U.S. Core Data for Interoperability (USCDI) Task Force Recommendations

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Carolyn Petersen, co-chair
Robert Wah, co-chair
Health Information Technology Advisory Committee
Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Carolyn and Robert,

The Health Information Technology Advisory Committee (HITAC) asked the U.S. Core Data for Interoperability Task Force (USCDI TF) to provide recommendations around the proposed Data Elements in USCDI v1. This transmittal letter offers these recommendations, which are informed by deliberations among the Task Force subject matter experts.

USCDI Task Force Charge

The USCDI TF was charged with reviewing the newly specified Data Elements proposed in the USCDI v1. The specific charge was to provide recommendations on the following:

- Inclusion of New Patient Demographics Data Elements
    - Address; Phone Number
- Inclusion of Provenance Data Elements
    - Author; Author's Time Stamp; Author's Organization
- Inclusion of Clinical Notes Data Elements
    - Consultation Note; Discharge Summary Note; History & Physical; Imaging Narrative; Laboratory Report Narrative; Pathology Report Narrative; Procedure Note; Progress Note
- Inclusion of Pediatric Vital Signs Data Elements
    - BMI percentile per age and sex for youth 2-20; Weight for age per length and sex; Occipital-frontal circumference for children <3 years old
- Missing Data Elements within Proposed Data Classes

Recommendations

Guiding Principles

As part of the deliberation process, the USCDI TF discussed a number of topics relating to the new proposed Data Elements and the following recommendations focus on including, revising, omitting and/or adding Data Elements to USCDI v1. When considering and discussing recommendations, the TF applied three guiding principles: (1) to identify Data Elements from which to build the basic foundation for interoperability, (2) to avoid Data Elements that seemed too granular for v1 and, therefore, best left for subsequent revisions, and (3) to balance the burden to developers with the benefit to interoperability for each additional Data Element.

Specific Recommendation

Inclusion of New Patient Demographics Data Elements

Demographic information collected on patients represents a valuable Data Class within the USCDI v1. It is important that the most impactful and available demographic data is captured and shared as part of USCDI v1. To that end, the TF discussed the primary uses that demographics support prior to evaluating the specific Data Elements within this Data Class. The task force identified (1) patient matching, (2) identity verification, and (3) clinical care as the primary use cases which demographic Data Elements support. The patient demographic Data Elements recommended by the TF support one or more of these use cases.

ONC proposed the following new Data Elements to include in USCDI v1:

- Address
- Phone number

Recommendation 1. **The TF recommends including Address for USCDI v1 with the following additional sub-recommendations:**

a. **Use both current and previous addresses.**

b. **Require addresses to be entered using standardized format and content.** Both have been shown to improve patient matching and to reduce data entry errors.[1,2]

c. **Include a designation for individuals experiencing homelessness, including displaced persons and refugees.** This designation identifies a population at high risk for adverse health outcomes and addresses persons displaced by natural and other disasters who pose data matching challenges.

d. **Explore the feasibility of using and/or supporting an international address standard given the increasing international exchange of health data.**

Recommendation 2. **The TF recommends including Phone Number for USCDI v1 with the following additional sub-recommendations:**

a. **Use mobile phone number as the primary phone number and landline as the secondary phone number.** Identifying both mobile and landline numbers is useful in patient matching and identity verification.

b. **When entering a phone number in a child's record, make a clear distinction between whether the number is that of the parent/guardian or whether it belongs exclusively to the child.** This differentiation is critical to support efforts to protect adolescent confidentiality.

Recommendation 3. The TF recommends that the following additional Patient Demographics Data Elements also be included in USCDI v1:

a. **Destination(s) for electronic communications.** The TF identified the need for "electronic" address(es) to enable the exchange of electronic information. This could be a personal email

[1] https://academic.oup.com/jamia/article-abstract/26/5/447/5372371?redirectedFrom=fulltext
[2] http://perspectives.ahima.org/wp-content/uploads/2014/12/PatientMatchingAppendixA.pdf)

account (with security disclaimer), Direct address, or other URL (e.g., personal health record, gateway).

b. **Preferred method(s) and destination(s) of communication.** The TF recommends having a field to capture the patient's preferred destination(s) and method(s) of electronic communication. For example, this would facilitate receipt of the latest encounter record.

