OCHIN

A driving force for health equity

Submitted via https://www.healthit.gov

April 15, 2024

Micky Tripathi, PhD MPP
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
330 C Street SW, 7th Floor
Washington, DC 20201

Re: *Draft U.S. Core Data for Interoperability (USCDI) version 5*

Dear National Coordinator Tripathi,

On behalf of OCHIN, I appreciate the opportunity to submit the following comments in response to the *Draft U.S. Core Data for Interoperability (USCDI) version 5.* OCHIN is a **national nonprofit health information technology and research network** with over two decades of experience transforming health care delivery, providing leading-edge technology, data analytics, research, and support services to **nearly 2,000 community health care sites with 25,000 providers in 40 states, reaching more than 8 million patients** in rural and underserved communities. OCHIN applauds the Office of the National Coordinator of Health Information Technology's (ONC) efforts to drive widespread adoption of national digital data and technical standards to advance interoperability.

OCHIN is committed to driving the widespread development, testing, and adoption of national standards that support interoperability and the suitability of health data for a full range of uses in health care. National data standards are the foundation needed to improve the quality of care, bend the cost curve, and empower patients, while paving the way for payment and delivery transformations, particularly for community-based providers that do not have the resources to comply with varied local, regional, state, and national standards. Further, widely adopted national standards are essential to address structural inequality in health care as well as mounting timely, data-driven responses to public health emergencies. Finally, reducing complexity and duplication not only decreases costs and resource needs, but can facilitate solutions that address clinician cognitive fatigue and can contribute to streamlined clinical practice that are critical to address workforce challenges.

Recommendations

OCHIN strongly supports the inclusion of the following additional digital data and technical standards to the U.S. Core Data for Interoperability:

- **Social Determinants of Health**. OCHIN applauds ONC for its strong commitment to driving national digital data and technical standards related to SDOH. OCHIN recommends ONC clarify that the data elements – Date of Diagnosis and Date of Resolution apply to both the Problems and SDOH Problems/Health Concerns data elements. This ensures that the resolution of SDOH needs can be documented along with clinical ones.

- **Sexual Orientation and Gender Identity**. OCHIN applauds ONC for advancing efforts to support informed clinical care for patients that address their specific needs. OCHIN recommends ONC update the Use Case Description for the Sex Parameter for Clinical Use to align with the **updated HL7 Gender Harmony specification**. We also recommend specifying that this data element is context dependent and should not be interpreted as a singular assessment. For some patient populations, Sex Parameter for Clinical Use may be different at the same point in time for different assessments or procedures (e.g., imaging studies vs. laboratory). The data element should include associated metadata identifying the source (e.g., individual self-report, clinical observation) and method of collecting values.

- **Addressing Needs of Patients Who Prefer Language Other Than English.** OCHIN supports the inclusion of the data element, Interpreter Needed. According to the U.S. Census Bureau, 22% of people in the United States spoke another language besides English at home with 8.4% reporting speaking English less than "very well." In the healthcare settings, language barriers can hamper patient decision-making autonomy. Compared to people who speak English, individuals who speak another language aside from English disproportionately experience less access to regular care or be satisfied with their care. They also are at greater risk of adverse effects from poor understanding of diagnoses, low health literacy, and being misunderstood by their physicians. Collecting patients' self-reported need for interpretation services can help healthcare organizations eliminate guesswork or assumptions on whether their patient needs an interpreter, which improves the patient experience and ensures a more patient-centered process that ultimately helps improve care provided and clinical outcomes. Of the 3.7 million patients that we serve through OCHIN Epic, more than 34% preferred care in a language other than English, a large proportion of whom speak Spanish (24%). OCHIN's MyChart patient portal supports 13 languages, from Spanish and Chinese to Portuguese and Russian, to support our patients' access to their electronic medical records and help champion their own care for better outcomes through language they prefer.

- **Improving Interoperability of Patient Preference for End of Life Care and Driving Equity**. Patient informed preferences for end of life care, particularly for underserved patient populations, are not accessible and readily available. The lack of standardization and interoperability means that the most underserved patient populations and their health care providers do not have access to this critical information to inform care when it is needed. OCHIN supports standardization and interoperability in this important area of health care delivery.

- **Need for Data Standardization in Maternal and Reproductive Health.** Improving maternal and reproductive health outcomes and reducing health disparities remains a key priority in driving equity in health care. For example, maternal morbidity and mortality rates remain unacceptably high in the U.S., particularly among minority communities, with higher rates of severe maternal morbidity among Black (139.0 per 10,000 delivery hospitalizations) and American Indian/Alaska Native (99.6 per 10,000 delivery hospitalizations) communities as compared to White communities (69.9 per 10,000 delivery hospitalizations). Including data elements related to maternal and reproductive health in USCDI v5 will help ensure information essential for a successful pregnancy and reproductive care is conveyed to every member of a mother's care team. OCHIN supports the inclusion of uniform, standard questions around maternal and reproductive health, specifically the use of data elements captured as part of the Self-Identified Need for Contraception (SINC) and

Pregnancy Intention Screening Question (PISQ). Although two separate data elements, we support including both to reflect and help generate more data around maternal and reproductive health.

