Healthcare Terminologies and Classification: Essential Keys to Interoperability

The Stakes

The language of medicine and health is as complex and vast as the concepts it represents—and it is continually changing to reflect new knowledge, skills, and capabilities. Healthcare terminologies and classifications are the systems that describe, organize, and standardize this rapidly evolving language. They serve as dictionaries that organize and define words and related concepts. They enable information capture, storage, exchange, and retrieval. Indeed, language even shapes our thoughts and actions.

Imagine if there were no *Webster’s Dictionary*, no metathesaurus for Web searches, no *Roget’s Thesaurus*, or no Dewey decimal system. Just as we rely on language tools in our daily lives to help us communicate and understand meaning, terminologies and classifications enable communication with understanding throughout healthcare.

Specifically, healthcare terminologies and classifications help us standardize descriptions of the causes of death and of illness (morbidity), types and causes of injury, functional status and disability, treatments, procedures, and the interventions of physicians, nurses, and other caregivers. They also help us to capture symptoms, signs, complexity of service, and other characteristics of care or the persons receiving that care.

Terminologies and classifications form the information content in the electronic health records (EHRs), including the personal health record (PHR). 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 capable of delivering on the promise of safer and more cost-effective results.

To succeed in its transition to an interoperable healthcare system, the US must overhaul the current ways in which terminologies and classifications are governed, developed, implemented, and maintained. While significant progress has been made in the US, there is much more that needs to be done if terminologies and classifications are to enable and not impede the national agenda for health transformation through information technology (IT).

As professional groups representing experts in medical computing, classification and terminology development and application, the American Health Information Management Association (AHIMA) and American Medical Informatics Association (AMIA) share a concern for current US practices. Accordingly, the two groups convened a joint Task Force to study the challenges and offer actionable recommendations to improve how the US develops, distributes, maintains, and uses healthcare terminologies and classifications.


“If...changes...are not made, it is unlikely that the goals of the nationwide health information agenda can be achieved.”

—“Healthcare Terminologies and Classifications: An Action Agenda for the United States”
The Current Situation

A clinical terminology is a set of terms and their synonyms that standardize the recording of patient findings, circumstances, events, and intervention to support clinical care, decision support, outcomes research, and quality improvement. A classification system groups similar diseases and procedures and organizes related information for easy retrieval or other purposes.

Today there are more than 20 comprehensive terminology and classification systems, plus a number developed for a particular specialty or application. However, there is no deemed authority or even policy arrangement in the US to ensure that development, distribution, and maintenance are coordinated in a comprehensive manner for effective design and use to support an interoperable health information network. This creates a number of challenges, such as:

• Lack of standards for terminology development resulting in incompatible data formats that limit translation and interoperability and increase administrative costs
• Outdated classification systems are in use long beyond their useful life (for example, ICD-9-CM), which diminishes the value of data that is costly to gather and puts the US increasingly out of step with international progress
• Uncoordinated release schedules for new versions increase maintenance costs and data trending difficulties
• Poor compliance with guidelines and, for some systems, a lack of basic guidelines for system use decrease the data quality and the value of comparing and trending data
• Difficulty converting data encoded in one terminology or classification to another in the absence of nationally recognized standards

These and other challenges have been recognized by many industry experts and by advisory groups such as the National Committee on Vital and Health Statistics for many years, but recent national health IT initiatives in the US and other countries have created a new environment for classifications and terminologies and has highlighted problems with the US management of this important domain despite some important gains. In recent years, important foundational steps include:

• In 2003, the National Library of Medicine (NLM) licensed SNOMED CT®, making it freely available throughout the US via the Unified Medical Language System
• SNOMED CT recently made the transition to an international SNOMED standards development organization known as the International Health Terminology Standards Development Organisation (IHTSDO). This should accelerate use and learning and linkages to international classification systems
• The Healthcare Information Technology Standards Panel (HITSP) is charged with harmonizing standards required to enable the secure exchange of patient data across the system
• The American Health Information Community is aware of these issues as a result of its own investigations and the recent report from the President’s Commission on Systemic Interoperability
To take advantage of the opportunities begun by the NLM, HITSP, and the formation of the IHTSDO, the US must address its fragmented governance, proprietary licensing, uncoordinated release cycles, and lack of standards development distribution and maintenance standards. If these issues are not systematically addressed, the goal of achieving interoperability may never be met.

**Current Release Cycle**

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


**The Vision and US Gaps**

The joint Task Force’s proposed US terminologies and classifications strategy requires:

- Effective and coordinated governance responsible for policies and procedures for development, distribution, maintenance, licensing, and use
- Transparent and open business practices by all participating organizations, including algorithms, public input, and fees for sustainability
- Robust business automation tools to deliver efficient and reliable results including robust implementation guides
- Active collaboration in the international community for terminology and classification development and maintenance
- Sufficient long-term funding to support this strategy

This vision and its associated challenges are not unique to the US. Other countries have designed solutions to address governance, collaboration, transparency, and business process needs, or are doing so. In particular, the Task Force studied Australia, the United Kingdom, and Canada and found instructive lessons for the US.

