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

May 13, 2019

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Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
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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
 - o 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;
 Occipitofrontal circumference for children <3 years old
- Missing Data Elements within Proposed Data Classes

Guiding Principles and Scope

The primary focus of the TF in Phase 1 was to make specific recommendations to include, revise, omit or add specific Data Elements to USCDI v1. The TF did not consider how the proposed Data Elements could be incorporated into current or future record systems. Nor did the TF make any recommendations regarding how that might occur.

Unless otherwise indicated, all of the TF recommendations apply to USCDI v1. Those recommendations that apply to subsequent versions of USCDI are labelled as such. The TF provided citations for the purpose of showing examples of applicable standards, however the TF recommendations are agnostic regarding transport. The TF assumed that all USCDI data elements will be tightly specified and semantically interoperable.

Specific Recommendation

Inclusion of New Patient Demographics Data Elements

The TF identified (1) Patient matching, (2) Identity verification, and (3) Clinical care as the primary use cases supported by demographic Data Elements. The Patient Demographics 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. Accept Address for USCDI v1 Patient Demographics as proposed by ONC with the following additional recommendations:

- a. Include both current and previous addresses
- b. Encourage the use of the USPS format and content for addresses. The TF recognized that standardized address formats improve interoperability, improve patient matching and to reduce data entry errors. 1.2. The TF also recognized the need for address verification web services at a reasonable cost; and that ONC should encourage health systems to adopt them.
- c. Explore the feasibility of using and/or supporting an international address standard. Potentially important given increased international exchange of health information.

Recommendation 2. Accept Phone Number for USCDI v1 Patient Demographics as proposed by ONC with the following additional recommendations:

- a. Include designations for both mobile and landlines. Software should support multiple phone numbers.
- b. Include a designation indicating whether each phone number is that of the patient or of another party. Software should support the designation of "Private" and "Shared" for phone numbers. This differentiation is important to support efforts to protect adolescent confidentiality, but applies as well for any patient who has a number used by a parent, spouse or guardian.

The TF recommends the addition of the following Data Elements to USCDI v1 Patient Demographics:

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)

Recommendation 3.: ONC include Destination(s) for electronic communications. Software should support the collection of email addresses; and ONC should consider requiring the collection of additional addresses (e.g. Direct address, PHR, provider gateway) in future versions of USCDI.

Recommendation 4: ONC include the individual(s) with authority to consent to treatment and data use. Software should support collection of the identity of the individual(s) with the authority to consent to treatment and data use, including name, contact information, and relationship. This is required for the care of minors and for individuals who cannot give consent and have guardians or activated health care proxies.

Recommendation 5: ONC include the Last four digits of the Social Security Number. ONC should consider requiring systems to support the last four digits of the Social Security Number. The TF recognized the value of this data element for patient matching but also noted associated privacy concerns.

Recommendation 6: ONC include Optional identifiers including IDs issued by State or Federal governments. Systems should support state license/state identification numbers for the purposes of patient matching. ONC should consider supporting passport identification numbers for the purposes of patient matching.

Recommendation 7: ONC include Self-reported gender identity. There are robust recommendations for how to collect gender identity in an electronic health record in the ISA. ³ Self-reported gender identity is important for public health and for a health equity. Systems should continue to record sex assigned at birth.

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. The Provenance Data Elements recommended by the TF support one or more of these use cases.

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

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

Recommendation 8. Accept Author's Organization for USCDI v1 Provenance as proposed by ONC

Recommendation 9: Accept Author for USCDI v1 Provenance as proposed by ONC with the following additional recommendations:

a. ONC should require the identity of the Author for certain data classes where the Author is straightforward and important. Examples include notes and medication prescriptions. These

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

are situations in which the author is easily established as the creator of a progress note, the originator of a prescription, or the source 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 these very specific data types.

b. For data classes other than notes and medication prescriptions, use Author Organization. Future versions of USCDI should include more granular definitions of Author. 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 additional Data Classes, future USCDI versions should include standardized, role-based descriptions to identify authors with more specificity.

Recommendation 10: Amend Author's Time Stamp as written in the proposed rule to Time Stamp for USCDI v1 Provenance. Time stamp should be implemented locally. Each system can apply its own standards for Time Stamp in order to assert provenance.

The TF proposes the following additional data elements for consideration in USCDI v1 Provenance:

Recommendation 11: ONC should consider adding a unique organization identity and implement in USCDI version 1 if an adequate candidate is identified. The TF was unable to propose a taxonomy that covered all entities for this purpose. In situations where it is important to identify the organization it would be reasonable to start with a limited taxonomy.

Recommendation 12: ONC should require that software is capable of indicating when the patient is the author of the data.

Inclusion of Clinical Notes Data Elements

The TF identified two use cases that are supported by the Clinical Notes Data Class: (1) improving accessibility to information through more granular sorting of incoming notes based on content and (2) improving communication across the care continuum. The TF considered these use cases when discussing and determining recommendations for the Clinical Notes Data Elements in this Data Class. The Clinical Notes Data Elements recommended by the TF support one or more of these use cases.

