E-HIM Strategic Initiative: Core Data Sets

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A strategic focus for AHIMA is to facilitate the transition from paper to electronic records and redefine HIM roles in the process. Identifying and establishing standards in electronic health information management (e-HIM™)—the management of health records, data, and information collected, processed, stored, and transmitted using electronic technologies—will position AHIMA and its members as leaders in the transition process as health information management moves from a paper-based environment to an electronic one.

What Are Core Data Sets?

The Nova Scotia Department of Health defines core data sets as "the shareable electronic patient demographic and essential 'persistent' clinical information necessary to provide informed medical care."[1] Data sets provide the means to record and communicate the most relevant and timely facts about a patient's health information and healthcare. Patient information developed using core data sets must be readily available to the patient's healthcare providers to facilitate continuity of care.

The healthcare industry has a legacy of core data sets because there has not been a standard in which to map a comprehensive model. Because of this lack, core data sets have been developed in various settings. The industry is now moving toward identifying a comprehensive data set that maps back to electronic health record (EHR) functions.

The comprehensive standard for core data sets should be developed in the public domain in conjunction with voluntary, standards developing organizations such as Health Level Seven (HL7) and the American Society for Testing and Materials (ASTM), so they may be implemented in proprietary EHR systems and also used as a fully interoperable transport standard between EHR systems.

Interoperable electronic information exchange is vitally important as it impacts both patient safety and the cost of healthcare. A comprehensive core data set supports this goal by allowing for:

- Data transfer necessary for continued patient care in this time of short stays and mobile patients
- Consistency in data transfer
- Consistent information submission for reporting agencies
- Easy data exchange without increasing costs

The goal of the EHR is real-time collection, done once, with all downstream users benefiting from the process, as well as avoiding duplicate or inconsistent data collection.

Background

On April 26, 2004, President Bush announced to the American Association of Community Colleges that:

> Within 10 years, every American must have a personal electronic medical record... The federal government has got to take the lead in order to make this happen by developing what's called technical standards… We've set out money to encourage demonstration projects that will show the healthcare providers the need to use electronics to make their records system more modern.[2]

AHIMA has anticipated this goal for many years. Previous projects aimed at core data sets and standards development include and are available to AHIMA members in the FORE Library: HIM Body of Knowledge at www.ahima.org:

- Amatayakul, Margret. "NCVHS: Uniform Data Standards for Patient Medical Record Information (PMRI)." AHIMA Convention Proceedings, October 2001.
- Brandt, Mary. "Health Informatics Standards: A User's Guide." *Journal of AHIMA* 71, no. 4 (2000): 39–43.
- "Core Data Sets for the Physician Practice Electronic Health Record." AHIMA e-HIM Practice Brief series, no. 5, October 2003.
- Murphy, Gretchen, and Mary Brandt. "Health Informatics Standards and Information Transfer: Exploring the HIM Role." *Journal of AHIMA* 72, no. 1 (2001): 68A–D.

AHIMA has been working with HL7, a standards developing organization, to develop electronic standards. The mission of HL7 is:

> To provide standards for the exchange, management, and integration of data that support clinical patient care and the management, delivery, and evaluation of healthcare services. Specifically, to create flexible, cost effective approaches, standards, guidelines, methodologies, and related services for interoperability between healthcare information systems.[3]

In April 2003, the HL7 board of directors authorized the development of a functional model of an electronic health record system, believing that the EHR functional model will improve the quality of care, reduce the cost of care, and provide better access to clinical data.[4] On April 7, 2004, HL7 announced that the Version 3 Standard: Patient Administration, Release 1 passed the ballot stage and was approved as a draft standard for trial use (DSTU).[5]

Knowing that once this work was approved as a DSTU, AHIMA established a work group in January 2004 to research the core data sets and current standards in the healthcare industry and to evaluate whether those standards can possibly be linked to the HL7 functional model. It is important to note that while there is likely much to be learned from looking at data standards developed outside the United States, specifically the CEN/TC 251 European Standardization of Health Informatics, the work group focused on what is and what was being developed within the US.