c. **The individual with authority to consent to treatment and data use.** The TF recommends adding the identity of the individual(s) with consent authority. This is essential for the care of minors and for individuals with guardians or activated health care proxies.

d. **Last four digits of the Social Security Number.** The TF recommends the addition of this Data Element to improve patient matching and identity verification.

e. **Optional identifiers including IDs issued by State or Federal governments.** The TF recommends including other government issued IDs such as: driver's license, State issued ID, Passport, Military Service number to improve patient matching and identify verification. There should be fields for this information if the individual wants to provide it voluntarily.

f. **Self-reported gender identity.** The TF recommends adding standards-based fields given the importance of this item for patient care. The Interoperability Standards Advisory (ISA) identified mature standards to support these Data Elements.[3]

Inclusion of Provenance Data Elements

The TF identified three use cases that are supported by the Provenance Data Class, which include: (1) establishing trust in a data source, (2) deduplication of Data Elements, and (3) Data Element versioning. The TF considered these use cases when discussing and determining recommendations for Data Elements in this Data Class.

ONC proposed three new Data Elements for the new provenance Data Class:

- Author's Organization
- Author
- Author's Time Stamp

Recommendation 4. **The TF recommends the use of Author's Organization for USCDI v1 as the appropriate first level to establish provenance with the following additional sub-recommendations:**

a. **Use Author's Organization in place of Author.** The TF was struck by the difficulty of consistently defining and identifying the author of a particular Data Element, in part due to the lack of standard nomenclature. The process of consistently identifying the author is further complicated by the variation of author types which change depending on the Data Class. For example, the author of a lab test could be the equipment, the technician, or the lab director. The author of a vital sign could be the agent that measures the vital sign or the agent that records it. The author of an interdisciplinary assessment could be a team member, the entire team, the department, or institution. In these examples, the author could be either a person or

[3] https://www.healthit.gov/isa/sex-birth-sexual-orientation-and-gender-identity

a machine. In all of these examples, it would be easier to unambiguously identify the organization that encompasses the author(s) than to identify the actual author(s). The TF feels that "Author's Organization" is the appropriate level at which to initiate provenance rather than at the level of "Author". For the reasons given above, it is easier to establish provenance at the level of the organization that generated the Data Element than at the level of the author. In the case of patient generated data, the author and organization would be the same.

b. **Employ a standard nomenclature to uniquely identify each Organization**. The unique identity of the organization that was the source of the Data Element is required for provenance. Each organization's unique identity is important to establish provenance for each Data Element that originates within that organization or that is altered by that organization.

c. **Consider NPI as an appropriate identifier for an organization**. NPI covers most but not all organizations. Another mechanism may be needed to establish a unique identify for organizations without an NPI.

d. **Unique Patient Identifier needed for patient generated data**. There is no master patient index to unambiguously and uniquely identify the source of patient generated data. Patient matching and identity verification are the currently available approaches. ONC might consider encouraging those organizations that have established a master patient index to create a unique identity that can be used for patient generated data and establish that identity as part of provenance.

Recommendation 5. **The TF recommends limiting the use of Author for USCDI v1 with the following additional sub-recommendations:**

a. **Use Author only when the Author is easily and unambiguously established.** There are situations in which the author is easily established such as the creator of a progress note, a prescription, or an element of patient reported data. In such cases the identity of the author is clear, unambiguous, and valuable for establishing and communicating provenance. Given the difficulty of unambiguously identifying the author for most Data Element classes, the TF recommends that the use of Author should be limited to very specific data types.

b. **Use Author's Organization as the primary level of identity.** The TF recommends initially identifying the Author at the level of the organization that originates the Data Element, in effect substituting Author's Organization for Author. In this construct the individual patient is an Organization of one and all other Authors are part of more easily identified organizations such as a health systems, hospitals, practices, labs, etc.

c. **Propose more granular definitions of Author in later versions of USCDI.** The TF views the current recommendations as being the first step in building detail that enhances the documentation and communication of provenance data. As a consensus emerges around defining an "Author" with additional granularity for specific Data Classes, future USCDI versions could include standardized, role-based descriptions to identify authors with more specificity.

Recommendation 6. **The TF recommends replacing Author's Time Stamp with Author's Organization's Time Stamp for USCDI v1 with the following additional sub-recommendations:**

a. **Use Author's Organization's Time Stamp:** The TF defines this as the "date and time the Data Element is available for use other than by the author."

