Response to ONC 2016 Standards Advisory: Patient Clinical "Problems" (i.e., conditions)
Public comments submitted on April 20, 2016

Introduction

The Office of the National Coordinator for Health Information Technology (ONC) has opened a public comment period[1] for the 2016 Interoperability Standards Advisory document[2] in preparation for developing the 2017 advisory.

We appreciate the opportunity to provide our feedback, which we hope compliments earlier PCORnet responses[3]. These comments represent the individual views of the authors. These comments do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), the PCORI Board of Governors, or other organizations and governmental entities collaborating in the development of PCORnet.

The Patient Clinical "Problems" (e.g., condition) standard in the Standards Advisory

The Standards Advisory is important for a national Learning Health System (LHS)
The ONC Standards Advisory is targeted to clinical system implementation. The standards also have a critical impact on all downstream uses of these data, including quality measurement and improvement, population health improvement and clinical research to benefit patients. Standards are a key driver of data collection practices, structuring, semantic compliance, and syntactic interoperability.

Additional Issues for Consideration
The Problem/Condition standard in the current Standards Advisory includes only SNOMED-CT, however across health systems and within EHR products, condition data is mapped to multiple standards (e.g., ICD, CPT, SNOMED-CT), not just SNOMED-CT. Mapping from one standard terminology to another does not solve the problem, and the implications of mapping data that was collected in a different standard terminology to SNOMED-CT are unknown. The current Standards Advisory lists two standards for Encounter Diagnoses (ICD10 and SNOMED), but only SNOMED for Condition. However, if an organization uses ICD10 for Encounter Diagnoses, that may end up being the standard they use for problem/condition data as well.

There are several different interface terminology products in use (e.g., Intelligent Medical Objects, IMO) across healthcare systems in the United States. The mapping from clinical concepts to standard terminologies that takes place "under the covers" is proprietary, thus the degree of variation between products, or different versions of the same product cannot be discerned. Additionally, while the cross walk from a unique concept to codes in standard terminologies may not vary by implementation, the content and order of the pick-list providers select from can be different across EHR systems, vendors, and healthcare organizations. This creates the possibility for more variation in the way clinical "problems" or conditions are captured (and coded) across the U.S. In addition, if a terminology product like IMO is used to code problems within the EHR, processing encounters may involve two different mappings: IMO->SNOMED for problems and IMO->ICD-10 for encounter diagnoses, which adds to the potential sources of variation.

Conditions recorded in the problem list or medical history are often patient reported, thus exact onset dates and/or codes that precisely describe these conditions are not always available and may be approximated.

The distinction between data generated in the context of an encounter diagnosis vs. conditions in the problem list or medical history is important, and it's not clear how apparent this distinction is. Encounter diagnoses represent conditions that co-exist at the time of the encounter or episode of care and affect the treatment received; whereas a well maintained problem list and medical history provides a clear picture of a patient's current or resolved conditions, whether or not these are addressed during a given encounter or episode of care.

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[1] https://www.healthit.gov/standards-advisory/2016, accessed 2016-02-21.
[2] https://www.healthit.gov/sites/default/files/2016-interoperability-standards-advisory-final-508.pdf, retrieved 2016-02-21.
[3] Several members of this group contributed to comments on the draft Interoperability Roadmap v1.0 and 2015 draft Standards Advisory; please see https://github.com/CDMFORUM/CDM-GUIDANCE/wiki/CDM-related-Public-Reponses

Conclusions

Based on the experience of data partners across PCORnet, Problem/Condition data are being collected and stored in a greater number of terminologies than currently listed in the Standards Advisory, and even among those partners that can generate Problem/Condition data in SNOMED-CT, the information is often captured in some other coding scheme (i.e., IMO). We, the undersigned, suggest that ONC consider expanding the list of acceptable terminologies or developing/sanctioning a validated mapping from typical source terminologies to SNOMED-CT. The mapping question is of particular importance. Gathering information about the concept-to-code interface terminology mapping that is occurring across the healthcare system landscape should prove quite beneficial, as these mappings are used to generate problem list codes for millions of patients across the U.S. every day. Not understanding how these mappings are constructed or maintained results in a significant knowledge gap, particularly if problem list data are to be used in downstream analytics or decision support. At a minimum, ONC should also request additional metadata be captured along with the code, for instance, whether it was selected directly by the provider or generated as a result of a mapping.

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