Healthcare Terminologies and Classifications:

An Action Agenda for the United States

American Medical Informatics Association
and American Health Information Management Association
Terminology and Classification Policy Task Force

AMIA   AHIMA

Acknowledgements

AHIMA and AMIA Terminology and Classification Policy Task Force Members

Table of Contents

3

This white paper is a revised version of a paper originally released by AHIMA and AMIA in 2006.

Executive Summary

Terminologies and classifications form the foundations of information content in the electronic health record (EHR) and are the basis for research, public health reporting, and healthcare payment.[1] They are integral to interoperability and, thus, a successful national health information system that promises increased patient safety and reduced costs.

Although there has been significant progress in the United States to better understand the role terminologies play in our health information systems, and to make terminologies more broadly available in machinable forms, more must be done to ensure that this progress serves as a robust foundation for the information content of the EHR.

The healthcare industry–including the government, professional organizations, public and private institutions, and health informatics and information management professionals– must address the issues before the US healthcare system is marginalized. To not do so would mean continued reliance on poor-quality data for decision making and the spending of dollars to retrofit a system that is obviously broken.

This report describes challenges that require action. It proposes the formation of a centralized terminology authority, and other steps, to address these challenges.

Task Force Vision and Recommendations

The American Medical Informatics Association (AMIA) and the American Health Information Management Association (AHIMA) are pleased with the progress made thus far and are committed to the development of the emerging national health information system. But both organizations recognize that additional resources and appropriate funding are needed to build on initial work for healthcare terminologies and classifications strategy, governance, and development and maintenance processes.

To address these issues, AHIMA and AMIA convened a Terminology and Classification Policy Task Force composed of experts in medical and nursing informatics (a field that studies the support of medicine by information systems), health information management professionals, experts in nosology (the branch of medicine that deals with the classification of diseases), and educators. The group's goal was to develop recommendations for the major challenges that would help establish a process that results in interoperability. The Task Force has formulated a vision and associated goals and recommendations that it hopes will be used to frame a public-private dialogue about how to redesign the US approach to healthcare terminologies and classifications against a backdrop of international approaches and achievements.

The vision consists of the following:

- US governance occurs from a national perspective against a backdrop of international agendas.

- US policy coordinates with other countries, and the US actively collaborates and shares costs.

- Coordination and collaboration occurs with international terminology and classification development and maintenance initiatives.

4

---

1. For purposes of this report, an EHR is defined as an information system designed to provide access to complete and accurate clinical data, practitioner alerts and reminders, clinical decision support systems, and links to medical knowledge. Giannangelo, K. (Ed). *Healthcare Code Sets, Clinical Terminologies, and Classification Systems*. AHIMA. [Note: Within this definition, a personal health record (PHR) only qualifies as an EHR if it is part of an EHR having the identified capabilities.]

- Terminologies, classifications, and maps form a coherent set of policies and procedures for openness and ensured performance.

- Transparency of process exists even when the development organization maintains the system within its own organization.

- Infrastructure for development and maintenance of the terminology is subject to an open process.

- Business process automation is implemented, allowing organizations to participate and track the terminology and classification development processes, reducing cost, and automating many aspects of the system release cycles.

To implement this vision, the Task Force recommends that the healthcare industry—government, public and private institutions, and professional organizations—collaboratively undertake the following tasks:

- **Create a publicly funded research and development project** to prepare specifications for coordinated solutions and where possible, consolidate terminology.

- **Secure funding for the planning and development of a centralized authority,** representing both public and private stakeholders, to manage the funding and be responsible for overseeing US terminology and classification development and maintenance, including the supporting systems.

- **Develop a governance model** for the central authority that is accountable to the needs of the end users and implementers, and also has accountability for the funding of the central authority.

- **Commit to the adoption of sound principles for operation of a terminology and classification standards development organization.**

The Task Force believes that the items on this agenda must be accomplished. To this end, AHIMA and AMIA are ready to lead, in concert with the appropriate government agencies, the US effort for terminologies and classification reform. They recognize the US agenda for health information reform will require strong public and private collaboration. In the months to come, AHIMA and AMIA will convene stakeholders to build a broader understanding of the current problems, generate wide support for, and begin to construct a road map for change.

5

Healthcare Terminologies and Classifications: An Action Agenda for the United States

Background

Healthcare classifications (systems that arrange together similar diseases and procedures and organizes related entities for easy retrieval) and clinical terminologies (standardized terms and their synonyms that record patient findings, circumstances, events, and interventions) are the systems that describe, organize, and standardize the rapidly evolving language of medicine. In addition, terminologies and classifications form the information content in the electronic health record (EHR) and the personal health record. They are the basis for public health reporting, performance measurement and quality reporting, research, and billing and payment for healthcare services. They are integral to interoperability, and thus, to deployment of a nationwide health information network (NHIN) capable of delivering on the promise of safer and more cost-effective results.

An NHIN and the interoperable exchange of health information between standard EHRs of healthcare data depend on:

- Clinical content identified with clinical terminologies, which maintain highly specific and descriptive patient care data and classifications for aggregate reporting that can be reliably captured, encoded, exchanged, and interpreted

- Common information models

- Management and coordination of the various terminology and classification systems in a synchronized fashion for a streamlined life cycle

How Terminologies and Classification Systems Are Used

Clinical terminologies and classification systems have been in use for many years—for example, the International Classification of Disease (ICD) was created in the 19th century as a way to identify the causes of death. The Systematized Nomenclature of Medicine (SNOMED) began as an enhancement to the Standard Nomenclature of Diseases and Operations, first published in 1965 and used to organize information from surgical pathology reports.

In addition to their lengthy history, terminologies and classifications can be used in different ways. For example, terminologies are used primarily to capture clinical information. As such, they are highly detailed and have substantial granularity, but at the same time they lack reporting rules and guidelines.

Classification systems are intended for secondary data use, including quality of care measurement, reimbursement, statistical and public health reporting, operational and strategic planning, and other administrative functions. While reporting rules and guidelines for administrative code sets exist, not everyone is following them.

In the United States, the most commonly used systems are the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) and the Current Procedural Terminology (CPT®). These systems are used to organize specific diseases and procedures in a general classification schema. This allows the specific diseases and procedures to be grouped into more broad-based categories and then used for reimbursement (ICD-9-CM codes to

Diagnosis-Related Groups), quality of care measures (ICD-9-CM codes to patient satisfaction rankings), or resource utilization measures (CPT codes to cost of care). Because classification systems are considered broader ways to classify specific diseases and procedures, they are not the most appropriate system to use to identify and capture the clinical aspects of an episode of care.

For example, in ICD-9-CM and its 10th revision, ICD-10-CM, a hospital stay for a newborn is represented by codes identifying the type of birth (that is, live-born infant, single or multiple births, born in hospital or outside of hospital, and vaginal versus cesarean delivery) and medical conditions or risk factors the infant may have. In contrast, SNOMED CT® codes provide the complete clinical detail for a healthcare encounter. The Apgar score (an assessment of the physical condition of a newborn infant), for example, would be represented by separate SNOMED CT® codes for the cardiac score, respiratory score, muscle tone, reflex response, and color.[2]

Together, terminologies, such as SNOMED CT®, and classification systems, such as ICD-9-CM, ICD-10-CM, and ICD-10-PCS, provide the common medical language necessary for the EHR and for population health reporting, quality reporting, personal health records, safety, clinical trials, biosurveillance, and reimbursement.

Terminologies, Classifications, and Information Models

But simply having a list of relevant words is not the same as representing all the relevant data in a computable form. The process of data or information representation begins with information models, not just the terms and codes alone. For clinical data representation, a library of shared models linked to value sets drawn from standard coded terminologies and classifications is needed. This means resolving issues related to the interface between information models.

Both the National Committee on Vital and Health Statistics (NCVHS) and the Institute of Medicine have noted that standard representation of the full meaning of patient medical data requires integrating terminology models with models of context and other structural relationships.[3,4] The NCVHS has also concluded when patient medical record information standards do not include a comprehensive information model and terminology model, mapping is made more difficult.

Terminologies, Classifications, and Mapping

Mapping is a process that links the content from one terminology or classification scheme to another.[5]

Many factors within the healthcare industry are driving mapping technology, including the movement to adopt EHRs and create a NHIN.[6] Efforts to control increased administrative costs within healthcare are also a factor. The shortage of qualified coders increases costs and inefficiencies. These issues exacerbate the need for computer-assisted coding (the automatic generation of codes based on clinical documentation) and the use of mapping technologies to increase productivity and coding consistency. Today, computer-assisted coding and mapping systems are an achievable vision for the future, but there is still some way to go.