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 13. The TF recommends the inclusion of the following notes as proposed by ONC in USCDI v1:

- Consultation Note
- Discharge Summary Note
- History and Physical
- Procedure Note
- Progress Note

Recommendation 14. The TF recommends that Imaging Narrative be amended to Diagnostic Imaging Report. The Diagnostic Imaging Report is now available for use and should be included in USCDI v1. Imaging Narrative is duplicative.

Recommendation 15: The TF recommends not to add the Laboratory Report Narrative in USCDI v1 Clinical Notes Data Elements as proposed by ONC. This note is duplicative of the Laboratory Results data class.

Recommendation 16: The TF recommends not to add the Pathology Report Narrative in USCDI v1 Clinical Notes Data Elements as proposed by ONC. This note is duplicative.

The TF request that the following note types be included in USCDI v1 Clinical Notes Data Elements:

Recommendation 17. Continuity of Care Document. Continuity of Care Document is commonly used and widely adopted.

Recommendation 18: Operative Note. Operative Note is commonly used and widely adopted.

Recommendation 19: Miscellaneous Note. Miscellaneous Note is a placeholder for new, as yet unspecified, document types (e.g. sharing pricing data with patients and providers). The definition of "miscellaneous" will change as more explicitly named notes are added. This note should only be used for content that is not adequately transmitted in other note types.

Recommendation 20: Include Transfer Summary Note as optional in USCDI v1. 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 and includes information that is irrelevant to the next care team while often omitting information essential to ongoing patient care. A Transfer Summary note is best sent at the time of transfer. A Discharge Summary Note can be sent when finalized.

Recommendation 21: Include Advance Care Planning Note as optional in USCDI v1. Advance Care Planning Note has significant clinical importance especially in settings that perform emergent interventions. HL7 standards currently exist. The C-CDA version of this note is the first C-CDA to be constructed for patient use.⁴

Recommendation 22: Include Care Plan Note as optional in USCDI v1. Care Plan Note has not been widely adopted, but is increasingly used to coordinate care of clinically complex individuals.

⁴ http://wiki.hl7.org/index.php?title=Revisions for C-DA R2.1 Advance Directives Templates

The TF recommends that the following note types be considered for a future version of the USCDI:

Recommendation 23: 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.

Recommendation 24: 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: (1) exchange of vital sign measurements and (2) exchange of 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 25. The TF recommends that BMI percentile per age and sex for youth 2-20 be adopted as part of USCDI v1 with the following additional considerations.

- a) The requirement to store and exchange this calculated value presents a significant burden for systems that do not already store these values, but rather dynamically calculate and display them to users, based on a specific nomogram, without storing the values generated. A reasonable alternative for systems that do not store these calculations is to send the underlying measurements (weight, age, sex) for the receiving site to be able to perform the calculations based on their usual processes.
- b) ONC should consider requiring the storage of this data element whenever the system provides it to the patient/guardian, acknowledging that such storage may be in the form of a copy of a patient handout or growth chart as opposed to a discrete data item.

Recommendation 26. The TF recommends that Weight for age per length and sex be adopted as part of USCDI v1 with the following additional considerations.

- a) Amend data element to "Weight for length percentile by age and sex for youth 2-20"
- b) The requirement to store and exchange his calculated value presents a significant burden for systems that do not already store these values, but rather dynamically calculate and display

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

- them to users, based on a specific nomogram, without storing the values generated. A reasonable alternative for systems that do not store these calculations is to send the underlying measurements (weight, age, length, sex) for the receiving site to be able to perform the calculations based on their usual processes.
- c) ONC should consider requiring the storage of this data element whenever the system provides it to the patient/guardian, acknowledging that such storage may be in the form of a copy of a patient handout or growth chart as opposed to a discrete data item.

Recommendation 27. The TF recommends that Occipitofrontal circumference for children under 3 years old be adopted as proposed by ONC in USCDI v1.

Inclusion of 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 28. Add provider demographic data elements to the Care Team Members Data Class in USCDI v1:

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

Recommendation 29. Add Indication and/or associated diagnosis for each medication in USCDI v1Medications Data Class ONC include the following medication Data Element to the Medications Data Class. The absence of this medication information presents serious risks to patient safety.

Recommendation 30: Include a designation and address entry standards 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.

Inclusion of Missing Data Class for a Subsequent USCDI Version

Recommendation 31. The TF recommends beginning the process to develop a Quality Measures Data Class in a subsequent version of USCDI. There is an important use case for the generation, documentation, and exchange of data used in standardized quality measures. There are Data Elements used in quality reporting that are scattered throughout the USCDI and across many Data Classes. By creating a Data Class for the specific elements used for quality measurement and reporting, the TF believes it will be possible to identify gaps in Data Elements and enhance the quality reporting process. The TF also recognizes the difficulty of implementing this recommendation but believes it is important to start.

Other Recommendations

Recommendation 32: The TF recommends beginning the process to assign a unique and persistent identity for each Data Element with a governance structure to oversee its use. The TF had no specific recommendations regarding the implementation of this recommendation.

We appreciate the opportunity to summarize the work of this Task Force and provide it to you for consideration.

Respectfully submitted,

Christina Caraballo

Terrence A. O'Malley