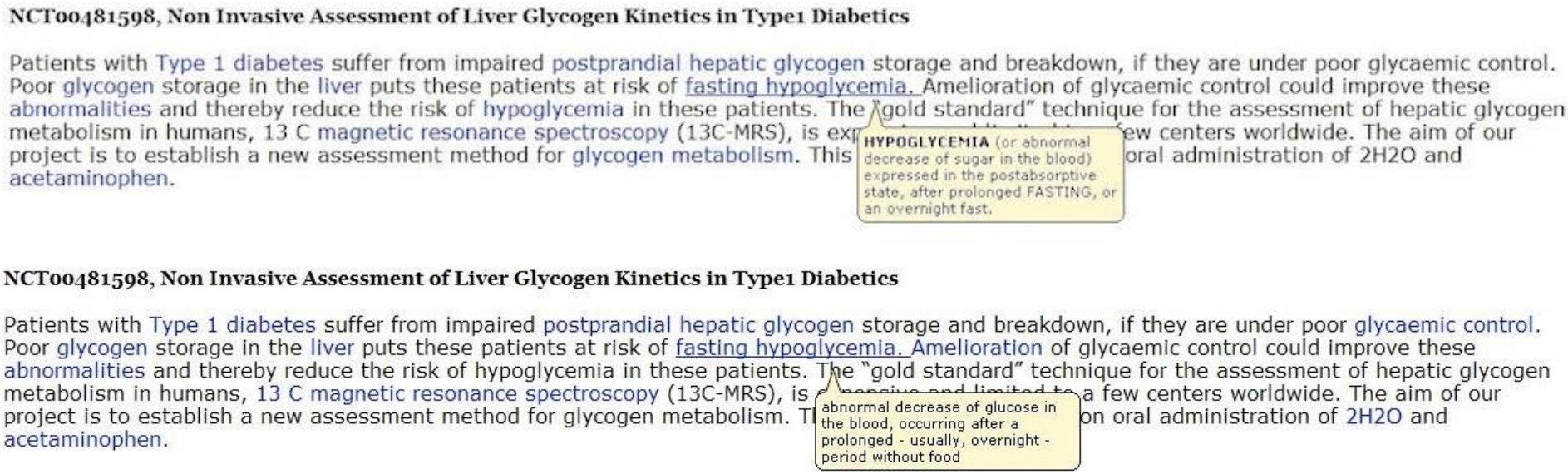
- Difficult to identify
- Likely to be ubiquitous
  - Due to difference in context, experience, education
- Difficult to remediate

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 hypoglacemia. 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 humand, 13C magnetic resonance spectroscopy (13C-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 2H2O and acetaminophen.

Attempts to Provide Vocab Support



- 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 be converted into energy. As a result, the levels of blood glucose get can 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 2H2O 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
- ……