7

---

2. Dougherty, M. "Standard Terminology Helps Advance EHR." *Journal of AHIMA* 74, no. 10 (2003): 59-60.

3. National Committee on Vital and Health Statistics. Patient medical record information terminology analysis reports. 2002.

4. Institute of Medicine. "Key Capabilities of an Electronic Health Record System." Letter Report of the Committee on Data Standards for Patient Safety, Board on Health Care Services, Institute of Medicine, 2003.

5. Available at www.nlm.nih.gov/healthit.html.

6. Available at www.nlm.nih.gov/healthit.html.

An EHR that can map from a reference terminology to a classification system is rare. There are currently no nationally or internationally recognized standards for map development and validation. In addition, there is a lack of coordination among terminology and classification development organizations, which inhibits the development of maps. There is also no standard definition of a "valid" map. Iterative research and development is needed, along with testing in real environments, to achieve a usable map.

The NLM has taken a lead in this important area and has made maps from SNOMED CT® to ICD-9-CM, SNOMED CT® to CPT, and a LOINC to CPT preliminary draft available. These maps can serve as a starting point for the development of standards and for testing the utility of different mapping approaches.

Magnitude of the Problem

The terminologies and classifications life cycle—in particular, development, distribution, and maintenance—is complex. This complexity causes problems for all who deal in some form or another with them. There are a relatively small number of vendors, and existing systems are not able to seamlessly exchange information with other systems. This makes commercial offerings challenging and creates a high risk of vendor lock in[7] and significant susceptibility to vendor failure. In addition, no comprehensive open source development environment exists, resulting in

authoring environments that are not sufficiently responsive to improve the creation and revision of terminologies. The outcome is the creation of content in the system based on a defined need rather than desirable characteristics of a controlled clinical terminology.[8] Current terminology efforts typically do not meet rudimentary development practices considered routine for software development in other industries or subject domains. Terminology systems also probably do not meet Food and Drug Administration standards[9] for embedded software—yet many should.

The situation is complicated by the lack of business process automation[10] across organizations or departments for updating or maintaining the terminology. Even a single organization is required to use multiple tools if it is to function today. Appendix A illustrates this complexity for four healthcare organizations.

Adoption and implementation are in themselves complicated issues, with many governing bodies determining what system should be adopted and implemented. In addition, while there have been discussions about the basic principles for maintenance and what the ideal process should look like, attributes and standards for terminology development and maintenance processes have not been brought forth, discussed, or agreed to by the principal stakeholders—that is, the owners of the terminologies and classifications and the users of the systems. Simply finding out what systems already exist, what they are

---

7. Wikipedia states vendor lock-in is a situation in which a customer is so dependent on a vendor for products and services that he or she cannot move to another vendor without substantial switching costs, real and/or perceived.

8. Cimino, J. "Desiderata for Controlled Medical Vocabularies in the Twenty-First Century." *Methods of Information in Medicine* 37 (1998): 394-403.

9. Many of the regulations enforced by the Food and Drug Administration (FDA) with regard to medical devices can be found in Title 21 Code of Federal Regulations (CFR) Part 800 to Part 1299. The information required in a 510(k) submission is defined 21 CFR 807.92. Among the list of 510(k) submission requirements is software development, verification and validation information.

10. Wikipedia states business process automation is the process of integrating enterprise applications, reducing human intervention wherever possible, and assembling software services into end-to-end process flows.

used for, when they were adopted and implemented, who maintains them, and what the release cycles are can be an onerous task.

Today's proprietary standard development models hamper development and maintenance of terminology standards by prohibiting open publication of content. Terminology systems are significantly lacking in any principled approach to validation and quality assurance.

Despite its essential need, insufficient funding has also plagued the development and maintenance of clinical terminologies and classifications for years. The bulk of the work is done by volunteers—experts in medical and health informatics, health information managers, and experts in nosology (the branch of medicine that deals with the classification of diseases).

Other widely acknowledged problems include:

- The lack of sufficient incentives to cooperate

- Systems are seen as independent when they are highly interdependent

- A general lack of understanding of how encoded data can support initiatives such as quality or patient safety in the healthcare environment

The Vision and Goals for the US

The American Medical Informatics Association (AMIA) and the American Health Information Management Association (AHIMA) are pleased with the progress made thus far and are committed to the development of the emerging national health information system. But both organizations recognize that additional resources and appropriate funding are needed to build on initial work for healthcare terminologies and classifications strategy, governance, and development and maintenance processes.

To address these issues, AHIMA and AMIA convened a Terminology and Classification Policy Task Force composed of experts in medical and nursing informatics (a field that studies the support of medicine by information systems), health information management professionals, experts in nosology, and educators. The group's goal was to develop recommendations for the major challenges that would help establish a process that results in interoperability. The Task Force has formulated a vision and associated goals and recommendations that it hopes will be used to frame a public-private dialogue about how to redesign the US approach to healthcare terminologies and classifications against a backdrop of international approaches and achievements.

The Vision: The Task Force's vision of the ideal state for terminologies and classifications takes into account key issues including governance, licensing, and the methods used in the terminologies and classifications life cycle—specifically, development, distribution, and maintenance. It consists of the following:

- US governance occurs from a national perspective against a backdrop of international agendas.

9

- US policy coordinates with other countries, and the US should actively collaborate and share costs.

- Coordination and collaboration occurs with international terminology and classification development and maintenance initiatives.

- Terminologies, classifications, and maps form a coherent set of policies and procedures for openness and assured performance.

- There is transparency of process even if the development organization maintains the system within its own organization.

- The infrastructure for development and maintenance of the terminology is subject to an open process. The characteristics of this process include:

    - Any classification algorithms required to transform terminology stated forms into inferred forms are publicly described and free of patent royalties so that any party may implement a terminology-capable classifier unencumbered.

    - Interfaces to the terminology development infrastructure (automated term submission process, automated update services, terminology configuration management services, and terminology authoring services) are publicly described and licensed under an open source agreement such as the Apache 2 license.[11] An open source license is meant to ensure that any party can freely develop software that can interact with or replace components of the terminology development infrastructure unencumbered by licensure fees, patent royalties, or from other

licensing restrictions that may require commercial organizations to disclose their proprietary source code. A license that requires a vendor to open their source code, such as the GNU (free software) style licenses, is inappropriate.

    - Any fees associated with mandated infrastructure necessary to implement the standard are under regulatory control to assure that fees to support the infrastructure are not diverted.

- Business process automation that allows organizations to participate and track the terminology development process, reducing cost and automating many aspects of the terminology release cycle is put in place.

The Goals: The goals of a coordinated policy for the US that enables the Task Force vision builds upon lessons from national and international efforts in three areas: (1) governance, (2) development and maintenance, and (3) acquisition, licensing, and implementation issues.

Governance

The Task Force recommended the establishment of a centralized oversight authority to accomplish these governance goals:

- Ensure consistency in processes, system coordination, responsiveness to end users (vendors and those who use their systems), and the availability of robust, valid maps.

- Adoption of uniform rules, regulations, and guidelines for standardized terminology and up-to-date classification systems across the country.

11. Available at http://www.apache.org/licenses/LICENSE-2.0.html.

- Ensure that the organizations authorized to develop, deploy, and maintain such standards and guidelines assume ongoing responsibility to provide clarity with a specific standard or guideline as required, publish and disseminate the standards or guidelines in a manner that is generally understood, and respond in a timely manner to all requests for clarification of standards or guidelines.

Simplifying Governance

Meeting this goal will require changes in the way in which the US governs terminologies and classifications. In the US, there is no centralized oversight of terminologies and classifications. Terminologies and classifications have their own governance process dictated by the organization who "owns" the system. Table 1 provides a summary of the owners and governance processes for various terminology systems currently used in the US. In many cases, the governance process is strictly an internal function of the terminology development organization with little detail available publicly. In a few cases, the governance process includes oversight by a committee composed of users and other stakeholders. The fragmentation illustrated in Table 1 prohibits interoperability. The number of systems in existence and the resulting acronym alphabet soup make apparent the existing complexity of governance.

An important consideration when choosing to integrate a component such as a terminology is to understand the governance model of the organization providing the component, either via license or through contribution to the public domain. For example, the problem with third-party control is particularly challenging for SNOMED CT® because the governance of SNOMED CT® development and licensing policies has been subject to approval by the CAP board of governors, not by the end users or licensees of the SNOMED CT® terminology standard. In contrast, HL7's board of directors is elected by the HL7 members and is fiducially bound to serve their interests. The proposed

formation of a new SNOMED SDO outside of CAP most likely will resolve this important governance issue.