Recommendation 7. The TF recommends creating a unique and persistent identity for each Data Element with the following additional sub-recommendations:

a. **Use four components.** The TF identified four items from which to construct a unique identity for each Data Element:
   - The uniquely identified source organization that generated the Data Element
   - The Author's Organization's Time Stamp indicating when that element was ready for sharing with users other than the author
   - The unique local identification code given to that Data Element by the source system/organization HIT system
   - The data type

b. **Maintain the unique identify when the Data Element is changed**. The TF envisions this identity will persist as the Data Element is shared across multiple sites and will enable several important use cases including de-duplication, machine sorting of Data Elements, and versioning at the level of the Data Element. If the Data Element is changed by an organization then a new set of unique identifiers are generated which create a new unique identity. In order to maintain provenance, this new identity is added to the original identity which persists. In this way a receiving system knows the original source of the Data Element as well as who and when it was changed thereby supporting versioning. If a Data Element changes (e.g., lab data changes from final to revised final, or preliminary to final), then the identity of the previous data instance is linked to the new one.

c. **Establish a governance structure for data labelling.** The TF recognized the need for a governance structure or shared contract that stipulates that if a Data Element is shared with only its original identity then the sharing organization asserts that its provenance is unchanged. If there is a new identity appended to the original identity then the sharing organization asserts that the Data Element has been changed.

Inclusion of Clinical Notes Data Elements

The TF identified two use cases that are supported by the Clinical Notes Data Class: (1) improving how incoming notes are sorted based on content and (2) improving communication across the care continuum. The TF considered these use cases when discussing and determining recommendations for Data Elements in this Data Class.

ONC proposed eight new note types to include in the clinical notes Data Class:

- Consultation Note
- Discharge Summary Note
- History and Physical
- Imaging Narrative

- Laboratory Report Narrative
- Pathology Report Narrative
- Procedure Note
- Progress Note

Recommendation 8. **The TF recommends that Consultation Note, Discharge Summary Note, History and Physical, Imaging Narrative, Pathology Report Narrative, Procedure Note, and Progress Note be adopted as proposed by ONC in USCDI v1.** The TF requests clarification regarding the inclusion of "Operative Notes".

Recommendation 9. The TF recommends that Laboratory Report Narrative be adopted in USCDI v1 with use restricted to special reports and narrative for specific laboratory results. The purpose of this restriction is to avoid sending result data in text fields that might otherwise be sent using discrete result component fields. For example, the results of a complete blood count should be stored and exchanged as discrete components (e.g., WBC, Hgb, Hct, etc. as opposed to a free text "blob").

Recommendation 10. The TF recommends that the following note types also be included in USCDI v1:

a. **Continuity of Care Document.** Continuity of Care Document is commonly used and widely adopted.

b. **Operative Note.** Operative Note is commonly used and widely adopted.

c. **Transfer Summary Note.** Transfer Summary Note has not been widely adopted but offers significant advantages compared to the Discharge Summary for specific clinical situations. The Transfer Summary provides specific information needed for the continued safe and effective immediate treatment of the individual. The Discharge Summary memorializes the hospitalization accordingly includes information that is irrelevant to the care team while often omitting information essential to ongoing patient care.

d. **Care Plan Note.** Care Plan Note has not been widely adopted, but is increasingly used to coordinate care of clinically complex individuals.

e. **Advance Care Planning Note.** Advance Care Planning Note has significant clinical importance. HL7 standards currently exist. This note is the first C-CDA to be constructed for patient use.[4]

f. **Miscellaneous Note.** Miscellaneous Note recognizes new, as yet unspecified, document types (e.g. sharing pricing data with patients and providers). The definition of this "miscellaneous" category will change as more explicitly named categories are added. This note should only be used for content that is not adequately transmitted in other note types.

