Interface Terminologies: Bridging the Gap between Theory and Reality for Africa

Andrew S. KANTER, MD MPH^{a,b}; Amy Y. WANG, MD^b; Fred E. MASARIE, MD^b;

Frank NAEYMI-RAD, PhD MBA^b; Charles SAFRAN, MD PhD^b ^a International Partnership for Health, NFP. Chicago, USA

^b Intelligent Medical Objects, Inc., Chicago, USA

Abstract. In the United States and Europe, electronic health records (EHRs) allow information technology and decision-support to facilitate the activities of clinicians and are considered an important component of health care improvement. However, actual adoption of EHRs by physicians has been slow and the use of decision support has been minimal. Part of the difficulty lies in the challenges that users face in capturing structured clinical information. Reference and administrative terminologies have been in use for many years and provide a critical infrastructure to support reimbursement, decision-support and data analysis. The problem is that physicians do not think and work using reference terminologies. Interface terminologies bridge the gap between information that is in the physician's mind and information that can be interpreted by computer applications. The maps from interface terminologies to appropriate reference terminologies enable advanced functionality in clinical information systems. The conflict between the need for timely adoption of health information technology and the need for standardization is also relevant to the problems faced by health information technology in Africa. The problem of clinicians having to communicate and/or record information in a format that is acceptable to someone else, somewhere else, leaves the true benefits of these systems beyond the reach of most in Africa. There is a growing effort in the United States to produce clinically-relevant interface terminologies mapped to standards. These interface terminologies can be expanded to incorporate the languages and clinical requirements of clinicians in Africa. The adoption of interface terminologies will help bring the value of standard terminology and the resulting benefits of decision-support, data analysis and information retrieval to parts of the world where they are needed most.

Keywords: Terminology-Vocabulary, Standards, EPR-CPR-EMR, Public Health Informatics, Africa

Introduction

Electronic health records (EHRs) are being implemented worldwide with the promise that they will not only dramatically improve the health care of individuals but also will expand knowledge about diseases and treatments, strengthen understanding about the effectiveness and efficiency of health care systems, and support public health. For health information systems to realize these benefits, however, two challenges must be overcome: 1) a critical mass of adoption must be achieved, and 2) different systems must be interoperable with one another. At a minimum, the data from these systems must be comparable. A paradox of some systems is that solutions that foster adoption may decrease interoperability, and vice-versa.

A key element in this conflict is the way terminology is used in health information systems. Standard terminology and structured data are a prerequisite for interoperability and sharing of medical information, decision-support and analysis. However, standard terminologies are unfamiliar and unnatural to most physicians, and as they struggle with applications that use them, they become frustrated. User adoption falls and errors can increase[ⁱ]. It has been estimated that in the US, adoption of EHRs is only 9-17% in ambulatory settings and only 12-20% in inpatient settings.[ⁱⁱ]

Can a highly usable terminology with links to reference terminologies and administrative classifications help solve both the problem of adoption and interoperability for both the developed and the developing world at once? We propose that it can and will introduce a program to test the hypothesis, called MGV-Net.[^{iv}]

1. Terminology about Terminology

Terminology is not just a list of names, or words, with numbers associated with them. A useful definition proposed by Chute which defines a terminology practically as: "that which enables users to invoke a set of controlled terms that correspond to formal concepts organized by a classification schema." [^v] We can then further break down terminologies based on their characteristics and purposes. One useful differentiation is between administrative terminology, reference terminology, and interface terminology.

Administrative terminology is used primarily for the classification of information and the administration of health care delivery or reimbursement. Two examples of administrative terminologies are the International Classification of Diseases (ICD) and the Current Procedural Terminology (CPTTM). ICD is maintained by the World Health Organization and has become a standard for epidemiological reporting and administrative purposes. The U.S. and other governments maintain enhanced versions of ICD, called clinical modifications, containing greater detail to represent diagnoses. CPT is published by the American Medical Association and used for describing procedures. Neither is well-suited for capturing clinical data for EHRs, but both have been widely adopted in non-clinical settings.[^{vi}] A reference terminology is a conceptbased, controlled medical terminology which allows for the complex organization and aggregation of clinical information. Examples include: the Systematized Nomenclature of Medicine–Clinical Terms (SNOMED®CT) and RxNorm.