Fragmentation of the governance process is also illustrated by the current situation with the ICD. While the National Center for Health Statistics (NCHS) maintains the US clinical modification if ICD-9-CM and ICD-10-CM for diagnosis coding, the Centers for Medicare and Medicaid Services (CMS) are responsible for development and maintenance of the procedure coding systems. While subject to a single coordination and maintenance committee, coordination of these two essential dimensions could and should be strengthened.

Recognizing that the US could learn much from other countries that have already redesigned their governance and support processes for terminologies and classifications, the Task Force studied the approaches taken by Canada, Australia, and the United Kingdom. Details for each country are found in Appendix B.

Development and Maintenance

The Task Force identified the following goals for terminologies and classifications development and maintenance:

- The infrastructure for development and maintenance of the terminology is subject to an open process. The characteristics of this process include:

  - Any classification algorithms required to transform terminology stated forms into inferred forms are publicly described and free of patent royalties so that any party may implement a terminology-capable classifier unencumbered.

  - Interfaces to the terminology development infrastructure (automated term submission process, automated update services, terminology configuration management services, and terminology authoring services) are

11

publicly described and licensed under an agreement at least as open as the Apache 2 license.

- Any fees associated with mandated infrastructure necessary to implement the standard are under regulatory control to assure that fees to support the infrastructure are not diverted.

• Robust methods for certifying terminology systems for use in patient-care applications are developed. These robust methods are patterned after those developed for other software components, whose failure may result in loss of life, such as the DO-178B "Software Considerations in Airborne Systems and Equipment Certification." Adapting that specification for terminology requires the terminology development organization to provide at least the following:

- Certification plan

- Development plan

- Verification plan

- Configuration management plan

- Requirements standards

- Design standards

- Verification cases and procedures

- Verification results

- Problem reports

- Configuration management records

- Quality assurance records

Need for a Standard Process

In comparison to the above goals, presently the US healthcare industry has no standard process for the development of terminologies and classifications. Typically, the processes for terminology and classification development vary, generally depending on the size of the development organization and the purpose of the standard. This variability is evident in Table 2.

Many systems are developed by professional associations and academic institutions, while others are developed by government agencies. Some organizations follow relatively formal sets of processes for developing and refining concepts, such as reliance on an editorial board for approval, whereas other organizations' processes may be informal. In addition, developers may create new terms at will without a formal or open process with input from the users of the system.

Each organization or developer determines their own maintenance process, and update schedules vary considerably. The level of resource commitment to ongoing system maintenance also varies, which in turn influences the maintenance process and the frequency of updates. In some cases, maintenance is handled entirely by the system developer, while in other cases, a committee of industry experts oversees the maintenance process.

Meetings to address maintenance issues may be open to the public or may be private. For those processes that include open meetings, final decisions regarding system modifications may be made privately rather than during the open meeting. Some processes allow submission of requests for modifications from any source, whereas others place restrictions on requesters. As shown by the variability in the level of detail outlined in Table 2, terminologies even vary in the level of transparency regarding their maintenance processes.

There is also considerable variability in the timing of the release of terminology or classification system modifications and their effective dates. As Table 2 shows, some terminologies do not have an established update schedule. And variability in the method of publicizing the modifications is an issue as well. For example, some systems are updated annually, others biannually, and still others are updated quarterly or even more frequently. Even for those systems that are updated annually or biannually, the effective dates still

differ. The variability in maintenance schedules is not purposeful or useful, as it increases the cost and complexity of using terminology and classification systems and keeping them up-to-date.

In some cases, a change in the system update schedule would require legislation. For instance, federal law mandates the implementation of ICD-9-CM updates on October 1 and CPT updates on January 1 for the use of these systems in the Medicare program. There is no central Web site for accessing system updates or an established, standardized process for notifying the healthcare industry of an update release.

The "official" source of clarification for using a particular terminology or classification and the process for obtaining an "official" answer are not always clear. The integrity of coded data and the ability to turn it into functional information require the use of uniform standards, including consistent application of standard codes, code definitions, and reporting requirements. In Table 2, the system developer is generally listed by default as the official source for clarification because there is no other identified source.

In many cases, there is no clearly defined process for obtaining clarification. As a result, obtaining guidance on the proper use of a terminology or classification is sometimes difficult, time-consuming, and expensive. To add to the complexity, there may be more than one official source for a system—for example, the American Medical Association is recognized as the source for information on the proper use of CPT codes for physician providers; however, the American Hospital Association is the official clearinghouse for hospital providers[12]

Acquisition, Licensing, and Implementation

The Task Force identified the following goals for terminologies and classifications acquisition and implementation:

- A licensing model that embraces the following:

    - More inventiveness, not the promulgation of monopolies (even nonprofit or regulatory ones) that stifle innovation and hamper collaboration

    - Open standards to overcome the challenges and standards development organizations that better serve the healthcare community needs by providing open standards

- Business process automation that allows organizations to participate and track the terminology development process, reducing cost, and automating many aspects of the terminology release cycle is put in place.

- Establishment of funds for healthcare standards in ways that do not rely on revenue generated by selling the standards themselves.

Acquisition and Licensing
The way in which licensing is done today is a far cry from the goal. Similar to the systems discussed in the previous section, healthcare standards that structure terminologies and classifications are developed by various organizations. These organizations are typically not for profit; however, the standards they produce are almost always released under proprietary licenses[13] along with fees—even though the efforts to produce those standards are often provided by resources external to the standards organization itself.

13

---

12. Available at www.ahacentraloffice.org/ahacentraloffice/html/coding_advice/hcpcs/index.html.

13. Wikipedia states that proprietary indicates that a party, or proprietor, exercises private ownership, control or use over an item of property, usually to the exclusion of other parties.

Take the case of standards development organization Health Level Seven (HL7). It has placed all intellectual property of its standards into the public domain; however, it retains the copyrights to published standards and sells the documents as a revenue-generating mechanism to help sustain the organization. The HL7 license requires that the specification documents must either be purchased or be available only to members who have limited ability to redistribute them to their customers. This inability to redistribute specifications has had a direct influence on the development and distribution of open source implementations of HL7 specifications, since the specifications of those implementations cannot be distributed to a group of potential implementers who are not HL7 members. Open posting of development content is thereby not allowed.

Even Logical Observation Identifiers, Names, and Codes (LOINC), a database protocol aimed at standardizing laboratory and clinical codes,[14] charges no license fee for allowed uses but has specific use restrictions. The LOINC Committee has retained the copyright to its content so that it maintains editorial control of the content. It prohibits LOINC content to be used to make a competing coding system for observations.[15] These restrictions prevent development or enhancement of other products in ways that may promote interoperability because the other products may be regarded as "promulgating a different standard" and therefore is prohibited by the LOINC license. For example, it would be a violation of the LOINC license to map LOINC into an existing terminology by assigning a new identifier to the LOINC code and creating the appropriate linkages to the concepts in the existing terminology. The inability to create linkages in this way is a barrier to creating true interoperability between LOINC and other important clinical terminologies.

The SNOMED CT® license is not standardized, and different organizations have different rights and responsibilities depending upon their particular license. The NLM version of the SNOMED license prohibits distribution of SNOMED content outside the US, and it also prohibits modification of SNOMED "core content." These restrictions make open collaboration around SNOMED-based content challenging for some and untenable for others. Many organizations are reluctant to engage in such collaboration when a third party is able to exercise unilateral control over content they may develop a dependency upon—*even when that content is based upon their own work*. The new SDO may remove some of the barriers to broader community participation in the enhancement and expansion of SNOMED CT®.

There are two types of CPT licenses, depending upon whether CPT codes will be used in a product that will be sold or distributed to others or whether CPT will only be used within a company and will not be redistributed. In both types, the license fee structure is per user. A user is defined as an individual who directly accesses CPT data in a product or, in the case where CPT is embedded in a product and not directly accessible, relies on embedded CPT data to perform his or her intended function with the product or its output. These license requirements increase the cost of products containing CPT content and inhibit widespread use of CPT. Also, determining the number of CPT users for the purposes of license fee calculation can be difficult.

---

14. See www.regenstrief.org/medinformatics/loinc/.

15. Available at www.regenstrief.org/loinc/license/. To prevent the dilution of the purpose of the LOINC codes and LOINC table of providing a definitive standard for identifying clinical information in electronic reports, users shall not use the RELMA program, RELMA Users' Manual, RELMA database, LOINC Users' Guide, LOINC database, LOINC table or related files, or the LOINC codes for the purpose of developing or promulgating a different standard for identifying laboratory test results, diagnostic study reports, clinical measurements and observations or orders for these entities in electronic reports and messages.

