Language Barrier: Getting Past the Classifications and Terminologies Roadblock

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Health IT is bogged down in a quagmire of unaligned classification and terminology systems. New recommendations from AHIMA and AMIA help point to the way out.

The healthcare industry is looking to IT to reduce costs, assess quality of care, and deliver services more efficiently. The core components of these IT tools are classification and terminology systems, the common medical languages used to encode clinical data such as a patient's physical signs, symptoms, medication sensitivities, treatment plans, and diagnoses.

Common terminologies and classifications used in the United States include the International Classification of Diseases (ICD), the Current Procedural Terminology (CPT), and the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT). There are a myriad of classifications and terminologies available in the US today-so many, in fact, that they are hindering the industry's health IT goals.

The Terminology and Classification Dilemma

Terminologies and classifications promise to provide the common medical language necessary for electronic health records and population health reporting, quality reporting, personal health records, safety, clinical trials, biosurveillance, and reimbursement. However, the state of terminologies and classifications in the US today is ineffective and in disarray. It consists of fragmented governance, proprietary licensing, uncoordinated release cycles, and a lack of available standards.

This has resulted in a number of industry problems, including a lack of interoperability between commercial environments and a terminologies and classifications stalemate preventing progress in establishing vocabulary standards to meet the nation's current and future healthcare needs.

In order to achieve health IT goals, classifications and terminologies must be standardized. Standardizing classifications and terminologies for electronic health records is essential to deliver on the promises of electronic decision support, quality monitoring, and medical research. However, the scope of standardization required goes beyond a single version of the content of a particular classification or terminology.

The Need for a Plan

Health record systems are dynamic and continually changing to reflect changing medical knowledge, best practices, and new therapies. To support such dynamic systems, terminologies and classifications must also be dynamic. They must respond to the needs of large and diverse groups of stakeholders. This responsiveness will require rigorously standardized processes and supporting infrastructure available to terminology and classification developers, system implementers, and end users.

Unfortunately, the required collaboration and coordination for this standardization and infrastructure has been elusive. Collaboration and coordination are difficult goals to accomplish, particularly when dealing with numerous public and private stakeholders, processes out of date with today's technology, and systems developed, distributed, and maintained in ways other industries abandoned years ago.

Positive steps are being taken toward collaboration and coordination nationally and internationally, resulting in foundational work and a platform for additional progress. These include the US government's license for SNOMED CT and most recently,

in late 2006, the efforts to form a SNOMED standards development organization that is jointly owned by countries committed to SNOMED's development.

To keep the momentum going, AHIMA and the American Medical Informatics Association (AMIA) developed a vision, goals, and recommendations that they hope 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. Following is an overview of the work from the organizations' joint Terminology and Classification Policy Task Force, as well as what AMIA and AHIMA foresee as the healthcare terminologies and classifications action agenda for the US.

Differentiating Classifications from Terminologies

Clinical terminologies and classification systems have been in use for many years. However, terminologies and classifications have different purposes, or use cases. Certain systems are appropriate for specific applications.

Terminologies are used primarily to capture clinical information. They are highly detailed and have substantial granularity, but 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, compliance is not at an acceptable level.

Systems such as ICD-9-CM and CPT 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, quality of care measures, or resource utilization measures. Because classification systems are considered broader ways to classify specific diseases and procedures, they are not the most appropriate system to use to annotate and aggregate the clinical aspects of an episode of care. Terminologies such as SNOMED CT provide the complete clinical detail of a healthcare encounter.

Together terminologies and classification systems 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.

-AHIMA–AMIA Terminology and Classification Policy Task Force

Who's in Charge? Who's Not in Charge?

The promise that classifications and terminologies offer cannot be fully realized given the poor state of current terminology and classification life cycles. The life cycles of US terminologies and classifications consist of a development, distribution, and maintenance approach that lacks a principled approach to validation and quality assurance. It results in poor data quality for decision making. Proprietary standard development models also impede development and maintenance of terminology standards by prohibiting open publication of content.

Another challenge to the US terminology and classification systems is insufficient funding. Most of the current work has been done by volunteers, which impedes progress and lacks the necessary resources to ensure quality. Resources and appropriate funding are needed to support what is no longer a healthcare system based only on administrative data.

One of the main contributions to the current dilemma is a lack of a centralized oversight authority to oversee the adoption of uniform rules, regulations, and guidelines for standardized terminology and up-to-date classification systems. Terminologies and classifications have their own governance process dictated by the organization that owns the system. In most cases, the governance process is strictly an internal function of the development organization with little detail available publicly. Other countries such as the United Kingdom, Australia, and Canada have already redesigned their governance and support processes in a coordinated manner for terminologies and classifications.

