United States Core Data for Interoperability (USCDI)
ONDEC (ONC Data Element and Class) Submission
CAP Comments

The CAP appreciates the opportunity to comment on the Centers for Disease Control (CDC)- National Program of Cancer Registries (NPCR) USCDI ONDEC data element submission. Comments focus on the usability of the proposed data elements and potential impact on pathologists and laboratories. Please contact hduncan@cap.org as needed for any follow up on this commentary.

Comments

1. The CAP applauds the efforts to standardize and structure cancer patient diagnostic data within electronic health records (EHRs) and other healthcare data collection and reporting systems. The CAP has partnered with the CDC, National Cancer Institute (NCI), World Health rganization (WHO), American Joint Committee on Cancer (AJCC) and other key stakeholders in related efforts to ensure cancer data fidelity, interoperability, and automated exchange in all aspects of healthcare and public health.

   The CAP hopes the efforts of the CDC-NPCR USCDI ONCDEC data element submission will lead to more support for work in knowledge representation and interoperability of data elements. The lack of knowledge representation and interoperability are critical gaps to effectively address, and why communication of data elements between systems continues to lag.

2. The CAP works to support pathologists in providing high-quality patient care and services through quality diagnoses, which includes excellence in diagnostic cancer reporting. Ensuring that the pathologist has the appropriate tools and support to report on these cancer cases is a top priority. CAP appreciates the intent of USCDI data elements in EHRs. CAP further advocates for the consideration of human factors in the implementation of USCDI data elements in EHRs and for opportunities to automate.

   Likewise, the implementation of USCDI data elements in EHRs will have unknown impacts on pathologists and their workflow in cancer case reporting. The impact will be determined by how these data elements are implemented into these systems. For example, the data elements could be present in the EHRs within a stand-alone form for compliance, as elements mapped to existing report structures, or as something pre-built into pathologist/physician reporting structure in the laboratory information systems (LIS). The implementation methodology may have anywhere from no impact to significant impact on pathologist reporting. No impact results when data flow design (knowledge representation, interoperability, and human factor implementation) is effective and automated. Significant impact stems from poor design of data flows, leading to excessive redundant work on behalf of pathologists and/or pathology staff to curate, manage, re-enter diagnostic data into downstream information systems.

   The CAP recommends accounting for human factors in evaluating the potential impact of how these data elements would be implemented in EHR systems during the ONCDEC pilot testing phases.

3. The terminology used in the proposed CDC USCDI data elements varies from the standards used in pathology cancer reporting, widely based on the WHO Blue Books, as well as the CAP Cancer Protocol data element content www.cap.org/cancerprotocols.

   These differences are as follows:

CDC proposed USCDI data element	CAP approximate existing data element
Tumor Histologic Type	Histologic Type
Tumor Behavior	Tumor Extension*

Tumor Primary Site	Tumor Site*
Tumor Laterality	Specimen Laterality
Tumor Clinical Grade	Histologic Grade*

** Please see examples below of how these are not exact 1:1 conceptual matches.*

The CAP understands that much of this is due to specific cancer registry use-cases and established terminology and wording, in addition to inclusion of either broader or sometimes more specific data elements than in the cancer pathology report.

For example, CAP uses "Tumor Site" as a multiselect option to select more specific areas for colon cancer, while the "Primary Tumor Site" CDC recommends may roll up these specific sites into a more general region of the colon. Another good example is "Tumor Clinical Grade," which may be intended to mean grade before the definitive resection or other treatment, rather than the CAP Cancer Protocol "Histologic Grade" which refers to the pathologist diagnosis.

These conceptual discrepancies may make it difficult to harmonize or map the pathology report with these data elements, depending on how this would be implemented. Even if this does not directly affect the pathologist workflow, there will likely be an additional mapping step needed to ensure that the USCDI data elements align with the elements in the cancer pathology report.

4. The CAP is aware of the challenges and maintenance of versioning, regarding the timing of implementation versus advancement of medical science and terminology standard updates. This includes ICD-O-3, SNOMED CT, and other content versioning and mapping from the WHO Blue Books, and how these data elements would be kept in alignment. Currently, there are lags between WHO Blue Book content release, clinical adoption and use, ICD-O-3 code release, SNOMED CT release, and cancer registry and public health mapping and adoption.

   The CAP recommends discussing and evaluating how these versioning challenges may affect the intended efficacy of implementation of these ONCDEC fields, and how these challenges can be mitigated. External efforts, such as the newly launched Cancer PathChart efforts supported by NCI-SEER and multiple stakeholders, may help to provide a longer term solution to some of these issues.