Even the NLM's Unified Medical Language System (UMLS) Metathesaurus, which serves as an official distribution vehicle for HIPAA standard code sets and US government target clinical vocabulary standards, requires a license. While content may be used with few restrictions, some vocabularies require separate agreements, which may involve fees, with the individual vocabulary producers.[16]

There are various justifications for resorting to proprietary licenses. These justifications range from "we must get revenue to support development of the standard" to "we must prevent fragmentation of the standard." Unfortunately, consequences of relying on proprietary licenses include deliberate or inadvertent creation of monopoly positions by standards development organizations and licenses that stifle opportunities for innovation.

Experience with open source software and the World Wide Web development have shown that licensing restrictions are not helpful—and are also not necessary to prevent fragmentation of the standard. The HTTP protocol and the success of the World Wide Web consortium (W3C) are successful and compelling demonstrations of the potential of alternative approaches. All W3C documents are under an open license that provides permission to copy or distribute, in any medium, for any purpose, without fee or royalty.[17] W3C operations are supported by a combination of member dues, research grants, and other sources of public and private funding. W3C operations do not rely on revenue from the specifications of the standard itself.

Eben Moglen, professor of law at Columbia Law School, states that open source software provides a "freedom to invent, not reinvent— not invent over again something someone else had invented and locked up, but invent in the way that inventing was done in the great spurt of 19th-century inventiveness."[18]

The recent dispute between two SDOs, HL7 and ASTM International, over ownership of ideas contained within the ASTM Continuity of Care Record (CCR) and the HL7 Clinical Document Architecture (CDA) is an example of challenges that are created when standards organizations do not publish their works under open licenses. Organizations should focus on innovation and building on the foundations provided by others. They should not be permitted to compete with each other for proprietary advantage.[19]

Implementation

Implementing terminologies and classifications is not an easy task. Distribution is part of what makes it difficult. Terminologies are usually distributed through the developer or a middle-ware software or system application vendor. With more than 100 terminology and classification systems, the communication of releases and updates affects the ease with which vendors can incorporate them into products for distribution.

For example, the NLM's UMLS has been designated as the central coordinating body within the US Department of Health and Human Services for patient medical record terminologies.[20] Coordination means the following:

- Uniform distribution of designated standard vocabularies through the UMLS Metathesaurus

- Reducing peripheral overlap and establishing explicit relationships between standard clinical vocabularies (for example, SNOMED, LOINC, RxNorm)

15

---

16. Available at www.nlm.nih.gov/pubs/factsheets/umlsmeta.html.

17. Available at www.w3.org/Consortium/Legal/2002/copyright-documents-20021231.

18. Available at http://news.com.com/Open-source+politics+are+American+as+apple+pie/2100-7344_3-6079401.html.

19. Available at www.healthcareitnews.com/story.cms?id=1292 and http://www.healthcareitnews.com/story.cms?id=3076.

20. Available at www.ncvhs.hhs.gov/040922lt.pdf.

- Aligning standard clinical vocabularies with standard record and message formats

- Mapping between standard clinical vocabularies and administrative code sets and/or other important vocabularies[21]

While the UMLS was envisioned as a distribution mechanism for clinical terminologies and classifications, it is not a major distributor because of publication delay and difficulty in extracting data formats. In addition, the UMLS is not governed by a mechanism that is directly accountable to implementers and EHR developers, which may help explain why they are going elsewhere for terminology content. Implementation therefore is made complicated as most vendors go to the source, or owner of the system, because of delay and complexity of user formats.

What to Do Next

The Task Force's recommendations call for funding to support the planning and development of an entity that would serve the public interest. This centralized authority, representing both public and private stakeholders, is expected to manage funding and be responsible for overseeing US terminology and classification development and maintenance policies.

There are many challenges for the healthcare industry—government, public and private institutions, and professional organizations—with regard to moving forward. A collaborative undertaking will be the key to success with the following:

1. Create a publicly funded research and development project to prepare specifications for coordinated solutions and where possible, consolidate terminology. The critical elements for the plan include policy, governance,

standards adoption, legal issues including licensing, technology, data integrity requirements, maintenance, education and conformance testing, and a road map for change so public and private industry sectors understand the goals, target, and the required actions.

The main objectives of this work would be to continue the work of the Task Force in partnership with the Office of the National Coordinator for Health Information Technology (ONC). AHIMA and AMIA will also coordinate with Healthcare Information Technology Standards Panel (HITSP) to harmonize work. The work will initially focus on research to identify a governance model and funding sources for the central authority. Thus, a significant part of the plan **would be the development of a governance model for the central authority** that is accountable to the needs of the end users and implementers, and also has accountability for the funding of the central authority. It will pursue recommendations that emerge from the research and development project outlined above. Australia's model has a number of desirable features. However, governance must also formally include care providers and other end users. It need not be a government responsibility—a quasi-governmental entity might meet this need quite adequately if permanence of the structure can be ensured.

In addition, moving from the current ineffective and fragmented strategy for adoption and maintenance of terminologies and classifications to a more efficient system will require a series of actions and long-range change strategies. Therefore, an additional outcome will be a road map for change so public and private industry sectors understand the goals, target, and required actions.

---

21. Available at www.nlm.nih.gov/nichsr/2005_NCVHS_July.ppt.

2. Secure funding for the planning and development of an entity that would serve the public interest.[22] A centralized authority responsible for overseeing US terminology and classification development and maintenance, including the supporting systems, is critical. Such an entity would represent both public and private stakeholders, manage funding, and be responsible for overseeing US terminology and classification development and maintenance policies.

Funding
Structuring a public-private effort to adjudicate and set policy for various stakeholders will require financial support (estimated to be between $5 and $50 million). These funds should be placed in one location to do ongoing monitoring, research, and evaluation results to address:

- Quality of encoded data

- Quality of encoding systems

- Value of encoding data

- Patient safety issues pertaining to encoded data

- Reproducibility of encoded data

- Quality, reproducibility, value, and patient safety pertaining to mapping and to different versions of encoded data in the same system

- Development and recommendations of standards for coded data (that is, for computer-assisted coding)

- Biosurveillance

- Use health informatics data to improve public health practices as well as medical readiness

Part of the funds would be used to support healthcare standards in ways that do not rely on revenue generated by selling the standards themselves. The authority will identify the

certification standards for terminologies and classifications in the EHRs and EHR systems and oversee the development of implementation guides. It must have sufficient authority to coordinate efforts among the various agencies and stakeholders to ensure congruency and collaboration, not competition.

Roles and Responsibilities of the Centralized Authority
The Task Force applauds the recent formation of the IHTSDO and is fully supportive of this development. However, US involvement as a charter member of the IHTSDO will require an entity responsible for overseeing US interests. The Task Force believes the central authority would best serve this role. The central authority would define the governance structure for the US role in the IHTSDO and would oversee the SNOMED national release center in the US, where questions regarding the process for requesting of new terms or establishing regional extensions would be resolved. With the aid of funds mentioned below, the US participation process in the IHTSDO will be defined.

The central authority, which will coordinate the funding of research, standards, grant review, and contracts, will also have responsibility for the stewardship of the funding noted above. This authoritative body will focus on processes for governing, maintaining, and distributing the terminologies and classifications. Its responsibility will be to align funding with policy and guide the contracts and grants process toward long-term goals.

Central Authority Commitment
The entity will commit to the **adoption of sound principles for operation of a terminology and classification standards development organization.** Primary among the principles is an infrastructure for development and maintenance that includes a

17

---

22. Available at www.jamia.org/cgi/content/abstract/5/6/503.

transparent process with policies and procedures that can support open standards and ensure that those who build content are engaged in any consolidation or integration of their products. This commitment would include:

- Simplified coding guidelines and reimbursement regulations so that mapping rules can be more readily developed and maintained.

- Use case maps from reference terminology to administrative code sets (for instance, SNOMED CT® to ICD-9-CM, SNOMED CT® to CPT, and LOINC to CPT) that are validated with an easy, no-cost distribution mechanism.

- Educational resources to train healthcare professionals on the use and interpretation of coded data and its relationship with clinical terminologies, classification systems, and mapping technologies. Since much of this relationship is still misunderstood and somewhat difficult to fully grasp, educational resources that clearly and succinctly describe the mapping process and the importance of reference terminologies and classification systems are truly needed.

Centralized Authority Relationships
The Task Force recommends creating a terminology group made up of both public and private organizations to assist the central authority. This group would be contracted and therefore not dependent on "voluntary" commitment. It will be responsible for establishing the standards used for certification of terminologies and tools.

The Task Force supports the Healthcare Information Technology Standards Panel (HITSP) basic standards readiness criteria as a starting point for the work of this centralized authority. HITSP's Tier 2 criteria take into consideration issues the Task Force identified

as necessary for ridding the development, implementation, and maintenance process of its complexity and to structure governance in a coordinated fashion.

