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Dr. Micky Tripathi
National Coordinator
Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
Mary E. Switzer Building
330 C Street SW
Washington, DC 20201

Dear National Coordinator Tripathi:

Thank you for soliciting comments on the Office of the National Coordinator for Health Information Technology's (ONC) standard data set for exchange. The United States Core Data for Interoperability (USCDI) will reduce burdens associated with data exchange, ensure both patients and providers receive standard and complete data in real-time, and has the potential to allow for seamless exchange of vital clinical information to public health agencies during crises like the COVID-19 pandemic. Overall, however, USCDI version 2 represents a missed opportunity by the agency to accelerate the comprehensive, standard exchange of data— including information needed for public health action. When finalizing the proposed version, ONC should ensure the USCDI includes data needed for public health and health equity, which can help public health agencies fight the current pandemic—and be better prepared for future crises.

The Pew Charitable Trusts is a non-profit research and policy organization with several initiatives focused on improving the quality and safety of patient care. Pew's health information technology initiative focuses on advancing the interoperable exchange of health data and improving the safe use of electronic health records (EHRs).

As part of implementing the 21st Century Cures Act, ONC developed the USCDI as the national standard data set that EHRs must exchange with each other. The data set consists of multiple data classes, each with various constituent data elements. Having a consistent and standard data set that all systems must be able to exchange helps ensure the sharing of critical patient information across multiple providers to improve care coordination—regardless of which EHR system it came from—and that patients can have access to their own data, such as through health apps on their smartphones. However, despite these potential benefits, the current version of the USCDI does not include all of the information needed to fill existing gaps in data exchange. The USCDI draft version 2 provides an opportunity for the agency to take further action to improve nationwide health data exchange—including making it easier to share data with public health agencies—through the use and advancement of standardized data classes and elements.

The COVID pandemic has heightened the existing gaps and challenges in data exchange. Over 40% of lab results sent to public health agencies are missing critical patient contact information,

hampering officials' ability to conduct contact tracing.[1] Immunization data shared with the Centers for Disease Control and Prevention are missing race and ethnicity information nearly half of the time, threatening any chance of equitable vaccine distribution.[2] Epidemiologists also frequently lack information related to occupation, pregnancy status, and travel—all of which are important for conducting case investigations and risk assessments, as well as implementing mitigation strategies. Given these existing gaps, ONC should ensure the USCDI includes data needed for public health and health equity, which can help public health agencies fight the current pandemic—and be better prepared for future crises.

The USCDI should be strengthened in the following three ways in order to improve public health and health data exchange:
- The US Postal Service (USPS) address standard should be a required standard for the "address" data element within the patient demographics data class;
- ONC should include all of the data elements needed for public health reporting as part of USCDI version 2; and
- ONC should accelerate the inclusion of social determinants of health (SDOH) data elements in USCDI version 2.

Require US Postal Service address standard to improve patient matching

Patient matching, or the ability to accurately link each individual's records from multiple doctors' offices or hospitals, remains a perennial problem in health care. A report commissioned by ONC found that up to half of the information exchanges made by health care organizations may fail to accurately match records for the same patient.[3] Ineffective patient matching can have patient safety and cost ramifications. Patients may receive inappropriate care and face the possibility of medical errors if information used for treatment is missing or inaccurate; in one survey, one in five hospital chief information officers said that patient harm occurred within the previous year due to a mismatch.[4]

Currently, different health care facilities traditionally compare patients' names, dates of birth, and other demographic data to determine if records refer to the same individual. They use algorithms to conduct these matches, and also employ staff to manually review records. This process often fails to accurately link records because of typos entered into the system; similarities in names, birth dates or addresses among different patients; changing information, such as when individuals move or get married; lack of standardization in demographic data entry; and many other reasons.[5] As more care has shifted to outside of the traditional hospital setting, the COVID-19 pandemic has exacerbated the need for short-term interventions to tackle the challenges and effects on care that incomplete data and inaccurate patient matching can cause.

Using additional data elements to verify individuals' identities can help do that. ONC rightly added more demographic data to the USCDI in version 1, including current and previous addresses; phone number (as well as the type of number, such as a cellphone or home landline);

and email address. Going forward, ONC should incorporate additional demographic data elements, including the health plan ID or Medicare Beneficiary ID, for matching and other health plan-centric use cases. These data elements provide a standardized way to link records across systems and would strengthen any standard to match patient records to provide care.

The USCDI further requires standards for phone number and email address. However, despite research that shows the benefit of also using a standard for addresses, the USCDI does not require one.

The US Postal Service (USPS) address standard should be required for the "address" data element within the patient demographics data class. Research demonstrates that formatting addresses according to USPS address specifications would accurately link an extra 3% of patient records.[6] A hospital system with a match rate of 85 percent, for example, could see its unlinked records reduced by 20 percent just by standardizing how addresses are depicted. Inconsistent documentation, in addition to data entry mistakes, produces high variation among addresses; using the USPS standard would significantly reduce that.

ONC stated that implementing the available USPS standard would create a burden on provider organizations. However, vendors—not providers—would be responsible for developing and implementing the standard within health IT systems. Additionally, USPS operates a free service to standardize addresses that is used widely by the shipping industry. Were this service made available for use in health care, the burden of implementation would be greatly reduced.

ONC further stated that the USPS standard was not used in the USCDI due to the allowed variation within it. Instead, ONC created Project US@, a multi-stakeholder initiative to create a health care-specific format for address, building off of and removing existing variation in the USPS standard. However, this process will take time to develop a more specific standard, and ONC should not delay adoption of the USPS standard in the interim. Even with the variation allowed in the USPS standard, adoption would lead to fewer discrepancies and differences in address depiction than exists today.

