

Policy Agenda for the Next Decade: Creating a Path for Graceful Evolution and Harmonized Classifications and Terminologies Used for Encoding Health Information in Electronic Environments

by Margaret M. Foley, PhD, RHIA, CCS; Regina M. Glenn, MS, RHIA, CCS; Peggy L. Meli, PhD, RHIA, LHRM; and Rita A. Scichilone, MHSA, RHIA, CCS, CCS-P, CHC-F

Introduction

Health information management (HIM) professionals' involvement with disease classification and nomenclature in the United States can be traced back to the early 20th century. In 1914, Grace Whiting Myers, the founder of the association known today as the American Health Information Management Association (AHIMA), served on the Committee on Uniform Nomenclature, which developed a disease classification system based upon etiological groupings. The profession's expertise and leadership in the collection, classification, and reporting of health data has continued since then. For example, in the early 1960s, another HIM professional (a medical record librarian) served as the associate editor of the fifth edition of the Standard Nomenclature of Disease (SNDO), a forerunner of the widely used clinical terminology, Systematized Nomenclature of Medicine Clinical Terms (SNOMED-CT). During the same period in history, the medical record professionals working in hospitals throughout the country were responsible for manually collecting and reporting disease and procedure information from medical records using SNDO.¹ Because coded data have played a pivotal role in the ability to record and share health information through the years, creating the appropriate policy framework for the graceful evolution and harmonization of classification systems and clinical terminologies is essential.

Key words: SNOMED-CT; ICD-9-CM; ICD-10-CM; classification; terminologies

As we near the close of the first decade of the 21st century, this article examines the continuing and future leadership role of the HIM profession in classification and clinical terminology policy development and research to provide an evidence base and compelling case for changes that enable greater acceptance of and ease of use of standard coding systems.

Recent HIM Involvement with Classification and Terminologies

The past few decades have seen significant changes in the processes and purposes for clinical data representation with a variety of classifications and terminologies. As the process has evolved, so has the

HIM practitioner's role, for example, moving from data abstractor/coder to terminology asset manager and health informaticist.² In 1979, when the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) was adopted for use in the United States, coded data were used mainly for research and hospital-based indexing and limited external reporting needs. In the late 1970s and the 1980s, coded data on floppy disks eight inches wide were mailed to data services to compile the abstracted data. Disease, operation, and physician indexes (reports) were sent back to the hospital on large piles of fanfold paper. Today, readily accessible encoded data are integral to every aspect of healthcare, including payment of medical claims, quality-of-care analysis, health information exchange, and pay for performance, as well as a variety of public health reporting and research uses. Presently, encoded data are produced in normal workflows as part of standard data sets sent electronically to payers and other business associates via secure data interchange standards. Aggregated coded data are now available on the Centers for Medicare and Medicaid Services (CMS) Hospital Compare Web site, on the National Center for Health Statistics (NCHS) Web site, and on individual state Web sites. A classification system, such as ICD-9-CM, organizes clinically descriptive information as output from healthcare encounters. Output code sets such as ICD-9-CM, Healthcare Common Procedural Coding System (HCPCS), and Current Procedural Terminology (CPT) are mainly used for administrative and statistical reporting, while clinical terminologies such as SNOMED CT and Logical Observation Identifiers, Names, and Codes (LOINC) are used to express clinical concepts required for software applications that support direct patient care.³

Options for clinical data representation have grown. More than 25 classification and clinical terminologies are used to represent healthcare data captured within the electronic health record (EHR) environment. However, little coordination exists for the development, maintenance, and implementation of these various code sets.⁴ A unified model of change must be made clear to policy makers to build the foundation that will support a new kind of healthcare marketplace. The graceful evolution along with harmonization efforts between the standards organizations responsible for revision of these useful systems will go a long way toward fulfilling the promise of electronic health records. As long as we continue to wrestle with the tower of Babel that comprises our coded data systems today, it is very difficult to achieve the benefits of comparative data needed for evidence-based research.

HIM Expertise in Classification and Terminologies

The HIM profession's long history of working with classification systems and terminologies has equipped practitioners with the skills to effectively implement and use various code sets, transition and translate from one system to another, conduct research related to the use of the code sets, and advocate for needed policy changes.

Over the years, HIM practitioners have managed several substantial transitions in the use of coded data systems. Examples of widespread adoption of new systems that required implementation and development of expertise in using the classification systems include the shift from the Hospital International Classification of Diseases Adapted (HICDA) to ICD-9-CM in the late 1970s, the adoption of HCPCS/CPT to report hospital services in the late 1980s, and the more recent challenge of identifying appropriate terminologies for capturing problem list information within an electronic health record system.⁵⁻⁷ Additionally, HIM professionals have been instrumental in assisting physician practices with requirements of payers, including the government, for submission of diagnosis and procedure codes on claims for professional services at the end of this decade.