These criteria were developed to screen the potential candidate standards, including terminologies and code sets. They are used by HITSP and its technical committees for evaluating standards for possible use in the HITSP Interoperability Specifications. Tier 2 criteria[23] are placed into the following categories:

- **Suitability:** the standard is named at a proper level of specificity and meets technical and business criteria of use case(s)

- **Compatibility:** the standard shares common context, information exchange structures, content or data elements, security, and processes with other HITSP harmonized standards or adopted frameworks as appropriate

- **Preferred Standards Characteristics:** approved standards, widely used, readily available, technology neutral, supporting uniformity, demonstrating flexibility and international usage are preferred

- **Standards Development Organization and Process:** meet selected criteria, including balance, transparency, developer due process, stewardship, and others

- **Total Costs and Ease of Implementation**

Role of AHIMA and AMIA

AMIA and AHIMA are committed to a global approach to health-related terminologies and classifications and seeing the recommendations in this report move forward. Both organizations are prepared to engage with others to accomplish the following next steps:

23. Standards Readiness Criteria, Tier 2, Version 1.0

- **Develop a planning grant.** The grant would continue the work of the Task Force in partnership with the ONC. AHIMA and AMIA will also coordinate with the HITSP to harmonize work.

- **Engage informatics and information management leaders** in increasing the awareness of the interdependencies of encoding data with terminologies, classifications, and with issues of reimbursement. It is important to understand how encoded data can support other initiatives such as quality or patient safety in the healthcare environment.

- **Enlist the support of other key organizations** in these efforts, such as the HHS/Centers for Medicare and Medicaid Services (CMS), including the ONC, large integrated healthcare organizations like Kaiser Permanente, Veterans Health Administration, National Institutes of Health, including the National Cancer Institute and the National Library of Medicine, foundations such as the California Healthcare Foundation, large insurance organizations such as Blue Cross/Blue Shield, and others such as the Certification Commission for Healthcare Information Technology.

- **Create educational resources** to train healthcare professionals on the use and interpretation of coded data and its relationship with clinical terminologies, classification systems, and mapping technologies.

- **Broadly publicize these recommendations** to those whose support is needed to adopt them.

Conclusion

The members of the Task Force believe the state of terminologies and classifications in the US is ineffective and in disarray and necessitates immediate action. The healthcare industry – including the government,

professional organizations, public and private institutions, and health informatics and information management professionals – must respond to the chaos and address the issues before the US healthcare system is marginalized. To not do so would mean continued reliance on poor-quality data for decision making and the spending of dollars to retrofit a system that is obviously broken. If the changes outlined in this paper are not made, it is unlikely the goals of the national health information agenda can be achieved.

Moreover, without question there is a need for worldwide comparability of healthcare data to improve the effectiveness of global public health policies and programs. To meet this need a variety of health-related terminologies and classifications identifying the clinical data is required. However, just having these systems available does not mean the data can be used and exchanged. The various systems must be coordinated and managed in a synchronized fashion. Processes for developing, releasing, implementing, and maintaining terminologies and classifications must be streamlined. They must have an effective life cycle infrastructure to improve quality and simplify reliable and maintainable health data. The recent global progress with SNOMED gives special urgency to this matter for the US. We must get our collective house in order; the lack of a coherent healthcare system in the US and the lack of prospects anytime soon for a coherent system cannot be allowed to prevent progress in this extremely important domain.

Achieving the goal of a well-organized, coordinated health-related terminologies and classifications governance structure and efficient development, implementation, and maintenance processes will take time. The industry is challenged to continue forward while new approaches are being designed, tested, and funded. An industry dedicated to prompt response and collaborative work can build solutions for today's turmoil and ensure better health information management for the nation and the world.

19

Table 1. Governance of Various Terminology Systems in the United States

Name of Terminology	Owner	Governance Process
ABC Codes	Foundation for Integrative Healthcare	Terminology development is coordinated through the Foundation for Integrative Healthcare (FIHC) and its practitioner association constituents (called member associations).
Clinical Care Classification	Virginia Saba	Terminology updates are vetted through an Advisory Board.
CDT	ADA	ADA manages and provides staff to coordinate the technical review and revision process. A Code Revision Committee composed of representatives from the ADA, America's Health Insurance Plans, the Blue Cross/Blue Shield Association, Centers for Medicare & Medicaid Services, Delta Dental Plans Association, and National Purchaser of Dental Benefits.
CPT	AMA	AMA oversees a CPT Editorial Panel that is responsible for development and maintenance. The Panel is composed of 15 physicians and two non-physician healthcare professionals appointed by the AMA Board of Trustees.
DSM	APA	APA Division of Research manages the DSM revision process.
Global Medical Device Nomenclature	CEN	The European Committee for Standardization body (CEN) owns the copyright, but has delegated administration to the Maintenance Agency Policy Group (MAPG). MAPG includes representatives from the FDA as the US regulatory body, the European Community, the Japanese Ministry of Health, Labour, and Welfare, and five nominees approved to represent CEN, five nominees approved to represent ISO interests, and a representative of the Global Harmonization Task Force.
HCPCS Level II	CMS	The CMS HCPCS Workgroup is responsible for development and maintenance.
ICD-0	WHO	WHO Collaborating Centres govern development and maintenance.
ICD-10	WHO	WHO Collaborating Centres govern development and maintenance.
ICD-10-CM	NCHS	NCHS governs development and maintenance.
ICD-10-PCS	CMS	The Division of Acute Care within the Center for Medicare Management of CMS governs development and maintenance. ICD-10-PCS was developed by 3M HIS under a CMS contract.

Table 1. Governance of Various Terminology Systems in the United States *continued*

Name of Terminology	Owner	Governance Process
ICD-9-CM Diseases and Procedures	NCHS and CMS	NCHS governs development and maintenance of ICD-9-CM diagnoses; the Division of Acute Care within the Center for Medicare Management of CMS governs development and maintenance of ICD-9-CM procedures; American Health Information Management Association, American Hospital Association, CMS, and NCHS (known as the Cooperating Parties) are responsible for development of official coding guidelines for proper use of ICD-9-CM codes.
ICF	WHO	WHO Collaborating Centres govern development and maintenance.
International Classification of Primary Care	Wonca International Classification Committee	World Organization of Family Doctors governs development and maintenance.
LOINC	Regenstrief Institute	Regenstrief Institute and LOINC Committee govern development and maintenance process. The LOINC Committee is composed of representatives from a number of organizations representing both the public and private sectors.
MEDCIN	Medicomp Systems	Medicomp Systems is responsible for maintenance and development.
MedDRA	ICH MSSO	MedDRA Maintenance and Support Services Organization (MSSO) serves as the repository, maintainer, and distributor of MedDRA as well as the source for the most up-to-date information regarding MedDRA and its application within the biopharmaceutical industry and regulators. The MSSO includes a group of internationally based physicians who review all proposed subscriber changes and provide a timely response directly to the requesting subscriber.
NANDA	NANDA International	NANDA is responsible for development and maintenance.
NDF-RT	VA	Ongoing development and maintenance is supported under the VA's Enterprise Reference Terminology project.
NDC	FDA	The Center for Drug Evaluation and Research within the FDA is responsible for ongoing development and maintenance.
NIC	University of Iowa	University of Iowa College of Nursing, Center for Nursing Classification and Clinical Effectiveness is responsible for ongoing development and maintenance.
NOC	University of Iowa	University of Iowa College of Nursing, Center for Nursing Classification and Clinical Effectiveness is responsible for ongoing development and maintenance.

21

Table 1. Governance of Various Terminology Systems in the United States *continued*

Name of Terminology	Owner	Governance Process
Omaha System	Karen Martin	Karen Martin is responsible for ongoing development and maintenance with updates and feedback from the Omaha System users group.
Perioperative Nursing Data Set	Association of Perioperative Nurses (AORN)	AORN is responsible for ongoing development and maintenance.
RxNorm	NLM	NLM is responsible for ongoing development and maintenance.
SNODENT	ADA	The Advisory Committee on Dental Electronic Nomenclature, Indexing, and Classification (ACODENIC) processes requests for modifications and Council on Dental Benefit Programs have final approval. ACODENIC is composed of representatives from all of the recognized dental specialty organizations, payers, and the ADA.
SNOMED CT®	CAP	Within the governance structure of CAP, SNOMED International manages the ongoing maintenance and continuing evolution of SNOMED CT®. It accomplishes this through the SNOMED International Authority, SNOMED International Editorial Board, and Working Groups. The SNOMED International Authority has direct responsibility for terminology-related activities. The SNOMED International Editorial Board is responsible for scientific direction, editorial processes, and scientific validity. The Board is composed of voting members and organizational liaisons. This process is under revision; currently the process is private and the editorial board is closed.
Universal Medical Device Nomenclature System (UMDNS)	ECRI	ECRI governs ongoing development and maintenance.

