

Tentative title: Squaring the circle: Managing local healthcare terminologies in the age of standardization

Program theme: Terminology and standards

Track: Applications of Informatics

Organizer:

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Abstract

Healthcare has benefited from the increasing maturity, availability and implementation of standardized vocabularies. However, many healthcare organizations continue to maintain local terminologies. In doing so, healthcare institutions, individually as well as collectively, expend significant resources on local terminology creation, maintenance and mapping to standardized vocabularies. The purpose of this panel is to describe current approaches to managing both standardized and local terminologies, elucidate challenges and opportunities, and discuss future-oriented strategies for making the process more efficient and effective. The Regenstrief Dictionary, Logical Observation Identifiers Names and Codes (LOINC), Medical Entities Dictionary (MED) at Columbia University Medical Center and the Research Entities Dictionary (RED) at the NIH will serve as case studies. The panel will discuss how a variety of tools, such as the Distributed Terminology System from Apelon, can support local terminology efforts.

After participating in this session, the learner should be better able to:

- describe the major standardized vocabularies for representing content in electronic health records (EHR), and their strengths and weaknesses;
- discuss reasons and approaches for managing local terminologies; and

- describe developments to will make managing standardized vocabularies and local terminologies in a system context easier and more efficient.

General description of panel

Healthcare has benefited from the increasing maturity, availability and implementation of standardized vocabularies, such as the International Classification of Diseases (ICD), the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT), Logical Observation Identifiers Names and Codes (LOINC), and RxNorm. Resulting benefits include enhanced interoperability, communication among health care providers, measurability of outcomes and reusability of data for various purposes. The implementation and integration of standardized terminologies into electronic health record systems (EHR) is fairly well-understood and common. Many standards developing organizations (SDO) are using well-structured and formalized processes for updating and maintaining their standards.

However, despite these developments, many healthcare organizations continue to maintain local terminologies. Reasons for this circumstance include the need to represent content not available in standardized terminologies, specific preferences and needs of clinicians, researchers and administrators, and the needs of local communities. In doing so, healthcare institutions, individually as well as collectively, expend significant resources on local terminology creation, maintenance and mapping to standardized vocabularies. The purpose of this panel is to describe current approaches to managing both standardized and local terminologies, elucidate challenges and opportunities, and discuss future-oriented strategies for making the process more efficient and effective. The panel will focus on issues such as:

- How useful and appropriate are major standardized vocabularies for representing content in EHRs? Where do they excel/fall short?
- Why would healthcare institutions need/want to maintain a local terminology?
- How are standardized and local terminologies managed together in the context of commercial EHR systems?
- What are good operational processes for implementing standardized vocabularies and, at the same time, creating/maintaining necessary local terminology/ies to achieve a smooth, integrated whole?
- What tools are available to manage local terminologies? How well do they work? Where do they fall short?
- How can the results of local terminology creation/management processes feed back to the "greater good", e.g. others who are engaged in the same kinds of efforts or standards developing efforts?
- What novel directions, such as crowdsourcing, exist for local terminology management?

Dan Vreeman will describe the history, purpose, and ongoing evolution of the Regenstrief Dictionary. The Regenstrief Dictionary is a homegrown terminology created in 1972 as a core component of the Regenstrief Medical Record System. Now, more than 40 years later, it has given birth to the most widely adopted standard for observations, LOINC, and continues a central role in the operation of the Indiana Network for Patient Care, the country's largest health information exchange. The Regenstrief Dictionary contains 46,000 concepts covering areas such as diseases, drugs, lab tests, nursing orders and survey questions/answers. Many of these terms are linked to standard vocabularies. However, we have become acutely aware of the need to evolve our strategy for managing our terminology needs. Current efforts duplicate much work that already has been done in standard vocabularies. In addition, the software applications

Regenstrief is developing would be more generalizable if they were written on top of standard vocabularies. Dr. Vreeman will present Regenstrief's current strategy for adopting standard terminologies while retaining advantages of local dictionary development. In this context, he will discuss challenges and opportunities for terminology management, personnel resources, needed software tools and collaboration with local healthcare institutions. He will also share lessons learned by "eating what we cook" from Regenstrief's unique role as both an SDO and end user of standard vocabularies.

Mark Tuttle will discuss tools and processes for terminology management, drawing on the example of the NLM Unified Medical Language System (UMLS) Metathesaurus. He will describe Apelon's product and service suite focused on support for local terminology efforts, including the Distributed Terminology System, an open source terminology server. Mark will illustrate terminology development, maintenance and deployment with examples from the National Cancer Institute, the Veterans Health Administration and the Department of Defense. He will review lessons learned from more than two decades of terminology mapping and describe emerging best practices in terminology mapping workflow management.

James Cimino will describe the history, current state, purpose of and strategy to evolve the Medical Entities Dictionary (MED) at Columbia University Medical Center and the Research Entities Dictionary (RED) at the NIH Clinical Center. Each of these is a homegrown terminology that contains the controlled terminologies used by clinical and clinical research systems in their respective organizations. Each consists of an ontological structure that includes a multiple hierarchy, a set of high-level organizing concepts, low-level terms used to code actual patient data, and knowledge concepts to support representation of additional knowledge. Development of the MED was begun in 1988 and includes over 160,000 terms. Development of the RED was begun in 2008 and includes over 280,000 terms. Dr. Cimino will describe how these resources adapt to new terminologies (including standards), remain current with existing terminologies, and support a variety of patient care and research functions.

Why the topic of this panel is timely, urgent, needed and attention grabbing

There is an inherent tension between increasing standardization of content in healthcare and the continuing need for representing local content. As more healthcare institutions adopt standardized vocabularies, their limitations, as well as the limitations inherent in maintaining/evolving them, become more apparent. Standard and local terminology management tend to consume a significant, but largely invisible, amount of resources at healthcare organizations. In an age of increasing cost reduction, institutions are looking for answers to solve this problem.

A list of discussion questions to enhance audience participation

- How many of you represent healthcare delivery organizations? How many of those use ONLY standard terminologies in the EHR?
- How much effort/money do you think you spend on local terminology creation, management and mapping?
- What are your main challenges in managing the implementation of standard and/or local terminologies?

All panelists have agreed to participate on this panel at #AMIA2014.