Mapping is the process by which content in one code set (classification or terminology) is linked to content that is the same or substantially similar in another code set.⁸ Mapping is essential when a new system is adopted for longitudinal data comparison. Data maps allow data captured in both the old and new systems to be linked or compared for specific use cases. Mapping also allows for the reuse of data captured with one code set for purposes requiring another code set. For example, data originally represented with SNOMED-CT concepts could be mapped to ICD-9-CM codes for billing purposes.⁹ Successful mapping initiatives require a thorough understanding of the map's purpose and of the structure and use of the source and target code sets. HIM professionals have demonstrated extensive expertise in map development to link classifications to other classifications, procedure coding systems, and reference

terminologies. For example, Butler has played a critical role in the development of the general equivalence mappings created to facilitate the translation of data between ICD-9-CM and ICD-10-CM/Procedure Coding System (PCS).¹⁰ Wilson has been instrumental in the development of a LOINC to CPT mapping.¹¹ Imel worked closely on the development of a SNOMED-CT to ICD-9-CM mapping.¹² The International Health Terminology Standards Development Organization (IHTSDO) uses HIM professionals to develop the SNOMED-CT to ICD map that is included in the current national release.

Classification and terminology–related research conducted by HIM professionals has greatly expanded the body of knowledge within this domain. The following examples illustrate the wide variety of topics studied. In 2008, Giannangelo and Fenton examined the use of SNOMED-CT in EHRs.¹³ Fenton and Gamm (2007) examined the effect of financial incentives, practice characteristics, and regulatory guidelines on the use of coding and documentation technology by physician practices.¹⁴ In 2005, Parmanto et al. provided a framework for designing a healthcare outcome data warehouse.¹⁵ Watzlaf et al. (2007) studied the effectiveness of ICD-10-CM for reporting public health data.¹⁶ In 2000, Berthelsen conducted a nationwide analysis of ICD-9-CM data quality.¹⁷

On an ongoing basis, the HIM profession has effectively advocated for regulatory and legislative changes related to the implementation of ICD-10-CM/PCS, the adoption of standardized clinical terminologies, and workforce training needed to implement new classification and terminologies.^{18–20} This extensive experience with many aspects of terminology and classifications uniquely positions this profession for identifying and creating related policy and research initiatives for the future of the U.S. health system. In 1963, the American Association of Medical Record Librarians and the American Hospital Association issued a joint statement to administrators and all medical record librarians in the United States for indexing hospital records by diseases and operations using HICDA. Collaboration was important to stakeholders then, and today the stakes are higher and many more groups are involved in healthcare delivery than ever before.

Classification and Terminology Issues Needing Policy and Research

As evidenced by the description of the current state of the practice, policies are needed in the areas of expanded work force development, funding support for contemporary terminology preparation including ICD-10-CM/PCS implementation, development of data maps, and creation of a centralized terminology management and maintenance organization. We must have a consistent and comprehensive way to leverage technology so that machine-readable processes reliably support the workflow and innovations can be shared. Time and resources must not be wasted on disjointed update cycles and proliferation of systems that are unable to exchange data without expensive customized interfaces. All these activities require public policy support with private industry cooperation. Graceful evolution planning is required to avoid future ICD upgrade dilemmas where the cost becomes prohibitive when a policy delay creates a data disparity that is difficult to resolve without extraordinary effort.

Millions of dollars are lost within the healthcare system due to its vulnerability to fraudulent and abusive billing practices, identity theft, and other criminal or unethical behaviors. This is another major challenge to the American healthcare sector requiring the attention of policy makers combined with the vigilance of the health information management profession.²¹ This issue is beyond the scope of this article.

Work Force Development

Many experts have identified the training and retraining needed to prepare a work force qualified to implement, maintain, and reap the benefits of electronic health record systems and health information exchange in the United States.^{22–26} To date, efforts at federal legislation to support widespread training have failed.²⁷ Advanced-level educational programs (e.g., master’s level and beyond) and subspecialty education and training opportunities (e.g., terminology mapping, data structure, and data analytics) are needed. Policy efforts that will provide incentives for private support or publicly funded approaches to widespread educational opportunities for ground-level knowledge workers in applied informatics and the

use of encoded data systems are needed to spur progress toward a less costly, more accurate data management process within healthcare provider organizations.

ICD-10-CM and ICD-10-PCS

At the dawn of the millennium, the coding community expected movement toward the latest version of ICD for disease classification and a replacement for the ICD-9-CM procedure classification. Now, almost nine years later, there is movement toward using the U.S. adaptation of ICD-10 and a specially developed procedure classification. Professional leadership is encouraged to support and push for national adoption of this emerging global standard. ICD-10-CM and ICD-10-PCS are available now for system implementation. Since HIM professionals are experts in code data management in health record systems, they are well prepared for the upcoming changes. ICD-10-CM and ICD-10-PCS bring major changes in format, size of the code sets, and detail. Although the change will bring improvements in code coverage and granularity, expansion room, and comparability with the rest of the world, a federal mandate to switch reporting in these systems will also bring implementation challenges and costs, create extensive training needs, necessitate educational program adoption, and present significant economic challenges for system developers that support healthcare providers.

