

Health information technology data standards get down to business: maturation within domains and the emergence of interoperability

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Health information technology (HIT) standards are not new. Arguably, they date to the canonical list for causes of death in the London Bills of Mortality of 1528, which was later formalized during the middle of the 19th century into what we now recognize as the International Classifications of Diseases (ICD). Beginning in the middle of the 20th century, HIT standards evolved beyond vital statistics and began to capture data related to clinical morbidity, thereby facilitating nascent decision support, outcomes research, evidence generation, and health care quality improvement initiatives. Alas, with that expansion came a proliferation of competing and overlapping standards, giving substance to the critical aphorism that “the only nice thing about standards is that there are so many to choose from.” The emergence of large-scale computerization throughout health care in the last half century has further accelerated this divergence of standards, creating a veritable cacophony of noninteroperable medical record content, data exchange formalisms, and data silos.

This special issue on data standards was prompted by a palpable maturation among HIT standards in clinical practice and biomedical research in just the last decade. There has been remarkable cooperation among HIT standards development organizations, including the new agreement to harmonize and coordinate overlapping content in Systematized Nomenclature of Medicine—Clinical Terms (SNOMED CT) and Logical Observation Identifiers Names and Codes (LOINC), and the historic cooperation between the SNOMED CT and ICD developers to create ICD11 on the semantic foundation of SNOMED CT. In parallel, there have also been unprecedented consolidation and harmonization of orthogonal standards into an emerging suite of specifications for health and biomedical observations such as the ONC Meaningful Use and the NIH Common Data Element efforts within the United States. While far from comprehensive or fully coherent, the current state of HIT standards is at a turning point, where we appear to be making more effective progress and practical applications than most would have predicted from the bad old days of just a few decades ago. The goal of this special focus issue of the *JAMIA* is to provide a forum for the latest evaluation of HIT standards in contexts of Meaningful Use, biomedical research, and big

data. *JAMIA* editors solicited this focus issue with the hope that HIT standards and recent consolidation initiatives had indeed adequately matured so that the informatics community would respond with successful demonstrations for how particular standards can and will effectively support biomedical and population health applications. We thus broadly solicited scholarly contributions that would address evaluation, application, consolidation, or domain extensions of biomedical data standards within the framework of biomedical informatics, and we explicitly requested authors to provide supporting data, rigorous evaluation, or evidence of relevant consensus to support their work. We were not disappointed and enjoyed the opportunity to review many rich submissions for this highly competitive volume. We present in this issue the best of these submissions, collectively covering wide spectra of domains, applications, and approaches. The selected articles represent the full continuum of molecular, clinical, organizational, and population data, address a range of objectives from evaluation to application, and illustrate multiple approaches to HIT standards and interoperability from domain-specific to broad integration.

Exemplifying the increasing coordination between multiple standards is the characterization of genetic data, as standardized by the Human Gene Nomenclature Committee with LOINC laboratory reports for genetic data.¹ This represents the reuse of existing standards for genomic specification within an established framework for health data exchange and messaging. In work that also binds the basic science world to clinical practice, this history and success of the Human Proteome Organization Proteomics Standards Initiative details the broadly-based collaborations that have led to an increasingly mature and practical specification of proteomic findings.² Similarly, poison control centers have demonstrated how they can collaborate with emergency departments by adopting their reference model for health information exchange to work within the HL7 Consolidated Clinical Document Architecture standard.³ This is an elegant demonstration of a community with an important clinical data exchange requirement choosing to embrace and enable an emerging mainstream mechanism, as opposed to the traditional solution of building yet another syntax to implement their reference model. On a more abstract

level is the description of how the venerable Clinical Element Models can be systematically transformed into the openEHR archetype representations by invoking shared Web Ontology Language (OWL) formalisms.⁴ This demonstrates how the Clinical Information Modeling Initiative, through fostering community consensus on modeling syntax and languages, can stimulate informatics work that can harvest legacy content while strengthening standards harmonization and coherency.

Demonstrating that not all standards are final or even fully robust, methods for discovering errors in large-scale terminologies, specifically SNOMED CT, substantially enhance the scale and completeness of quality assurance work within complex data standards.⁵ Such work has consistently demonstrated room for improvement in these large data specifications, and these standards together with their user communities are by far better for it. Correspondingly, a systemic review of the HL7/LOINC Document Ontology Role Axis highlights many shortcomings in representing clinical-role behaviors that are encountered in real-world resources.⁶ Such work, again, can and will feed back to the standards developers, making these components more robust within suites of HIT data standards. The pattern of empirical discovery is also evident in the systematic “bottom-up” evaluation of nursing documents across many standards developing organizations (SDO) contributors.⁷ Specifically, in the generation of eMeasures, clear and specific refinements of many clinical standards are needed and will, no doubt, come about because of these careful, reality-based evaluations.

Continuing within the nursing domain, investigators demonstrate how collaboration across organizations working with established standards enables detailed and informatics messaging around hospital-acquired pressure ulcers.⁸ These efforts can directly address ONC challenges for the development of mobile applications to improve clinical care around this all too frequent complication of chronic care. Expanding from the specific to the strategic, a consensus community developed national action plans for collecting comparable nursing data to support secondary use as well as clinical care.⁹ By and large, nursing data is not yet systematically integrated into electronic health records, impoverishing both the care process and outcomes research. This national action plan promises to advance the evaluation and practice of nursing by supporting the generation of comparable nursing data for quality reporting and translational research.

Domain-specific adaptations of existing data models and semantics obviously can extend to many other areas of health care. An evaluation of an oncology-specific implementation guide of the consolidated clinical data architecture standard is described as a case example, which completed the full HL7 ballot process.¹⁰ The paper also describes its clinical implementation by two organizations, which validated the overall strategy of domain-specific adaptations of established HIT standards. In a related domain-specific HL7 effort, the maturation of data elements for emergency departments is described.¹¹ This process also involved the use and mapping of many related data standards. Meanwhile, the critical evaluation

of semantics and value set binding to clinical models in the domain of heart failure demonstrates a pathway for semantically accurate interoperability in complex clinical domains.¹² They were able to simplify that complexity into a framework of semantic patterns, enabling coherent access to heterogeneous data resources.

Finally, the harmonization of distributed, heterogeneous clinical data into a shared specification based on HL7’s Virtual Medical Record specification illustrates how data standards can help integrate existing data, even if those data were not collected with fully specified or shared standards specifications.¹³ This paper shows how meta-standards can facilitate the integration of patient information from heterogeneous sources, a fundamental and all too common requirement for clinical decision support systems in the United States.

Taken together, the papers presented in this special focus issue inform us about the state of HIT standards and their evolution. Clearly, they highlight that far more work remains, but more pertinently the overarching message is that collaboration, coordination, and convergence is occurring and may even be considered as the default effort. This is in vast contradiction to an earlier era when virtually every biomedical data standards development organization felt obligated to publish a competing “me too” standard, if only so that the products of their competitors would not succeed. We have all grown beyond that. HIT standards are now widely recognized not as commercial ventures in and of themselves but as critical public resources that can stimulate innovation and support applications that impact provider behaviors and patient outcomes. Efforts today are clearly focused on effective communication, semantic consistency, and interoperability. We can be sanguine about the likely state we may find ourselves in within the next decade. We have arrived at an era of real progress. Albeit slow, the maturation of practical, coherent, and interoperable biomedical data standards is undeniable and bodes well for clinical data interoperability.

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