Conclusion

As a learning collaborative and research network, OCHIN knows first-hand that the quality of data has a direct impact on the quality and accessibility of care, particularly for underserved or marginalized communities. Ensuring all providers and patients benefit and participate in a national data standardization effort is key for success. Thank you for the opportunity to comment. Please contact me at **stollj@ochin.org** should you have any questions.

Sincerely,

Jennifer Stoll
Chief External Affairs Officer

Social Determinants of Health

Data Class: Problems

OCHIN recommends ONC clarify that the data elements – Date of Diagnosis and Date of Resolution apply to both the Problems and SDOH Problems/Health Concerns data elements. This ensures that the resolution of SDOH needs can be documented along with clinical ones.

Patient Demographics

Data Element: Interpreter Needed

OCHIN supports the inclusion of the data element, Interpreter Needed, given the high proportion of non-English preferring patients served by OCHIN members, making it a highly relevant standard for our members. According to the U.S. Census Bureau, 22% of people in the United States spoke another language besides English at home with 8.4% reporting speaking English less than "very well." In the healthcare settings, language barriers can hamper patient decision-making autonomy. Compared to people who speak English, individuals who speak another language aside from English disproportionately experience less access to regular care or be satisfied with their care. They also are at greater risk of adverse effects from poor understanding of diagnoses, low health literacy, and being misunderstood by their physicians. Collecting patients' self-reported need for interpretation services can help healthcare organizations eliminate guesswork or assumptions on whether their patient needs an interpreter, which improves the patient experience and ensures a more patient-centered process that ultimately helps improve care provided and clinical outcomes.

Data Element: Name to Use
Data Element: Pronoun
Data Element: Sex Parameter for Clinical Use

OCHIN appreciates the includes of the Pronoun and Name to Use data elements in the Patient Demographics/Information data class and the Sex Parameter for Clinical Use to the Observations data class. Including these data elements align with directives to address health disparities faced by patients in the LGBTQ+ community and, for OCHIN, the standards align with the digital data standards we have developed for our members.

Data Element: Sex Parameter for Clinical Use

OCHIN recommends ONC update the Use Case Description for the Sex Parameter for Clinical Use to align with the updated HL7 Gender Harmony specification. We also recommend specifying that this data element is context dependent and should not be interpreted as a singular assessment. For some patient populations, Sex Parameter for Clinical Use may be different at the same point in time for different assessments or procedures (e.g., imaging studies vs. laboratory). The data element should include associated metadata identifying the source (e.g., individual self-report, clinical observation) and method of collecting values.

Advanced Directives

Data Element: Advanced Directive Observation

Historically, electronic health record systems historically stored scanned images of paper advance healthcare directive documents and stored them without a requirement to make them available to other available to other systems. The COVID-19 public health emergency underscored the importance of increasing preparation and ready accessibility of current advance care planning tools to aid patients and their clinicians when their patients are in crisis. **OCHIN supports the promotion of the Advanced Directive data element from Level 2 to USCDI v5 as the draft Advanced Directive Observation data element, will facilitate interoperability for certified health information technology data exchanges, especially in the face of natural disasters and public health emergencies**. Such standards will guide work among states developing registries as well as developer creating tools to support advance care planning.

Promoting the Advance Directive Observation data element to USCDI v5 supports a critical component of the clinical workflow process, which helps ensures the individual's personal preferences for care delivery are met and moved the needle forward for improving health equity for the underserved and marginalized. It also helps to create a more personalized health care delivery system that is respectful of individual differences and values.

OCHIN recommends the inclusion of an Advance Directive data class in USCDI v5 which would group all relevant document types that individuals' care teams and medical providers should to inform individualized and personalized care delivery. Data elements associated with the Advance Directive data class encompass various healthcare encounters and care settings and are not encounter-specific.

OCHIN recommends moving the Advance Directive Observation data element to the Advance Directives Class rather than the Observations Data Class to align with the grouping mechanism and context associated with data classes. However, OCHIN is open to being associated with the Observations Data Class if ONC believes that the dual Data Class association will be meaningful to certified electronic health record technology.

Maternal and Reproductive Health

Data Class: Health Status Assessment
OCHIN supports the inclusion of uniform, standard questions around maternal and reproductive health, specifically the use of data elements such as the Self-Identified Need for Contraception (SINC) and Pregnancy Intention Screening Question (PISQ). Maternal health care requires the use of data elements unique to prenatal care. Prenatal care is a collaborative practice that requires several transitions of care in the ambulatory and acute environments, necessitating a standard and universal data entry and retention system. These data elements inform all clinicians caring for actively pregnant patients and are conveyed in nearly every transition of care. Ensuring that these elements are required for maternal health in any national data standard is essential. Additional data elements that should be the focus of HHS (and by extension ONC) efforts to address maternal health equity include:
- Estimated Due Date – This element is critical for clinicians when patients present in labor.
- Cervical exam – This element details observations such as dilation, effacement, and station.
- Fetal heart tones – Establishes fetal viability.
- Fundal height – Indicates fetal growth.

- Fetal number
- Gestational age
- Fetal presentation – This element is key for preparation of delivery.