Making Sense of Standards: New HL7 Group Seeks to Coordinate a Multitude of Health Data Standard Efforts

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Early efforts to create health data standards were led primarily by vendors, with support from providers. Vendors were right to take the reins on these standards, as most addressed technical issues related to interfacing best-of-breed systems or transmitting transaction data for reimbursement. We have come a long way since these initial efforts.

Current standards address data items with related attributes, electronic health records, dataexchange, clinical decision support, research, and other topics related to content and use of clinical data. These efforts are driven almost exclusively by those with technical expertise but with limited clinical experience and knowledge.

Everyone into the Water

Fortunately, the clinical community has become aware of the need for clinically oriented health data standards such as data elements and associated terminologies, and it has begun independent efforts to create these resources.

There are more than 50 groups with active projects developing various health data standards. Their focuses include data elements, minimum data sets, clinical models, templates, archetypes, and metadata registries. Organizations engaged in related activities include:

- Health Level Seven (HL7)
- Clinical Data Interchange Standards Consortium (CDISC)
- Cancer Biomedical Informatics Grid (caBIG)
- US Health Information Knowledgebase (USHIK)
- CDC Data Elements for Emergency Departments (DEEDS)
- Open Group's Universal Data Element Framework (UDEF)
- Tolven Healthcare Innovations
- American Dental Association
- ASTM
- Detailed Clinical Models Collaborative (DCM)
- openEHR
- National Cancer Institute (NCI)
- National Heart, Lung, and Blood Institute (NHLBI)
- National Institute of Allergy and Infectious Diseases (NIAID)

Many other professional clinical societies also have efforts under way, such as the End Stage Renal Disease core data set from the Centers for Medicare and Medicaid Services and the Forum of Networks initiative, the International Organization for Terminology in Anesthesiology (IOTA), and the National Cardiovascular Data Registry (NCDR) from the American College of Cardiology Foundation. The Healthcare Information Technology Standards Panel just recently initiated an effort to create basic demographic data elements

Unfortunately, these efforts are not coordinated and often lack technical awareness. The overlapping and inconsistent results also defeat the goals of semantic and functional interoperability. Much of the work is based on the ISO standard ISO 11179.

HL7's Effort to Coordinate Standards

HL7 recently formed the Clinical Interoperability Council (CIC) to bring the healthcare community together to coordinate the process and develop content and clinical functionality standards. HL7 invites all professional clinical specialty organizations and related interest groups to participate in defining the processes, generating clinical content, identifying required tools, and influencing the dissemination processes.

Each participating clinical group is asked to identify two to five individuals to represent the clinical domain. These individuals help define the shared methodology, lead their organizations' contributions, and advocate the production and use of health data standards.

The clinical domain work is expected to be performed within the regular forums of each clinical society, consistent with agreed-upon procedures. The work then will be delivered in a common resource. Any overlaps, interfaces, key decisions, and issues that come up across domains will be dealt with at HL7 meetings following proven well-documented decision-making processes. Common interests and new projects also will be identified and defined at these joint meetings. The first meeting is scheduled for September 20 at the HL7 plenary meeting in Atlanta, GA.

CIC is expected to deal only with clinical content and other clinical aspects of the standards being created. CIC products will then be passed into the "technical" part of HL7 to populate the appropriate standards. HL7 believes that it is important that CIC focus only on the clinical component and not on making informaticists or technologists of this community.

Interoperability depends on precise, unambiguous, atomic terms with a full set of attributes including name (terminology), definition, data type, units, value set, and other attributes. If a master set of these data elements is defined and maintained, most of the impediments associated with obtaining interoperability can be overcome. An organization would not be expected to use all the data elements; however, it would use only data elements that are defined in the master data element set.

Initially, CIC will work on creating a master set of data elements. This project will include creating a well-documented set of procedures, including an inventory of existing collaborators, initiatives, and resource tools to support the creation and loading of data elements and terminology into a shared repository. Significant experience exists in the group that will expedite this phase. The generated terminology and data elements then will be compiled, enabling electronic dissemination, use, and integration with data models and clinical applications.

Great Expectations

CIC is anticipated to become a very important group, influencing health data standards policy and methodology decisions. Future activities might include defining data element sets transmitted based on clinical workflows (e.g., an acute cardiac patient being transferred from a community hospital to a fully equipped cardiac care center) or the content and knowledge definitions for decision support algorithms, disease management protocols, query scenarios, and information workflows.

Fostering interaction between this clinical community and the technical activities of HL7 is critical. CIC must leverage the success and technical knowledge of HL7 while supporting clinical experts in understanding what and how to influence the content of standards.

There are already several groups within HL7 that would interface with the new council. These groups include the electronic health records group, the vocabulary group, patient care group, the structured documents group, and the regulated clinical research information management technical committees, as well as a number of clinical domain specialty special interest groups representing cardiology, anesthesiology, pediatrics, and emergency medicine. CIC is expected to complement and serve as an additional resource to the many activities already under way in HL7.

The healthcare community must come together in a coordinated effort to generate a single, interoperable product to solve a critical problem we all share. With the proliferation of initiatives, time is important. HL7 is working with AHIMA, CDISC, and others to launch and support this project. HL7 provides an open consensus-based process and your leadership, support, and contributions are invaluable.

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