Interface terminology, sometimes called *clinical interface terminology* or entry terminology, is used to describe lists of terms and phrases which are a "systematic collection of health care-related phrases (terms) that supports clinicians' entry of patient-related information into computer program, such as clinical "note capture" and decision support tools."[^{vii}] An example of interface terminology includes IMO's Problem (IT)TM (previously known as Personal Health TerminologyTM).

2. What Is Different about Interface Terminologies?

In 1998, Cimino published his Desiderata for Controlled Medical Vocabularies[^{VIII}] which was a seminal work outlining the requirements for a successful terminology. In 2005, in response to concerns that terminology needs to more closely mirror clinical

reality, he proposed additional desiderata. Whereas the original desiderata focused on the structure and content of controlled terminologies, the additional desiderata focus on the purpose and use of terminology (see Table 1).[^{ix}] This recognizes that how terminology is used is as important as what the terminology is. Reference terminologies do well for aggregation, reuse and inferencing, but suffer problems with properly capturing and retrieving information easily and accurately *with the least amount of information loss as possible.* These latter three desiderata require terminology more which clinicians use in everyday practice and which more closely approaches the level of specificity known at the point-of-care. This is the role of an interface terminology. An excellent review of interface terminology by Rosenbloom, et. al. provides an overview of the different requirements of interface and reference terminologies.[vii]

Table 1: Additional Desiderata for Controlled Medical Terminology

Creating and managing a clinical terminology is difficult, particularly when you consider that terminology must support clinical applications, mapping to administrative and epidemiological coding schemes, and include multiple languages.^[x] Traditionally, the overarching design of terminologies included maps from reference terms to all other terms, including administrative classifications (see Figure 1 left). This was the most efficient method as different synonyms could then be mapped only once (to the reference term) and all subsequent maps would follow from the reference term. The difficulty arises when coding experts review the term-administrative code maps.



Figure 1: Traditional mapping between synonyms, reference terminology and administrative codes (left) Recommended organization with separate validated maps to administrative codes (right).

To ensure that coding is accurate, display terms should have explicit maps to administrative terms. For medico-legal reasons, the actual term chosen should have its mapping explicitly validated by a reputable organization like the American Health Information Management Association (AHIMA) (see Figure 1 right). This does not mean that interface terminologies should not be organized around concepts. It only suggests that the conceptual granularity of an interface terminology is often different that the reference terminology to which it is mapped. Interface terms still should have maps to concepts to ease updates and maintenance.

Interface terminologies should also be integrated with or have explicit maps to a reference terminology. Without the aggregation that is possible from a mapping to a reference terminology, there can be no consistent application of decision support and

analysis. The number of interface terms vastly complicates the visual representation of the data. It is much more feasible to write reports and decision-support rules against a parent reference term than all of the descendent reference terms plus.

However, reference terminologies frequently are missing concepts at relevant levels of clinical specificity. For example, SNOMED CT currently does not have reference terms for mild persistent asthma or mild intermittent asthma. However, these terms are in common use and are typically required for appropriate documentation and care of patients with asthma. Therefore, interface terms were created and mapped to the most relevant reference term(s). When more specific reference terms are subsequently added to SNOMED CT, the mappings from the interface terminology to SNOMED CT require updating, but terms used by clinicians (and front-end applications) would not have to change (see Figure 2).



Figure 2: Remapping occurs when new reference terms are added.

3. Benefits of Interface Terminologies

Explicit interface terminologies such as PHT have been shown to markedly improve clinician satisfaction with EHRs in the US. The explicit mappings to reference terminologies have also advanced adoption of SNOMED CT. [xi] Centralizing the customization and maintenance of the interface terminology eliminates local terminology requirements and their resulting non-interoperable systems. The ability to rapidly add terms with the right level of clinical specificity satisfies user needs and allows application developers to implement systems and functionality quickly. In addition, common users of an interface terminology can share data using either Traditionally, site-specific terminologies exist as interface or reference terms. extensions to the reference terminology and remain site-specific pending addition of those terms to the reference terminology. They would remain site-specific permanently if the terms ultimately were not submitted or accepted.[xii] The usability benefits of interface terminologies when combined with the standards and structure of reference terminologies should significantly improve adoption of health information systems, particularly EHRs.