Table 2. Development and Maintenance of Various Terminology Systems in the United States

Name of Terminology	Developer (private, govt., nonprofit, etc.)	Development and Maintenance Process	Official Source for Clarification	Release Schedule
ABC Codes	Foundation for Integrative Healthcare	FIHC validates requests for new codes or code modifications and Alternative Link makes final decision.	Alternative Link	Updated annually.
Clinical Care Classification	Virginia Saba	Terminology updates are vetted by Advisory Board.	Virginia Saba	There is no specific schedule for updates and revisions. Content is revised as clinical requirements change.
CDT	ADA	Open meetings, changes voted on by the Code Revision Committee.	ADA	Updated biannually at the beginning of odd-numbered years.
CPT	AMA	Open meetings, changes voted on by CPT Editorial Panel.	AMA, AHA provides clarification for use of CPT codes under hospital outpatient PPS.	Category I: January 1 Category II: biannually Category III: January and July
DSM	APA	Open process for input, final decisions are made by APA.	APA	No schedule. Current version is DSM-IV-TR and was published in July 2000. Last major revision was in 1994.
Global Medical Device Nomenclature	CEN	Open process for input, final decisions are made by Maintenance Agency Policy Group.		Updated at least annually.
HCPCS level II	CMS	Open meetings, open process for input. CMS makes the final decisions.	Individual payers, AHA provides clarification for use of HCPCS codes in hospital OPPS.	Some codes are updated annually (January 1), others are updated quarterly.

Table 2. Development and Maintenance of Various Terminology Systems in the United States *continued*

Name of Terminology	Developer (private, govt., nonprofit, etc.)	Development and Maintenance Process	Official Source for Clarification	Release Schedule
ICD-0	WHO	Current edition was developed through collaboration between WHO and the International Agency for Research on Cancer (IARC).	WHO	No schedule
ICD-10	WHO	Changes must be sponsored by one of the WHO Collaborating Centres for Classification of Disease.	WHO	Minor–annually Major–up to three years
ICD-10-CM	NCHS	Similar to that for ICD-9-CM. Must conform to constraints imposed by WHO for use of ICD.	Undetermined	Undetermined
ICD-10-PCS	CMS	Undetermined	Undetermined	Undetermined
ICD-9-CM Diseases and Procedures	NCHS and CMS	Open process for submitting requests for modifications and for providing public input on code proposals; NCHS and CMS have final approval. Four cooperating parties (AHA, AHIMA, CMS, NHCS) develop uniform guidelines for application of codes.	The AHA central office on ICD-9-CM	October 1; potential exists for second update to occur on April 1, but this has not occurred yet.
ICF	WHO	WHO Collaborating Centres	WHO	No schedule
International Classification of Primary Care	Wonca International Classification Committee	Developed and maintained by World Organization of Family Doctors (Wonca) International Classification Committee (WICC).	Wonca	11-year cycle
LOINC	Regenstrief Institute	Open Lab LOINC and Clinical LOINC meetings; maintained by LOINC Committee.	Regenstrief Institute	No set schedule, three to four times a year.

24

Table 2. Development and Maintenance of Various Terminology Systems in the United States *continued*

Name of Terminology	Developer (private, govt., nonprofit, etc.)	Development and Maintenance Process	Official Source for Clarification	Release Schedule
MEDCIN	Medicomp Systems	Developed and maintained by Medicomp Systems based on recommendations of a group of consulting editors from Cornell, Harvard, Johns Hopkins, and other major medical centers, with substantial input from user community-based physicians.	Medicomp Systems	Twice per year
MedDRA	ICH MSSO	Core subscribers may submit requests for new terms; MSSO makes final decision.	MSSO	Twice a year— March 1 and September 1
NANDA	NANDA	Anyone may submit a request to add a nursing diagnosis; member input sought at NANDA conference; NANDA makes final decision.	NANDA	Every two years
NDF-RT	VA	VA plans to maintain NDF-RT so that it remains fully integrated with RxNorm.	VA	Unknown
NDC	FDA	Drug manufacturers submit requests for changes; FDA makes final decision	FDA	Quarterly
NIC	University of Iowa	Content is added as requested or needed	University of Iowa College of Nursing, Center for Nursing Classification and Clinical Effectiveness	Every four years
NOC	University of Iowa	Content is added as requested or needed	University of Iowa College of Nursing, Center for Nursing Classification and Clinical Effectiveness	Every four years
Omaha System	Karen Martin	Content is added as requested or needed.	Karen Martin	No published schedule
Perioperative Nursing Data Set	AORN	Content is added as requested or needed.	AORN	No published scheduled

25

Table 2. Development and Maintenance of Various Terminology Systems in the United States *continued*

Name of Terminology	Developer (private, govt., nonprofit, etc.)	Development and Maintenance Process	Official Source for Clarification	Release Schedule
RxNorm	NLM	NLM adds new clinical drugs and links to additional drug terminologies and to refine the model in response to feedback.	NLM	Weekly, cumulative monthly
SNODENT	ADA	Open process for input and submitting requests for modification; Advisory Committee on Dental Electronic Nomenclature, Indexing, and Classification (ACODENIC) of the ADA processes suggestions concerning changes to SNODENT and forwards recommendations for modifications to the Council on Dental Benefit Programs of the ADA for approval.	ADA	Unknown
SNOMED CT®	CAP	A documented scientific process is followed that focuses on understandability, reproducibility, and usefulness. Content is defined and reviewed by multiple clinical editors, with additional experts consulted as necessary to review the scientific integrity of the content. The quality control process is continuously supplemented by feedback from users.	SNOMED International	Biannually –January and July
UMDNS	ECRI	Open process for requesting changes.	ECRI	Updated daily, but officially, it is updated annually.

26

Appendix A: Terminology Services and Tools

Terminology Development/Editing/Maintenance

Terminology development/editing/maintenance services support the formal representation of concepts and typically include functions such as provision of a reference model or set of reference models using some type of description logic or frame-based approach, automated classification of new terms through formal subsumption, and data to support version control. Some tools (for example, Galapagos) support distributed development and resolution of inconsistencies across modelers. These services should support not only atomic-level concepts and molecular expressions but also other formal structures such as clinical document architectures.

Examples: LexGrid, Medical Entities Dictionary (MED) editor, SNOMED CT® development tools, Terminology Development Environment (Apelon), Protégé (ontology development in either frames or OWL)

Terminology Browsers

Terminology browsers support the viewing (and sometimes editing) of a single terminology or a set of terminologies.

Examples (single terminology): Regenstrief LOINC Mapping Assistant (RELMA), Medical Entities Dictionary (MED) browser, CLUE (SNOMED CT®)

Examples (multiple terminologies): LexGrid (Mayo); Knowledge Source Server (Unified Medical Language System); Open GALEN; Mycroft (Apelon), Health Level 7 Common Terminology Services

Terminology Mapping

Terminology mapping tools support the mapping of terms from a source terminology (typically local terminology) to a target terminology.

Examples (single terminology): Regenstrief LOINC Mapping Assistant (RELMA); SNOMED CT® development tools

Examples (multiple terminologies): LexGrid (Mayo); Open GALEN; Health Level 7 Common Terminology Services

Concept-based Indexing and Retrieval

These services support content tagging, indexing and retrieval of document sets.

Examples: Unified Medical Language System (particularly MeSH), Concept-based Indexing & Retrieval Solution (Apelon); Open GALEN; Infobutton Manager (Cimino)

Terminology Import

Terminology import services support the import of terminologies in a variety of formats, e.g., UMLS, SQL, SQL Lite, Health Level 7 Version 3, Protégé.

Examples: LexGrid (Mayo)

Terminology Export

Terminology export services support the export of terminologies in a variety of formats, (for example, XML, OWL, RDF).

Examples: LexGrid (Mayo)

Natural Language Processing

Natural language processing tools parse natural language into syntactic and/or semantic structures and may map parsed terms to a standardized terminology.

Examples: MedLEE (Friedman)

Translation to Natural Language

Natural language translation services support the transformation of a formally represented concept into one or more natural language lexical expressions. For example, the same concept may be expressed in American English, UK English, and Spanish.

Examples: Open GALEN

27

Appendix A: Terminology Services and Tools *continued*

Clinical Terminology Server

Chute identified a set of nine desideratum for a clinical terminology server: word normalization, word completion, target terminology specification, spelling correction, lexical matching, term completion, semantic locality, term composition, and term decomposition.