Staying Tuned for Updates

System	Developer	Release Cycle
ICD-9-CM Diseases	National Center for Health Statistics	Twice a year. October 1; potential exists for second update to occur on April 1, but this has not yet occurred.
ICD-9-CM Procedures	Centers for Medicare and Medicaid Services	Twice a year. October 1; potential exists for second update to occur on April 1, but this has not yet occurred.
CPT	American Medical Association	Category I: January 1 Category II: biannually Category III: January and July
HCPCS Level II	Centers for Medicare and Medicaid Services	Some codes are updated annually (January 1), others are updated quarterly.

The staggered release cycles for ICD-9-CM, CPT, and HCPCS Level II illustrate the time-consuming and arduous task hospitals and other US providers face in maintaining classifications and terminologies.

An Example: System Maintenance

The circumstances hospitals endure provide a good example of the ineffective and disorderly state that exists in the US. HIPAA standard code sets include ICD-9-CM, under the responsibility of the National Center for Health Statistics (NCHS), for diagnosis codes and procedure codes for the Centers for Medicare and Medicaid Services (CMS); CPT, which is owned by the American Medical Association (AMA); and CMS's HCPCS Level II for procedure coding. Hospitals must use three procedure coding systems, with no centralized oversight authority overseeing the adoption of uniform rules, regulations, and guidelines.

In addition, CPT is copyrighted by AMA and requires licensing. This requirement increases the cost of products containing CPT content and hinders widespread use of CPT.

Distribution and maintenance causes another set of difficulties. A single coordination and maintenance committee does exist for ICD-9-CM revisions; however, distribution of ICD-9-CM changes occurs via the NCHS and CMS Web sites. Development and maintenance is the responsibility of the AMA CPT Editorial Panel and CMS HCPCS Workgroup for CPT and HCPSC Level II, respectively. Access to the changes is complicated.

Adding the staggered release cycle to this picture shows the time-consuming and arduous task hospitals and other healthcare providers must deal with on a regular basis (see "Staying Tuned for Updates," above). While there have been discussions about the basic maintenance principles and ideal process, desired attributes and standards have not been brought forth, discussed, and agreed upon by the principal stakeholders.

Four Recommendations

Taking into account the extent and significance of the problems identified, the AHIMA-AMIA task force identified specific recommendations for the healthcare industry (government, public and private institutions, and professional organizations) to undertake collaboratively:

- 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-which include rigorous quality assurance-required for operation of a terminology or classification standards development organization

Establishing a centralized, funded authority that focuses on processes for governing, maintaining, and distributing the terminologies and classifications is critical to simplification and synchronization. A US centralized authority that adjudicates and sets policy for various agencies and players-with one location for ongoing monitoring, research, and evaluation pertaining to research, standards, grant review, and contracts-will provide more efficient procedures and better financial control.

Even though maintenance has its own set of unique problems, it is crucial to enhancing the usability and reliability of terminologies and classifications. Deciding on what the maintenance attributes should be can affect the capacity of a terminology to evolve, change, and remain usable over time. The identification of the "official" source of clarification for using a particular terminology or classification will improve the integrity of coded data and the ability to turn it into functional information.

Five Challenges

Collaboration and coordination will be necessary to move forward with the establishment of rigorously standardized processes and a supporting infrastructure available to terminology and classification developers, system implementers, and end users. However, the task force also identified five challenges to success:

- Funds to structure a public-private effort to adjudicate and set policy for the various stakeholders. The central authority will have responsibility for the fund and will coordinate the funding of research, standards, grant review, and contracts. This entity would serve the public interest and be responsible for overseeing the US terminology and classification policies and processes for governing, maintaining, and distributing them.
- Formation of a terminology group made up of both public and private organizations to help the central authority. This group should not be dependent on volunteers but should have contracted resources that are capable of being responsible for establishing the standards used for certification of terminologies and tools.
- Simplified coding guidelines and reimbursement regulations, allowing for mapping rules to be developed with less difficulty.
- Easy, no-cost distribution method of validated use-case maps from reference terminologies to administrative code sets.
- Availability of educational resources on the use and interpretation of coded data and its relationships to clinical terminologies, classification systems, and mapping technologies.

Without question the development, adoption, implementation, and maintenance of terminologies and classifications must be simplified and coordinated in a way that meets the needs of large and diverse groups of stakeholders.

AHIMA and AMIA support a global approach for healthcare terminologies and classifications and believe the creation of a road map for change is necessary so public and private industry sectors understand the goals and target and the required actions. To accomplish this scale of change will require strong government, public, and private collaboration and tenacity to coordinate efforts.

AHIMA and AMIA are prepared to see the needed reform to terminologies and classifications happen through the development of a road map for change. Next steps to move the action agenda forward will be for AHIMA and AMIA to bring stakeholders together to build a broader understanding of the current problems, generate wide support, and begin to construct a road map for change.

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