4. Health Information Systems in Africa: Unique Needs

It would seem obvious that the rationale for using appropriate terminology in health information systems applies to Africa as it does for the US and Europe. This would be true, but there are particular conditions in which terminology is even *more important* for implementation in Africa. Although Africa has large English-, French- and Portuguese-speaking groups, there are numerous linguistic differences at the country and local levels. Significant differences exist in the names of specific disease entities, medications, and laboratory tests. Although Ministry of Health reporting for individual countries is frequently in one of the European languages mentioned above, local clinicians and providers who are recording the data may not speak these fluently. Conversely, clinicians trained in European languages may not be fluent in the languages used by their patients.

The gap between recording the information from the patient and what eventually arrives in the end as information, either locally or at ministerial level, is significant. Capturing knowledge in a manner in which it contains the most information is important, not only for the reasons propositioned by Cimino[ix], but also because much indigenous knowledge is being lost. Experience of health care providers in Africa is fragmented and knowledge is locked away in unanalyzed paper records and reports which take years to make their way to government where they are frequently ignored.[^{xiii}] Information technology should support the collecting and preservation of this knowledge, rather than suppress it.[^{xiv}] If terminology can help capture clinical experience accurately and quickly, it can then be put to use at the local and national level. Capturing the data using a method which incorporates reference terminology would make it possible for countries to share their knowledge of the status of health, disease and the effectiveness of interventions. In particular, the experience of neighboring countries would be more relevant to Africa providers and policy makers than data available from developed countries.

The need for information technology in the developing world is great. Effective implementation and application of health information technology will likely be required if any significant progress is to be made against the devastation of HIV/AIDS, tuberculosis and malaria.^[xv] The World Health Organization in its World Health Report 2006: Working Together for Health[xvi] identified the shortage of trained health workers as one of the most important obstacles to strengthening health care systems in developing countries. As health care providers in Africa are frequently undertrained and overworked, health information systems can help extend their efforts by improving efficiency, and the quality of care can be improved through the use of appropriate guidance and information. There are many obstacles to successful design and implementation of these systems in Africa, which have been previously described. One challenge is that systems designed for US and European health facilities may not be applicable in rural and urban developing countries. Terminology has been identified as an important barrier^{[xvii}], and a properly implemented interface terminology has the potential to solve this problem. Taking evidence-based experience from other African situations and applying them within the information system holds promise for improving quality and helping to train providers in resource-poor settings.

However, the inclusion of medical terms in local languages, important for an interface terminology, is difficult and requires access to experts and reference materials.[^{xviii}] To test whether it is possible, the Millennium Villages[™] Project (MVP) is building a network of health information systems called the Millennium Global Village Network (MGV-Net). MVP is the product of five years of intensive preparation by hundreds of scientists and development experts and works in eleven countries throughout Africa to help people lift themselves out of extreme poverty. MGV-Net uses a common data dictionary based on reference terminologies (SNOMED CT, LOINC and RxNorm), but employs a centralized Terminology Service Bureau (TSB) to manage an interface terminology distributed throughout the network.

The TSB is a critical component of the MGV-Net and maintains all terminology additions and mappings. To begin the process, a workbook identifying the most common diseases, diagnostic tests and medications was sent to all MVP villages for translation. Clinicians in each of the MVP countries will work together online as part of the TSB to update the database.

5. Conclusions

We began this paper with a discussion about how interface terminologies are different from reference terminologies, and why interface terminologies are necessary for adoption of health information systems in the developed world. We ended by extending the value of these terminologies to Africa, and showed that it was even more important to the success of health information systems in developing countries. Capturing data in a culturally-sensitive manner, incorporating populations frequently missed by traditional information systems is important to an equitable health system and even a human right. [^{xix}] The challenge is great for those working to alleviate poverty and improve health for those who most need it. We hope that health information systems which employ appropriate interface terminology to bridge the gaps between theory and reality will help overcome that challenge.

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