Relevant Links

Apelon, Inc.: www.apelon.com/products

Columbia University Biomedical Informatics: www.dbmi.columbia.edu/

HL7: www.hl7.org

The Lexical Grid: http://informatics.mayo.edu/LexGrid/index.php?page

Medical Entities Dictionary:

http://med.dmi.columbia.edu/

MedLEE - A Medical Language Extraction and Encoding System: http://lucid.cpmc.columbia.edu/medlee/

OpenGALEN Foundation: www.opengalen.org/index.html

The Protégé Ontology Editor and Knowledge Acquisition System: http://protege.stanford.edu/

SNOMED International: www.snomed.org

Unified Medical Language System Knowledge Source Server: http://umlsks.nlm.nih.gov/kss/servlet/Turbine/template/admin,user,KSS_login.vm

Table 1. Terminology Services and Tools in Four Organizations

Service	CUMC[2]	IHC[3]	Mayo[4]	VAMC[5]
Terminology Development/ Editing/Maintenance	MED	3M HDD	LexGrid	Apelon TDE/SDS Maint. App. Terminology
Browser	MED	IHC Search	LexGrid	Apelon DTS/SDS Maint. App.
Terminology Mapping	MED (1:1 only)	IHC Match	LexGrid	Apelon TermWorks
Concept-based Indexing and Retrieval	Infobutton Manager	IHC Infobutton	LexGrid	VETS/SDS Read-Only APIs
Terminology Import	MED	3M HDD	LexGrid	VETS
Terminology Export	MED	3M HDD	LexGrid	VETS/Database Replication
Natural Language Processing	MedLEE	IHC NLP	UIMA/LexGrid	
Clinical Terminology Server[1]	MED (word completion only)	3M HDD	LexGrid	VETS

Appendix A: Terminology Services and Tools *continued*

1. Word normalization, word completion, target terminology specification, spelling correction, lexical matching, term completion, semantic locality, term composition, and term decomposition.

2. At Columbia University Medical Center of New York Presbyterian Hospital, terminology services are supported through the Medical Entities Dictionary (MED), the Infobutton Manager, and the Medical Language Extraction and Encoding (MedLEE) system. The MED, a concept-oriented terminology, serves as the institutional data dictionary and uses a semantic network model that includes a classification hierarchy. MED-related applications support browsing, development, editing, and maintenance of the MED as well as terminology import and export. Terminology server functionality of the MED is limited. The Infobutton Manager is built upon the foundation of semantic relationships in the MED and provides context-specific links to information resources from within the clinical information systems (for example, at the time of order entry or when viewing laboratory results). MedLEE provides natural language processing for a variety of functions including decision support. These tools provide a rich foundation upon which to build a broader set of terminology services throughout the enterprise.

3. At Intermountain Healthcare the run time services, terminology database, and basic import and export programs are based on the Healthcare Data Dictionary (HDD) application provided by 3M Healthcare. The initial design of the software was described by Roberto Rocha (see "Designing a Controlled Medical Vocabulary Server: The VOSER Project," Computers and Biomedical Research, 1994.) Intermountain has built search programs and terminology matching programs that extend the original HDD functionality. Intermountain's Infobutton technology has been written locally, but is based largely on the model created by Cimino at Columbia. Natural language processing software has been created by Peter Haug and associated researchers at Intermountain.

4. At Mayo Clinic, production terminology services remains largely done through vendor products (for example, GE/IDX/LastWord). However, the research community is fully supported by LexGrid (http://informatics.mayo.edu). NLP tools were developed in collaboration with IBM and mounted on the Unstructured Information Management Architecture, though the entire suite remains open source. The LexGrid tools underpin vocabulary maintenance and support at HL7, the National Cancer Institute's Biomedical Informatics Grid, and the CDC Public Health Information Network.

5. At the Department of Veterans Affairs, Apelon is used for clinical terminology, but administrative terminology is homegrown. Terminology services are provided by a combination of VA-developed and commercial products. Currently, clinical and administrative (nonclinical) terminology are modeled, maintained, and deployed separately. Clinical terminology is modeled and maintained in the Apelon Terminology Development Environment. The VA-developed VHA Enterprise Terminology Services (VETS) tools to allow analysts to review and deploy terminology to VA sites as well as providing a real-time terminology server. Development and utilization of the terminology services are still in the early stages. Administrative terminology is developed and maintained in the VA-developed solution called Standard Data Service (SDS) maintenance application. SDS data is stored in a central Oracle database. Applications access the data via read-only APIs, and cache the data locally in either Oracle or Cache databases. Nightly replication keeps the databases in sync, should any changes occur in the SDS central database. Synchronization with Legacy files will be achieved through HL7 messaging.

Appendix B: Australia, the United Kingdom, and Canada

Australia

The organization principally involved in the identification and development of clinical data standards for use at the point of care in Australia is the National E-Health Transition Authority (NEHTA). NEHTA is a not-for-profit company jointly funded by Australian state, territory, and national governments. The board of NEHTA Limited is composed of chief executives from the health departments in each of these jurisdictions,[24] and NEHTA has received funding of $AUD130M from the Council of Australian Governments to establish the national infrastructure required to support a national approach to clinical terminologies and unique health identifiers. As part of its broader e-health agenda to accelerate the adoption of IT in the health sector, NEHTA is tasked with recommending and where necessary developing standards for clinical use.

NEHTA has recommended SNOMED CT® (developed by the College of American Pathologists) as the most appropriate and comprehensive clinical terminology capable of supporting a national approach to terminologies in Australia. NEHTA intends to customize SNOMED CT® where necessary to meet Australian needs.[25]

Classifications for statistical reporting have been developed by a number of organizations (including the Australian Health Information Council , and the National Health Information Group, which report to the Australian Health Ministers Advisory Council). The use of classifications is prescribed through national minimum datasets for reporting, as published in the National Health Data Dictionary. Supporting classifications include an Australian extension of ICD-10, designated as ICD-10-AM, which includes the Australian Classification of Health Interventions, which has been developed and is actively maintained by the National Centre for Classification in Health (NCCH). NEHTA, the NCCH, and the Australian Health Ministers' Advisory Council are all aware of, and are proceeding toward, a cooperative rationalization of the development, management, and governance of terminologies and classifications in Australia.

United Kingdom

In April 2002, several key recommendations were identified for IT in the National Health Service (NHS). These included increased and protected funding for IT, stringent, centrally managed national standards for data, and better management of IT implementation in the NHS. Following this, NHS Connecting for Health was established in 2005 with the primary goal of delivering the National Program for IT .

NHS Data Standards & Products (NHS DS&P) is part of the Technology Office of NHS Connecting for Health and is responsible for the introduction, development, and delivery of coding system products used in the patient records of the NHS Care Records Service. The products that NHS DS&P are responsible for include SNOMED CT®, the Read Codes, Dictionary of Medicine & Devices, ICD-10, OPCS4, and the NHS Data Dictionary. As part of the delivery and ongoing development, NHS DS&P also provides a number of other services delivering codes and data and quality standards to the NHS incorporating the National Administrative Codes Services, the Spine Directory Service (SDS), and the Information Quality Assurance Programme.[26]

An advantage of the organizational structure in the United Kingdom is that it is centrally managed, which allows Connecting for Health to inform the NHS about the use of terminologies and classifications that serve the needs of the health system.

30

---

24. National E-Health Transition Authority, www.nehta.gov.au/content/view/1/103.

25. Available at www.govhealthit.com/article94797-06-12-06-Print).

26. Connecting for Health, www.connectingforhealth.nhs.uk/technical/standards/.

Appendix B: Australia, the United Kingdom, and Canada
continued

Canada

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization. CIHI is a focal point for collaboration among major health players—from provincial governments, regional health authorities, and hospitals to the federal government, researchers, and associations representing healthcare professionals. Governance of the organization is made up of a board of directors that provides strategic guidance to both CIHI and the Health Statistics Division at Statistics Canada.

CIHI facilitates data quality and the consistent use of Coding Standards for ICD-10-CA and the Canadian Classification of Health Interventions (CCI) (developed to accompany the ICD-10-CA) and is advised on these topics by several committees.[27] The National Coding Advisory Committee provides CIHI with advice on the development and ongoing enhancement of coding standards. The Classification Advisory Committee also provides CIHI with advice on the maintenance and enhancement of ICD-10-CA and CCI.

The National ICD-10-CA/CCI Electronic Products Advisory Group provides advice on the ongoing development of new and enhancement of existing ICD-10-CA and CCI electronic products. This advisory group reviews proposals and provides feedback on the potential impact of changes on coding, data capture, and data quality and shares information and solicits feedback related to ICD-10-CA and CCI electronic products with provincial/territorial end users.

Canada Health Infoway, established in 2001, is a not-for-profit corporation, whose Members are Canada's 14 federal, provincial, and territorial Deputy Ministers of Health. Infoway's mission is to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis. Among its many standards-related initiatives, Infoway is currently leading a project to evaluate SNOMED CT® as the Canadian standard for reference terminology for use in the pan-Canadian Electronic Health Record.