“Current terminology efforts typically do not meet rudimentary development practices considered routine for software development in other industries or subject domains.”

—“Healthcare Terminologies and Classifications: An Action Agenda for the United States”
For example, these countries have centralized the governing structure responsible for terminologies and classifications and other health data standards. In Canada and Australia, the governing entities are independent, not-for-profit organizations. Today in the US, governance is fragmented, spread across multiple governmental agencies and private corporate and nonprofit entities. There is no deemed authority responsible for ensuring coordination of policies and procedures, nor an agreed-upon national policy to coordinate and at times adjudicate problematic issues and areas. Instead, each organization develops its own.

The Task Force also identified some crucial gaps between a workable vision and reality on the ground today. While HITSP designates terminologies and classifications system as the standards, it has neither the capability nor the mandate to ensure that the information content is complete and up to date. It also does not have the mandate to oversee how systems are deployed and used. These require highly specialized panels of experts who understand both the information content and its use and who can offer needed advice essential to a robust system.

Furthermore, healthcare data must be comparable worldwide to improve the effectiveness of global public health policies and programs. This is increasingly true in an era of highly mobile populations and rapidly spreading serious infections. At the same time, countries often pursue specific adaptations to meet their unique needs, for example, in performance measurement and payment.

Finally, today’s proprietary standard development models hamper development and maintenance of terminology and classification standards by prohibiting open publication of content. Terminology and classification systems are significantly lacking in any principled approach to validation and quality assurance. While this sufficed in the past, it is simply anachronistic to contemporary requirements.

Getting from the present state to the desired vision is challenging for the US because we begin in a highly fragmented, proprietary, and at times dysfunctionally competitive environment. As in other areas of health IT adoption, it is crucial to balance innovation with standardization. The Task Force fully understands this tension but believes it is important to manage it rather than act as though it is not an important issue. Achieving the vision will take additional study, funding, thoughtful consensus building, and a long-term commitment, but action is needed now to begin to address this agenda.

**A Short-Term Call to Action**

To achieve the vision in the longer term, the joint Task Force believes that the US must establish and fund, as soon as possible, a public or private authority responsible for ensuring the US has:

- Robust and up-to-date terminologies and classifications for interoperability between systems
- Standards for developing terminologies and classifications in the EHR and PHR, including implementation guides
- Principles and guidelines for development, distribution, and maintenance of systems and coordination across systems
- Effective, responsible, international participation

“**The Task Force believes that action on this agenda must be accomplished.**”

—“Healthcare Terminologies and Classifications: An Action Agenda for the United States”
• Timely and reliable industry guidance
• A coherent set of policies and procedures to ensure openness and performance for terminologies, classifications, and the systems that convert data encoded in one terminology or classification to another
• Business process automation to ensure cost-effective development of systems and cost-effective use by providers, payers, and other organizations

While federal and private entities have made genuine progress, the Task Force believes much more can be achieved. The industry must design solutions through consensus and secure commitments to move from the too-often-ineffective status quo. The Task Force urges implementing the following actions as the necessary steps to workable long-term solutions, as soon as possible.

Primarily, the Task Force recommends public funding for a research and development project involving other public and private stakeholders to develop specific strategies and plans for:

• Contemporary and standardized processes for development, adoption and maintenance of terminologies and classifications
• The structure, function, and operating practices for a US public/private authority to oversee terminologies and classifications
• Gaining commitment of terminology and classification stakeholders—developers, end users, and other service and technology suppliers—to principles and guidelines for open and transparent processes and solutions to enable cost-effective interoperability of complete and accurate information
• Designing the centralized authority, governance model, and principles for operation, as well as funding
• US participation in the IHTSDO

AMIA/AHIMA are prepared to lead such an effort.

Action Needed Now

There is significant progress in the US to better understand the essential role and characteristics of terminology and classification systems in health information systems and to make terminologies more broadly available in machinable forms. But the progress is not comprehensive, and it is not sustainable. The industry must design and implement open and transparent practices for development, distribution, and maintenance of terminologies classifications in the US.

The national health information network requires valid and reliable language tools, and this work must be moved to center stage. Working collaboratively with public and private stakeholders, our two organizations are willing to lead the important work of designing a road map for change.
Acknowledgements

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The American Health Information Management Association (AHIMA) is the
premier association of health information management (HIM) professionals. AHIMA’s
51,000 members are dedicated to the effective management of personal health information needed
to deliver quality healthcare to the public. Founded in 1928 to improve the quality of medical records, AHIMA is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning. To learn more, go to www.ahima.org.

The American Medical Informatics Association (AMIA) is the premier organization in the United States dedicated to the development and application of medical informatics in the support of patient care, teaching, research, and healthcare administration. AMIA links developers and users of health information technology, creating an environment which fosters advances that revolutionize healthcare. To learn more, go to www.amia.org.

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