Recommendation 11. The TF recommends that the following note types be considered for future versions of the USCDI:

[4] http://wiki.hl7.org/index.php?title=Revisions_for_C-DA_R2.1_Advance_Directives_Templates

a. **Referral Note.** Referral Note currently is less commonly used. The Interoperability Standards Priorities Task Force is investigating tighter specification of content in collaboration with the AMA and 360X. These additional specifications would be appropriate for future consideration by USCDI.

b. **Long Term Services and Supports Care Plan Note.** Long Term Services and Supports Care Plan Note is a bridge between providers of clinical services and providers of supportive services. It is currently in ballot at HL7 and should be added to a future USCDI version when standards are established.[5]

Inclusion of Pediatric Vital Signs Data Elements

The TF identified two use cases that are supported by the inclusion of Pediatric Vital Signs which include: (1) exchange of vital sign measurements and (2) exchange from calculated values derived from vital sign measurements. The TF considered these use cases when discussing and determining recommendations for Data Elements in this Data Class.

ONC proposed three new Data Elements to support pediatric vital signs:

- BMI percentile per age and sex for youth 2-20
- Weight for age per length and sex
- Occipitofrontal circumference under 3 years old

Recommendation 12. The TF recommends that BMI percentile per age and sex for youth 2-20 not be included as part of USCDI v1. This calculated value presents a significant programing burden for systems that do not already calculate and store these values. It was not clear to the TF that the benefit of sharing these calculations outweighed the cost of calculating and storing this information when compared with the minimal cost of sending the underlying measurements for the receiving site to perform the calculations based on their usual processes.

However, in the event that derived values are relevant for making current clinical decisions, and an organization already calculates and stores any derived measures such as BMI, height/weight by age and gender, blood pressure percentile by age and gender, they should be required to send these calculated values with the other vital signs.

Recommendation 13. The TF recommends that Weight for age per length and sex not be included as part of USCDI v1. This calculated value, which would more accurately be named "weight for length percentile by age and sex for youth 2-20", presents a significant programing burden for systems that do not already calculate and store these values. It was not clear to the TF that the benefit of sharing these values outweighed the cost.

Recommendation 14. The TF recommends that Occipitofrontal circumference for children under 3 years old be adopted as proposed by ONC in USCDI v1.

Recommendation 15. The TF recommends the following two additional modifications:

a. **Re-label "Height" to read "Height/Length"**
b. **Explicitly state that the other vital signs in USCDI v1 apply to all age groups**

[5] http://wiki.hl7.org/index.php?title=ELTSS:FHIR_IG_Proposal

Missing Data Elements within Proposed Data Classes

The TF recommends the following Data Elements for inclusion in USCDI v1 as part of currently proposed Data Classes.

Recommendation 16. The TF recommends adding the following provider demographics Data Elements to the Care Team Members Data Class:

a. **Name**
b. **Contact information**
c. **Identifier (e.g., NPI, certification, state license)**

Recommendation 17. The TF recommends adding the following additional Data Elements to the Medications Data Class:

a. **Date/time the list of current medications was reconciled**
b. **The identity of who reconciled the list**
c. **Indication or associated diagnosis for each medication**

Missing Data Class for USCDI v1 Data Elements

Recommendation 18. The TF recommends adding a Quality Measures Data Class in USCDI v1 by first identifying and cross-listing current USCDI v1 Data Elements used for tracking and measuring quality. There is an important use case for the generation, documentation, and exchange of quality data. Data Elements which are used in quality reporting are scattered throughout the USCDI and across many Data Classes. What is missing is a section of the USCDI for Data Elements that are needed for quality reporting. By creating a Data Class for the specific elements used for quality measurement, the TF believes it will be possible to identify gaps in Data Elements and enhance quality reporting. The intent is to make quality measurement easier by using structured Data Elements that are in the USCDI that are currently used in quality measurement and reporting. This recommendation supports the Conditions and Maintenance of Certification's Task Force Recommendations to use QRDA.

The TF suggests as a first step to identify Data Elements that are currently in USCDI v1 that are routinely used for tracking and measuring quality. The next step is to specify them as part of a new "Quality Measurement" Data Class. As new Data Elements and Data Classes are added to the USCDI, they can simultaneously contribute to the Quality Measurement Data Class. The reverse path into USCDI might also be possible if Data Elements are added to the Quality Measurement Data Class before being added to a clinical Data Class. As an example, Medicaid requires Hearing Screening, Developmental Assessments and Vision Screening as part of its quality measurement set. These elements could first appear in Quality Measurement and subsequently, for example, in a new, yet to be proposed, Pediatric Assessments Data Class. The third step is to unambiguously define these Data Elements so they can be used consistently and interchangeably across measures.

Respectfully submitted,

Christina Caraballo

Terrence A. O'Malley