Advancing Secondary Data Uses through Data Standards: HL7 Project Advances the “Collect Once, Use Many Times” Paradigm

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Organizations must consider a multitude of data standards and reporting requirements when capturing and aggregating healthcare data. These standards and requirements are vast in scope and complex to implement.

To help address these challenges, healthcare desperately needs clearly defined and harmonized clinical data content standards that support direct patient care, secondary data use, and widespread data exchange.

Clinical data content standards are typically developed in disease- or therapeutic-specific contexts by many distinct professional communities, such as quality measurement, research, and public health. These standards must be harmonized with complex national and international data standards and specifications.

That process, however, is difficult. The learning curve, technical skills, and costs required to conduct disease-specific data content standard projects are significant, and the potential for duplicate effort and conflicting data standards across clinical content areas is very real. For these reasons, the industry benefits from an open, standards-based process that includes:

- Thorough review of existing data content standards
- Analysis of the data requirements for both patient care and secondary uses
- Formal linkage of these requirements to EHR information models and functional specifications

To ensure that the final standards are useable and useful to all stakeholders within the disease domain, a significant and deliberate effort must be made to vet this information with numerous experienced and representative domain experts at each stage.

A Health Level Seven International (HL7) group has undertaken a project to address these issues by developing data standards for type 1 diabetes that would also allow secondary data uses.

Prototype Project Advancing Efforts

In early 2009 an innovative group of stakeholders in the HL7 community convened to create an approach to define clinical data content requirements for type 1 diabetes in a way that would allow such data to be collected once and used many times. The group launched the Diabetes Data Strategy (Diabe-DS) Prototype Project with a goal to develop a standards-based process and method to analyze and harmonize requirements that satisfy needs for patient care and secondary data use scenarios.

The Diabe-DS project team operates an open, volunteer membership model. Documentation is developed and maintained on a publicly accessible project Wiki to enable transparency and broad stakeholder input.[1] Volunteers represent diverse perspectives and include experts in HIM, informatics, EHR design and implementation, information technology, clinical research, epidemiology, and endocrinology.

The project's focus is on harmonizing data elements from various secondary use requirements. To date, the project team has collected and analyzed more than 250 relevant data elements from a variety of sources, including multiple clinical research protocols, quality measures, and public health data standards, in addition to international data requirements from Canada and the Netherlands.

The project team subsequently categorized the data elements by topic (e.g., physical exam, medications, problem/diagnosis, symptoms, etc.) and organized them into user-friendly information models, leveraging external standard information models, such as those defined by the former Health Information Technology Standards Panel wherever possible.[2,3]

Because the project leveraged existing artifacts, the process to analyze and harmonize similar concepts was critical to minimize duplicate efforts. Several "mini use case" scenarios were developed to help guide and inform the work effort and describe how data should be captured as part of the clinical care process and distinct data reuse scenarios (such as quality measurement or public health reporting).

Depending on the use case, the combination of data element attributes often present similar, yet distinctly different data elements. For example, a research use case scenario might define ketoacidosis using a LOINC code or lab value, whereas a quality measurement use case scenario might define ketoacidosis based on a SNOMED CT code from a problem list. Both use cases seek to identify patients with ketoacidosis, but each leverages different data sources and value sets to meet the defined need. For this example, in the context of the Diabe-DS project, two separate data elements would be defined.

Another critical component of the project involves developing user-friendly representations of the data elements in a Unified Modeling Language format with links to other national and international standard representations. This aspect of the project has been extremely valuable in helping dissect the expert-defined data elements into their most "atomic" data elements (the lowest level data point in which a concept can be collapsed) available or derivable from a patient's EHR. This process also helped identify gaps in existing national and international standards for future updates and enhancements.

Lastly, the Diabe-DS project aims to test the feasibility of linking key atomic-level data elements to EHR system functional requirements to advance EHR systems in a manner that enables appropriate and reliable capture and reuse of critical healthcare information.

Benefits to the Healthcare Industry

The Diabe-DS prototype is a novel project that is harmonizing data requirements for multiple secondary uses, and in turn harmonizing those elements with clinical data capture representations. The processes developed and lessons learned are applicable to other clinical domains.

Further, this project harmonizes data definitions, which are required to thoughtfully apply the standards, ensure high quality data capture at the point of care, and realistically repurpose the data for multiple use cases. If successful, the artifacts and methods will be applied to the development of common data elements for multiple other disease domains.

Additionally, this work provides a solution to replicate the "collect once, use many times" model, which will ultimately increase speed and efficiency of evidence-based care, population or public health surveillance, and quality and patient safety monitoring, ultimately improving healthcare science and care quality for patients everywhere.

Notes

1. Health Level Seven International. "EHR Diabetes Data Strategy." Available online at http://wiki.hl7.org/index.php?title=EHR_Diabetes_Data_Strategy.
2. Health Information Technology Standards Panel. "TN906–Quality Measures Technical Note." Available online at www.hitsp.org/ConstructSet_Details.aspx?&PrefixAlpha=5&PrefixNumeric=906.
3. Health Information Technology Standards Panel. "C80–Clinical Document and Message Terminology Component." Available online at www.hitsp.org/ConstructSet_Details.aspx?&PrefixAlpha=4&PrefixNumeric=80.

Additional Resources

Journal of AHIMA articles are available online in the AHIMA Body of Knowledge at www.ahima.org.

Birnbaum, Cassi. "One-stop Shop: An HIM Department's Journey to Centralize Core Data Services." *Journal of AHIMA* 78, no. 8 (Sept. 2007): 40–46.

Cimino, James J. "Collect Once, Use Many: Enabling the Reuse of Clinical Data through Controlled Terminologies." *Journal of AHIMA* 78, no. 2 (Feb. 2007): 24–29.

Hammond, William Edward, Charles Jaffe, and Rebecca Daniels Kush. "Healthcare Standards Development: The Value of Nurturing Collaboration." *Journal of AHIMA* 80, no. 7 (July 2009): 44–50.

Hammond, W. Ed, and Brian McCourt. "Making Sense of Standards: New HL7 Group Seeks to Coordinate a Multitude of Health Data Standard Efforts." *Journal of AHIMA* 78, no. 8 (Sept. 2007): 60–61.

Richesson, Rachel L., and Jeffrey Krischer. "Data Standards in Clinical Research: Gaps, Overlaps, Challenges and Future Directions." *Journal of the American Medical Informatics Association* 14, no. 6 (2007): 687–96.

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