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September 23, 2019

Dr. Donald Rucker
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

Re: Interoperability Standards Advisory

Dear National Coordinator Rucker:

Thank you for soliciting comments on the Office of the National Coordinator for Health Information Technology's (ONC's) Interoperability Standards Advisory (ISA). The update to the ISA affords ONC an opportunity to continue advancing interoperability by adding and refining data elements critical to care coordination and improved patient outcomes.

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, facilitating the development of new medical products and reducing costs. Pew's Health Information Technology Project focuses on advancing the interoperable exchange of health data and improving the safe use of electronic health records (EHRs).

Wide adoption and use of standards can help EHRs and other technologies more easily communicate data to give clinicians and patients the information they need to make informed decisions. To serve that goal, ONC publishes the ISA to detail what data standards exist, how widely adopted they are, and whether any federal mandates exist for them. By updating the ISA, ONC provides technology developers with a roadmap on which standards are mature and adopted, and which ones are emerging.

Opportunities to increase data in the ISA

To further increase the use of standards for interoperability, ONC should add and clarify information in three key areas: patient matching; clinical notes; and social determinants of health. Specifically, ONC can update ISA in the following ways:

- *Data for patient matching:* Currently, the ISA does not list many data elements important for patient matching, which is the ability to correctly link the different health records associated with each patient. ONC can improve the ISA's ability to guide patient matching efforts through better standards for existing data elements and by listing other data that could be used to link records.

First, ONC can specify standards for data elements that research has shown would improve match rates. For example, ONC, in recent proposed regulations, suggested including address in the U.S. Core Data for Interoperability (USCDI), which is a set of data elements identified as critical for care coordination and information exchange. While the inclusion of address in the USCDI ensures that EHRs will make it available for matching, ONC does not list an explicit standard, either in the USCDI or ISA.¹

To remedy this gap, ONC should further advance the use of the U.S. Postal Service (USPS) guidelines for address. These guidelines, for example, indicate the appropriate street suffixes to use. Pew-funded research at Indiana University revealed that use of the USPS guidelines for address can improve the accuracy of matching records by approximately 3 percent.² An organization with a match rate of 85 percent, for example, could see its unlinked records reduced by 20 percent with standardizing address alone. Separately, documenting last name according to the standard used by the Council for Affordable Quality Healthcare in conjunction with address could improve match rates from, for example, approximately 81 to 91 percent, which would reduce the number of unmatched records by half. Therefore, ONC should include address in ISA and specify the USPS guidelines to encourage further adoption.

Second, ONC in the ISA should advance the use of regularly collected demographic data elements for patient matching. ONC currently requires EHRs to make some demographic data—such as name, birth date, and sex—available. However, health records contain other information routinely collected that are not typically used or made available to match records.

For example, research published in 2017 showed that email addresses are already captured in more than half of patient records. The documentation of email is likely higher today given the adoption of patient-facing tools, like portals, that often require this information to register. ONC could improve match rates by identifying and including in the ISA other readily available data elements—such as email address, mother's maiden name, or insurance policy identification number—to provide health information technology vendors additional guidance on information they could use for matching.

- *Notes:* Clinical notes provide narrative context and information not otherwise captured in patients' records. For example, notes provide detailed descriptions of care plans or summaries of surgical procedures. Patients have indicated that access to notes helps them better understand their care, and makes them more likely to follow through on tests and referrals.³ When patients received access to their physician's clinical notes, some individuals—particularly those who are older, less educated, non-English speaking, and non-white—reported the greatest benefit.⁴

In the recent draft regulations, ONC proposed adding clinical notes to the USCDI. ONC provided different options for finalization: making all notes available; limiting note types to the seven listed by the Argonaut Project (a collaboration among technology developers and health care providers); or 11 types of clinical notes that would build on document types identified by Health Level 7 (the organization that oversees key common, industry-established standards for data exchange).⁵

Given the importance of clinical notes in coordinating care and informing providers, and because ONC proposed in regulations to require the inclusion of this information in the USCDI, the ISA should clearly indicate which standards exist for each of the different types of notes. Including those standards will help ensure that technology developers can more easily and consistently exchange clinical notes. Regardless of the approach ONC finalizes in its regulations, the ISA should list the necessary standards for consistent implementation.

- *Social determinant of health:* Each person's health is affected by a complex array of social and environmental factors that have typically been viewed as outside the medical context. Increasingly, many medical experts have focused on caring for patients more holistically by understanding the social and environmental factors that impact health, such as housing and employment status. In order to address these factors, or social determinants of health (SDOH), in a comprehensive and coordinated way, different facilities may seek to integrate this information into patient records. Incorporating information on housing insecurity, for example, into patients' records would give clinicians context when making clinical decisions and could help them refer patients to outside resources.

Researchers and developers in the health community are already working to determine how to best capture and use this information. For example, researchers at the University of California, San Francisco, developed the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences toolkit to aid providers in collecting SDOH.⁶ As these social factors are increasingly documented in patients' records, ONC in ISA should identify data elements and their associated standards to ensure greater consistency across technologies. Addressing this challenge with SDOH now prior to widespread capture and development can help prevent interoperability hurdles that exist with other information due to a lack of uniformity.

Conclusion

ONC's commitment to advancing adoption of data standards will improve interoperability so that patients receive higher quality, coordinated care. In revising ISA, ONC should specify additional data elements and standards that can improve patient matching, enable the efficient exchange of clinical notes, and support tools to address social factors that influence health outcomes.



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Thank you for the opportunity to provide comments on the ISA. Should you have any questions or if we can be of assistance, please contact me at 202-540-6333 or bmoscovitch@pewtrusts.org.

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The Pew Charitable Trusts

¹ Office of the National Coordinator, “HHS Proposes New Rules to Improve the Interoperability of Electronic Health Information,” <https://www.hhs.gov/about/news/2019/02/11/hhs-proposes-new-rules-improve-interoperability-electronic-health-information.html>.

² Shaun J Grannis et al., “Evaluating the effect of data standardization and validation on patient matching accuracy,” *Journal of the American Medical Informatics Association* 26, no. 5 (2019): 447–456, <https://doi.org/10.1093/jamia/ocy191>.

³ Sigall K. Bell, et al., “Tackling Ambulatory Safety Risks Through Patient Engagement: What 10,000 Patients and Families Say About Safety-Related Knowledge, Behaviors, and Attitudes After Reading Visit Notes,” *Journal of Patient Safety* (2018). <https://europepmc.org/abstract/med/29781979>. AND Eric Wright et al., “Sharing Physician Notes Through an Electronic Portal is Associated With Improved Medication Adherence: Quasi-Experimental Study,” *Journal of Medical Internet Research* (2015): e226, <https://www.jmir.org/2015/10/e226/>.

⁴ Jan Walker et al., “OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians’ Outpatient Visit Notes,” *Journal of Medical Internet Research* 21, no. 5 (2019): e13876.

⁵ Office of the National Coordinator, “HHS Proposes New Rules to Improve the Interoperability of Electronic Health Information,” <https://www.hhs.gov/about/news/2019/02/11/hhs-proposes-new-rules-improve-interoperability-electronic-health-information.html>.

⁶ Cantor, Michael N., and Lorna Thorpe. “Integrating Data On Social Determinants Of Health Into Electronic Health Records.” *Health Affairs* 37, no. 4 (2018): 585–90. <https://doi.org/10.1377/hlthaff.2017.1252>.