ICD-10-CM and ICD-10-PCS adoption requires new policies regarding implementation, training, education, and financing. Policies regarding how the implementation should occur, what training and education is mandatory, and who should receive that training and education, along with policies regarding the implementation costs, economic advantages, and economic disadvantages, will have to be created and put into place. Work must begin now to advocate for a national central authority to manage all required use of classification systems or other standard terminologies. This public-private entity should be charged with developing a process to ensure an evolutionary approach for upgrades required in systems consistent with the rest of the world in order to retain global comparability and data sharing. The policies and regulations set in place now will serve as guides for future policies in the creation and implementation of data sets and classification systems.

Mapping Initiatives

Mapping between clinical terminologies and classifications is a resource-intensive process that requires input from the source and target code sets and users familiar with the intended use of the map. Maps are an important feature of an interoperable and highly functioning health information system because they allow for the efficient process of collecting information once and reusing it for a variety of needs. Efforts to date by the National Library of Medicine, standards organizations, and private vendors to build maps have not been well validated due to the resources involved to conduct appropriate interrater reliability testing and fully validate and test the reliability of the map. To support a national healthcare technology agenda, policies must be implemented to identify a coordinated approach to map development, validation, and maintenance.^{28,29} Eventually a certification process using recognized map development principles, heuristics, and guidelines may be used to ensure reliability of maps for a particular use case.

One area of concern is the proliferation of terminologies, vocabularies, and classification systems or extensions of standards, which causes problems with data exchange between organizations. For example, there are at least 13 terminologies such as SNOMED-CT and LOINC recognized for clinical practice by the American Nurses Association (ANA) via the Nursing Information and Data Set Evaluation Center (NIDSEC).³⁰ MEDCIN, another clinical terminology, is used as a basis for some electronic health record systems.³¹ Another common classification systems used throughout the United States and the world is the Diagnostic and Statistical Manual of Mental Disorders, a classification for mental health professionals developed by the American Psychiatric Association. As a number of other terminologies and classifications exist and more are being developed throughout the world, the job of mapping becomes more complicated.

Multiple clinical terminologies have been recognized by professional organizations or adopted as a basis for electronic health records. The practice of medicine today requires specialized vocabularies for expression of facts, so it is important for contemporary coded data systems to avoid overlap and harmonize to complement rather than compete with each other. When two or more systems express the same concept in different ways, data cannot be shared with assurance of meaning the same thing unless there are map equivalents or formal integration between systems. A preferred future includes coordination through a centralized authority for terminology management. This facilitates control over inappropriate proliferation of disparate terminology standards and creates less complexity for health information exchange.

Centralized Terminology Authority and Governance

Electronic systems use coded data to express clinical concepts that make up the health record. Standard coding systems are designed to meet specific information retrieval and data analysis requirements. As the quest for interoperability between systems and the importance of data consistency and integrity intensifies, a critical need for infrastructure emerges. At the present time, there is no system designed to support the emerging needs of a networked healthcare delivery system. A task force of the American Medical Informatics Association (AMIA) and AHIMA developed an action agenda in 2007 to distill the issues, identify the problems, and recommend appropriate steps to resolve the lack of uniformity in terminology and classification management and release cycles. Without a central authority for healthcare terminology use in the United States, the cost of “no action” is significant. Updates to coding systems increase maintenance costs and lead to challenges in data trending. Coordinated governance is required for policies and procedures for development, distribution, licensing, and use of the standard terminologies required for reporting within the United States and for data comparability with the rest of the world.

Conclusion

Models created by HIM professionals to identify needed policy and research related to classification and terminology exist and work well. Examples include the 2007 AMIA and AHIMA Terminology and Classification Policy Task Force (discussed above) and the 1999 AHIMA Coding Futures Task Force.³² The Coding Futures Task Force used a process called scenario planning to consider how 1) the evolution and growth of medical terminologies, 2) enabling technologies for coded data, and 3) the emergence of an information economy might affect coding and terminology practice of the future. The 1999 Coding Futures Task Force members were visionaries. This group of experts accurately foresaw an environment in which multiple terminologies and standards would need to be managed and that technological breakthroughs and infrastructure improvements would change the domains of classification and terminology systems. In this new world, healthcare data are relied upon even more so for important functions ranging from management of healthcare for individuals and populations to outcome evaluation and research. Thus the need for quality data to support all these functions is essential. To reach the full potential of an efficient and effective process for health information exchange, more work needs to be done in evidence-based research and advocacy for new public policies for healthcare. The policy recommendations presented here provide a framework for HIM professionals to lead us forward into the next decade of clinical classification and terminology.

Margaret M. Foley, PhD, RHIA, CCS, is a clinical associate professor in the HIM program at Temple University in Philadelphia, PA.

Regina M. Glenn, MS, RHIA, CCS, is a HIM program director at Davenport University in Grand Rapids, MI.

Peggy L. Meli, PhD, RHIA, LHRM, is a human performance engineer with Lockheed Martin Simulation, Training and Support in Orlando, FL.

Rita A. Scichilone, MHSA, RHIA, CCS, CCS-P, CHC-F, is the director of practice leadership for AHIMA in Chicago, IL.

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