Include necessary public health data elements to benefit public health data exchange and health care

As the COVID-19 pandemic enters its second year, challenges with data exchange have exposed the gaps in our public health data infrastructure. However, COVID-19 is just the latest threat highlighting these deficiencies, and it will not be the last health threat the public will face. Alongside this pandemic, public health authorities continue to combat vaping-related illness, chronic diseases such as diabetes and hypertension, and sexually transmitted diseases such as HIV-AIDS, among other threats—including some that may be difficult to predict. A strong public health infrastructure, grounded in standardized data, can help the country be prepared to address future threats.

The USCDI represents a roadmap for the critical information that public health information technology systems need to collect. For example, lab information systems, pharmacy systems, and public health registries should be capable of including and exchanging USCDI data applicable to public health efforts. As such, the USCDI should include all of the data elements that public health officials need to prevent and mitigate crises.

Likewise, as vendors and health IT professionals prepare EHRs for the required use of standard application programming interfaces (APIs) to share health data, public health agencies should also plan for a future where APIs share relevant public health information. APIs provide an opportunity to more easily exchange data, and streamline the sharing of critical public health information from health care facilities to public health authorities.

In order for public health agencies to receive the data they need for contact tracing, case investigation, disease surveillance, and other critical activities, ONC should include the data elements needed for public health reporting as part of USCDI. Many of these data elements also have utility outside of public health:

- Add the following data to the existing "problems" data class: date of diagnosis, date of onset, and date of resolution. This information will give public health officials data to understand possible exposure times, calculate the incubation period of a pathogen, and provide needed information for contact tracing.
- Create a "Specimen" data class, and include all associated data elements (specimen collection data, specimen source site, specimen type). These data will help public health officials understand the type of lab test performed, and provide potential future information on efficacy of certain tests.
- Create a "Travel information" data class, and include all associated data elements (travel history dates, travel history location, travel plans dates, and travel plans location). Travel information helps public health officials understand the timeline of potential infection and whether the individual traveled to high-risk areas.
- Create a "Work information" data class, and include all associated data elements (combat zone period, employment status, farmworker status, job, retirement data, usual work, veteran status), which will help with understanding and identifying potential transmission and infection risk. For example, essential workers are at higher risk of exposure to COVID-19 than individuals that work from home. This information can also help non-public health use cases, such as to use clinical decision support (CDS) tools to evaluate orthopedic pain for individuals with manual labor-intensive professions.
- Create an "Observations" or "Perinatal" data class, and include all associated data elements associated with pregnancy (Apgar score, estimated date of delivery, gestational age, gestational age at birth, last menstrual period, M3 results, number fetal deaths at delivery, and pregnancy status). Information related to pregnancy helps officials determine the best treatment, follow-up and risk assessment for these patients, including whether certain conditions have worse fetal or perinatal health outcomes.

- Add "Death date", which allows for epidemiological analysis to understand a disease's severity and determine if certain conditions were ultimately fatal.

Including data needed for public health as part of the USCDI will ensure that all EHRs are able to document and exchange this information in a standard manner, including with public health agencies.

Accelerate Social Determinants of Health (SDOH) data elements in USCDI version 2

SDOH are often just as important—if not more so—to an individual's outcomes and health status than traditional health care, such as annual primary care visits or treating acute illnesses.[7] The COVID pandemic has also highlighted the importance of using data to improve equity of care, and how missing data can make it harder to target resources, distribute vaccines appropriately, and assess the risks to different communities. Yet, USCDI fails to include many important SDOH data elements. We encourage ONC to accelerate their inclusion of SDOH in USCDI version 2. Specifically, the agency should include the following data elements, recommended by the Gravity Project, as part of the SDOH data class:

- Employment
- Financial strain
- Food insecurity
- Health care access insecurity
- Housing instability and homelessness
- Incarceration history
- Income
- Insecure utilities
- Interpersonal violence
- Phone insecurity
- Social isolation
- Stress
- Transportation insecurity

In June of 2020, Pew conducted a survey of roughly 1,200 adults to determine their views on sharing certain types of health information. Seventy-five percent of respondents were comfortable discussing social determinants of health with their providers, and with having these data be documented in their EHR. However, when it came to these data being shared among providers, only 48% felt comfortable. Non-White respondents expressed a higher level of discomfort; for example, only 33% of Hispanic respondents were comfortable with providers sharing these data.[8]

However, providing additional information and context to explain why collecting and sharing

data on social determinants—including how that contributed to overall health—resulted in higher proportions of respondents expressing comfort with providers sharing that information. In a follow-up question, respondents were given information that stated lack of access to healthy food or housing can influence a person's health. After seeing this information, 62% of respondents—including 54% of non-White individuals—said they would support providers sharing such data.[9]
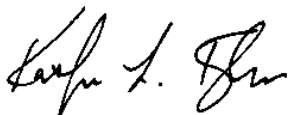
Providers and patients should discuss the importance of collecting and sharing social determinants of health to assuage any concerns individuals may have. However, when patients are comfortable and provide consent to document and share these data as appropriate, EHRs should be able to share SDOH using the same standards as clinical data. Given their significant benefits for improving patient care, SDOH elements should be part of the USCDI.

Conclusion

USCDI version 2 is an opportunity to ensure data needed for patient care and public health activities are included within standards for exchange. The COVID-19 pandemic has highlighted the existing gaps in current mechanisms for data exchange, both between health care facilities and with public health agencies. A comprehensive USCDI could help close these gaps and ensure complete, standardized data can be seamlessly shared with those who need it.

Thank you for the opportunity to provide comments on the USCDI version 2. Should you have any questions or if we can be of assistance, please contact Elise Ackley at eackley@pewtrusts.org or (202)540-6464.

Sincerely,

Kathy Talkington
Director, Health Programs
The Pew Charitable Trusts

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