31

---

27. Ibid.

Glossary

ABC Codes: A registered vocabulary of HL7 incorporated into the National Library of Medicine's Unified Medical Language System in 1998, describing the procedures, treatments, and services provided during an encounter with a complementary and alternative medicine, nursing, and other integrative healthcare provider.

American Dental Association (ADA): A professional dental association dedicated to the public's oral health, ethics, science, and professional advancement.

American Hospital Association (AHA): The national trade organization that provides education, conducts research, and represents the hospital industry's interests in national legislative matters.

American Medical Association (AMA): The national professional membership organization for physicians that distributes scientific information to its members and the public, informs members of legislation related to health and medicine, and represents the medical profession's interests in national legislative matters.

American National Standards Institute (ANSI): The agency that coordinates the development of voluntary standards to increase global competitiveness in a variety of industries, including healthcare.

American Psychiatric Association (APA): A medical specialty society with more than 35,000 member physicians in the United States and abroad who work together to ensure humane care and effective treatment for all persons with mental disorders.

ASTM (American Society for Testing and Materials): a scientific and technical organization for the development of standards on characteristics and performance of materials. The charter includes products, systems and services, as well as materials.

ASTM is the largest nongovernment source of standards in the US, comprised of more than 130 committees that publish 10,000 standards annually.

Computer-assisted coding (CAC): The use of computer software that automatically generates a set of medical codes for review/validation and/or use based upon clinical documentation provided by healthcare practitioners.

CEN (European Committee for Standardization): A set of standards from the voluntary work of participants representing all interests concerned (industry, authorities, and civil society) contributing mainly through their national standards bodies.

Centers for Medicare and Medicaid Services (CMS): The division of the Department of Health and Human Services that is responsible for developing healthcare policy in the US and for administering the Medicare program and the federal portion of the Medicaid program; called the Health Care Financing Administration prior to 2001.

Classification: A system that arranges together similar diseases and procedures and organizes related entities for easy retrieval.

College of American Pathologists (CAP): A medical specialty organization of board-certified pathologists that owns and holds the copyright to SNOMED CT®.

Current Dental Terminology (CDT): A coding system developed to report services performed by the dental profession; formerly called the Uniform Code on Dental Procedures and Nomenclature.

Current Procedural Terminology (CPT®): A comprehensive list of descriptive terms and codes published by the American Medical Association and used for reporting diagnostic and therapeutic procedures and other medical services performed by physicians.

Consolidated Health Informatics (CHI): A government initiative that adopts standards for domains related to health information for federal health data systems, facilitating communication among all federal health agencies.

Diagnosis-related Group (DRG): A unit of case mix classification adopted by the federal government and some other payers as a prospective payment mechanism for hospital inpatients in which diseases are placed into groups because related diseases and treatments tend to consume similar amounts of healthcare resources and incur similar amounts of cost.

Diagnostic and Statistical Manual of Mental Disorders (DSM): A nomenclature to standardize the diagnostic process for patients with psychiatric disorders; includes codes that correspond to ICD-9-CM codes.

ECRI: An independent nonprofit health services research agency established to promote safety, quality, and cost-effectiveness in healthcare to benefit patient care through research, publishing, education, and consultation; formerly called the Emergency Care Research Institute.

Food and Drug Administration (FDA): Federal agency responsible for protecting the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, the nation's food supply, cosmetics, and products that emit radiation.

Foundation for Integrative Healthcare (FIHC): A nonprofit foundation established in 1999 that, along with its practitioner association constituents, coordinates terminology development in ABC codes.

Free for use: The material is not copyrighted and no license is needed.

Health Insurance Portability and Accountability Act (HIPAA): The federal legislation enacted to provide continuity of health coverage, control fraud and abuse in healthcare, reduce healthcare costs, and guarantee the security and privacy of health information.

Health Level Seven (HL7): An organization that develops standards regarding clinical and administrative data and is accredited by the American National Standards Institute.

Healthcare Common Procedure Coding System (HCPCS): A three-level classification system introduced in 1983 to standardize the coding systems used to process Medicare and Medicaid claims.

Healthcare Information Technology Standards Panel (HITSP): A cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications.

Hypertext transport protocol (HTTP): The communications protocol that enables use of hypertext linking.

International Classification of Diseases—Oncology (ICD-O): A classification system used for reporting incidences of malignant disease.

International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM): A classification system used in the United States to report morbidity information.

International Classification of Diseases, Tenth Revision (ICD-10): The most recent revision of the disease classification system developed and used by the World Health Organization to track morbidity and mortality information worldwide.

International Classification of Function, Disability, and Health (ICF): A classification system released by the World Health Organization in 2001 that describes how people live with their health conditions.

33

International Organization for Standardization (ISO): The world's largest developer of standards whose principal activity is the development of technical standards that often have important economic and social repercussions.

Logical Observation Identifiers, Names, and Codes (LOINC®): A database protocol developed by the Regenstrief Institute for Healthcare aimed at standardizing laboratory and clinical codes for use in clinical care, outcomes management, and research.

MEDCIN®: A proprietary clinical terminology developed as a point-of-care tool for electronic medical record documentation at the time and place of patient care.

Medical Dictionary for Regulatory Activities (MedDRA): A vocabulary developed as a pragmatic, clinically validated medical terminology with an emphasis on ease-of-use data entry, retrieval, analysis, and display, with a suitable balance between sensitivity and specificity, within the regulatory environment.

NANDA: A classification of nursing diagnoses adopted by the North American Nursing Diagnosis Association. This system describes patients' reactions to diseases rather than classifying the conditions of diseases and disorders.

National Center for Health Statistics (NCHS): The federal agency responsible for collecting and disseminating information on health services utilization and the health status of the population in the United States.

National Drug Code (NDC): A code set used for medical codes maintained and approved by the FDA; the code set designated by the Department of Health and Human Services for reporting drugs and biologics on standard retail pharmacy transactions.

National Committee on Vital and Health Statistics (NCVHS): A public policy advisory board that recommends policy to the National Center for Health Statistics and other health-related federal programs.

Nationwide Health Information Network (NHIN): The United States' vision for a national health information infrastructure that makes secure transmission of person-specific health information from one location to another. NHIN is synonymous with the national health information infrastructure.

Drug File Reference Terminology (NDF-RT): A nonproprietary drug reference terminology that includes drug knowledge and classifies drugs, most notably by mechanism of action and physiologic effect.

Nursing Interventions Classification (NIC): A standardized classification of interventions that nurses do on behalf of patients in all care domains.

National Library of Medicine (NLM): The world's largest medical library and a branch of the national institutes of health.

Nursing Outcomes Classification (NOC): A standardized classification of outcomes developed for use in all settings and with all patient populations. It was developed to evaluate the outcomes of nursing interventions.

Prospective Payment System (PPS): A type of reimbursement system based on preset payment levels rather than actual charges billed after a service has been provided; specifically, one of several Medicare reimbursement systems based on predetermined payment rates or periods and linked to the anticipated intensity of services delivered as well as the beneficiary's condition.

RxNorm: A nonproprietary terminology developed by the National Library of Medicine that represents drugs at the level of granularity needed to support clinical practice.

34

Systematized Nomenclature of Dentistry (SNODENT): A comprehensive taxonomy that contains codes for identifying not only diseases and diagnoses, but also anatomy, conditions, morphology, and social factors that may affect health or treatment.

Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT®): A systematized, multi-axial, and hierarchically organized controlled terminology developed by the College of American Pathologists.

Standards development organization (SDO): A private or governmental organization involved in the development of healthcare informatics standards at a national or international level.

Terminology, clinical: A set of standardized terms and their synonyms that record patient findings, circumstances, events, and interventions with sufficient detail to support clinical care, decision support, outcomes research, and quality improvement.

Unified Medical Language System (UMLS): A multipurpose resource that includes concepts and terms from many different developed source vocabularies.

Universal Medical Device Nomenclature System (UMDNS): A standard international nomenclature and computer coding system for medical devices; developed by ECRI.

World Health Organization (WHO): The United Nations specialized agency created to ensure the attainment by all peoples of the highest possible level of health; the international organization responsible for a number of international classifications, including *The International Statistical Classification of Diseases & Related Health Problems* (ICD-10) *and The International Classification of Functioning, Disability & Health* (ICF).

35

American Medical Informatics Association
Leaders Shaping the Future of Health Information Technology

4915 St. Elmo Ave., Suite 401
Bethesda, MD 20814
www.amia.org

AHIMA
American Health Information
Management Association®

233 N. Michigan Ave., 21st Fl.
Chicago, IL 60601-5800
www.ahima.org