Previous Efforts

Other organizations have attempted similar projects in the past. The AHIMA work group acknowledges these efforts, which include:

- "Core Health Data Elements: Report of the National Committee on Vital and Health Statistics," 1996
- America National Standards Institute Health Informatics Standard Board undertook a similar project in conjunction with the development of the HIPAA regulations in 1996 (released in 1997) titled the "Inventory of Health Care Information Standards Pertaining to The Health Insurance Portability and Accountability Act (HIPAA) of 1996 (P.L. 104-191)"
- National Alliance for Health Information Technology's Standards Directory (released to the public in June 2004)

Collection Process

AHIMA established the core data set work group to explore information from a variety of sources, searching for core data sets with applicability to the HL7 functional model. The purpose of cataloging these data sets was threefold:

1. To ultimately map the data elements back to the EHR functional model
2. Help build the content for the EHR functional model in the process
3. Build a high level of confidence that the EHR will be relevant to the existing core data sets

The compiled list is not comprehensive, as there are a large number of data sets, both those that are available to the public and those that are private, and access to all within the scope of the work group was not possible.

The work group looked at organizations, their scope or focus, the type of data standards, and whether the group creates, approves, supports, or endorses established standards. Additionally, data sets were generally evaluated to see if they had any possible link to the HL7 standards and could compliment them. In many cases, the work group was able to indicate areas of a possible match.

While this process was helpful in identifying possible core data sets that can be harmonized with the HL7 ballot, we have only identified possibilities. Additional work is needed to discover which core data sets fit actual HL7 functional descriptions.

The result of the group's work is Appendix 1, available online at www.ahima.org in the FORE Library: HIM Body of Knowledge.

The Continuity of Care Record

One of the core data sets evaluated by the work group was the Continuity of Care Record (CCR), developed by ASTM, the Massachusetts Medical Society, the Healthcare Information and Management Systems Society, the American Academy of Family Physicians, and the American Academy of Pediatrics. The CCR is defined as a "document standard for a summary of personal health information that clinicians can send when a patient is referred and that patients can carry with them to promote continuity, quality, and safety of care."[6] The CCR may be used as a vehicle to exchange clinical information among providers, institutions, or other entities.[7]

The AHIMA work group found much of the draft CCR relates to the HL7 functional model. See Appendix 2 for a mapping model (available to AHIMA members only), which can be found online at www.ahima.org in the Body of Knowledge.

Challenges of a Comprehensive Core Data Set Adoption

Appendix 1 indicates one of the largest challenges to a comprehensive core data set adoption. There are many activities in place by numerous accredited standards developing organizations, trade associations, government agencies, and individual companies. The users of these standards cover the full spectrum of healthcare participants, from consumers to providers to payers, and each group has different but related sets of requirements related to standards. These efforts must be coordinated in order to develop complimentary or corresponding vocabularies and enable intraoperability.

The demand for online, real-time access to medical information through standardized data sets is critical for improving quality and safety in healthcare. This must be accomplished while preserving the confidentiality and privacy of the information, while at the same time controlling healthcare costs.

Conclusion

The adoption of health information standards is critical to the success of implementing an EHR. The number of organizations working independently to develop these standards complicates the development of a single standard, and the work will be arduous if the president's goal of an electronic health record for most Americans is to be met within 10 years. There is an enormous need for coordination of all efforts to leverage the synergy of the various efforts, harmonize vocabularies, and enable interoperability. HIM professionals have an obligation to use their unique skill sets and be involved in the groundbreaking activity of adoption of core data sets.

Notes

1. Nova Scotia Department of Health. "Nova Scotia Primary Health Care Renewal Projects." Available online at www.gov.ns.ca/health/phcrenewal/Core_Data_Set.pdf.
2. "President Unveils Tech Initiatives for Energy, Health Care, Internet." Available online at www.whitehouse.gov/news/releases/2004/04/20040426-6.html.
3. Health Level Seven (HL7). "What is HL7?" Available online at www.HL7.org/about.
4. HL7. "EHR Project Overview." Available online at www.hl7.org/ehr/documents/overview.asp.
5. "Health Level Seven (HL7) Recently Announced that Version 3 Standard: Patient Administration, Release 1 Has Passed the Ballot Stage and Has Been Approved as a Draft Standard for Trial Use (DSTU)." Health Level Seven press release. April 2004, Ann Arbor, MI.
6. American Academy of Family Physicians. "Continuity of Care Record." Available online at www.aafp.org/x24962.xml.
7. Massachusetts Medical Society. "Continuity of Care FAQs." Available online at www.massmed.org/pages/ccrfaq.asp.

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