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Don Rucker, M.D.
National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear National Coordinator Rucker:

Thank you for soliciting comments on the draft Trusted Exchange Framework and Common Agreement (TEFCA) to implement provisions from the 21st Century Cures Act (Cures) to support the exchange of healthcare data so that clinicians, patients, and caregivers have better information to make healthcare decisions. The development of the draft TEFCA—which creates a series of requirements to enable the exchange of information across healthcare organizations—by the Office of the National Coordinator for Health Information Technology (ONC) offers an opportunity to advance two key challenges to the interoperability of healthcare data: patient matching and data standards.

The draft TEFCA proposes policy, technical, and governance requirements for the exchange of healthcare data among Qualified Health Information Networks (QHINs) and their participants. A QHIN is a network of organizations that agree to the same technical infrastructure to share data. The draft TEFCA lays out the principles and requirements for a technical and governance infrastructure to support data exchange across QHINs based on a single common agreement on how to share information.

Opportunities exist to advance patient matching and use of standards

While the draft TEFCA would make progress toward enhanced interoperability, additional barriers to matching patients to their records and the use of data standards remain key challenges. Pew is conducting research in both these areas.

The goals of TEFCA and an interoperable healthcare system writ large—where patient data is available when and where it is needed—relies on the ability to accurately link each individual’s health records held in multiple locations—known as patient matching. The draft TEFCA recognizes accurate patient matching as essential for electronic health information exchange: QHIN participants need to ensure some patient demographic data is used. However, challenges linking patients to their records persist, and can lead to harm and unnecessary costs.

Pew has been conducting research to better understand challenges with patient matching and evaluate solutions to this interoperability problem. For example, we are assessing whether the use of more detailed standards for demographic data—such as name and date of birth—could help improve match rates. We are also examining whether individuals can be involved in

matching their records. Similarly, we are conducting focus groups with patients and interviewing healthcare facilities to understand how they view patient matching, and their perspectives on biometrics and other unique identifiers that could be leveraged. Alongside our research we are collaborating with experts to identify key characteristics that a nationwide patient matching strategy should exhibit to improve the accurate and consistent linking of individuals' data to their health records. Improved matching across networks can result in better patient care by facilitating access to relevant information to enable care coordination, integrate and reconcile data, and to avoid duplication of tests and other services.

The exchange of healthcare data—as envisioned in the draft TEFCA—also relies on healthcare facilities' sending and receiving clinical information (such as medication data and diagnostic results) so that it can be integrated into electronic data systems. The development of an exchange framework for QHINs to exchange data offers ONC an opportunity to underscore the importance of addressing standardization as a critical aspect of interoperability. To help improve the standardization of data, Pew is identifying solutions to address identified challenges—including actions that could be advanced by government or the private sector. Addressing challenges associated with standards can foster more accurate and robust data sharing so that the information is both available and usable by clinicians.

RCE should have an opportunity to iterate on TEFCA to advance interoperability

To oversee implementation of TEFCA and accredit organizations as compliant with the framework, ONC intends to task a single organization—the Recognized Coordinating Entity (RCE). The RCE, as envisioned by ONC, would work with QHINs, healthcare providers, health information technology vendors, and other stakeholders to implement and update TEFCA over time.

As ONC selects an RCE to administer TEFCA, the agency should ensure that patient matching and use of standards are a prioritized activity. For example, improvements to patient matching require collaboration among healthcare providers and technology vendors. The RCE can serve as a multi-stakeholder, trusted entity to identify more robust standards—such as those that would be needed to use biometrics—and approaches that can be leveraged across the healthcare industry to enhance patient matching. The RCE is similar in concept to what Pew has heard in our research: advancing matching could benefit from the identification of a neutral, trusted entity to advance a nationwide patient matching strategy, identify necessary standards, and encourage their adoption.

ONC should also clarify throughout TEFCA the roles that the agency and the RCE would each have in the implementation, evolution, and oversight of the framework. In some cases, ONC may seek to have a more active role, while in others the agency may want to provide the RCE with sufficient authority to advance interoperability on its own.

Draft TEFCA can further improve patient matching

Additionally, two provisions in the draft TEFCA could also help improve patient matching through the consistent use of demographic data and identity proofing.

Reliance on existing demographic data insufficient for long-term progress

The draft TEFCA recognizes accurate patient matching as essential for electronic health information exchange among QHINs, and includes provisions to encourage the capture and use of certain demographic data as identified in ONC’s EHR certification regulations. Those regulations currently encourage the exchange of the patient’s name, date of birth, address, phone number and other information to help match records for each person.

However, while these data elements help link records, they alone still lead to insufficient match rates, which can be as low as 50 percent when connecting records across organizations.¹ Other emerging data elements—such as unique identifiers, the use of email addresses, and biometrics—could further advance matching in the future. Additionally, the standardization of data elements may further enhance the utility of this information to improve matching.

Therefore, as ONC finalizes TEFCA, the agency should work with the RCE to ensure that the data elements and criteria used for matching can evolve over time. As significant variation exists among organizations and rapid innovation for patient identification continues, additional criteria may be needed to bring transparency to current matching methods, accommodate new matching attributes, and evaluate matching performance using existing methods. TEFCA should evolve to improve matching as technology matures and organizations adopt more sophisticated patient identification approaches (such as through the use of different tokens to uniquely identify individuals). ONC and the RCE should collaborate to ensure that the TEFCA requirements can adjust to accommodate these changes.

Identity proofing can help validate information to enhance match rates

ONC also includes requirements in the draft TEFCA to identity proof QHIN participants. Identity proofing and authentication involves a user (such as a patient) validating their information—typically to ensure that the individual seeking access to information is authorized to obtain the data. Identity proofing can be accomplished, for example, by verifying someone’s driver’s license, using their smartphone to validate information, comparing the address given by a patient to publicly available data, or having individuals answer a series of knowledge-based questions (such as to name the make and model of a car that they have previously owned).

Identity proofing can help deter fraud and misidentification, as individuals would face more requirements to validate who they are. Incorrect information can also affect match rates, and lead to records for two individuals being merged.

While identify proofing can help to ensure that patients’ information is accurate at any single point-in-time, challenges still persist for matching. For example, identity proofing on its own may not help match individuals who move addresses or change their name. Additionally, identity proofing may not be possible for all patients—including individuals who frequently change, or do not have, permanent addresses.

ONC should work with the RCE to clarify how identity proofing will occur, whether patients should always—to the greatest extent possible—be identity-proofed at healthcare facilities,

recommend potential technology types or approaches that are most realistic to use in healthcare, and provide other guidance. ONC should also coordinate with the RCE to clarify that, while identity proofing can help improve the security around accessing information, it is not sufficient for matching records.

USCDI key to exchanging robust data needed to inform care

Organizations that choose to participate in TEFCA are required to exchange a set of data elements called the U.S. Core Data for Interoperability (USCDI). The USCDI expands upon existing data that organizations are encouraged by federal regulations to exchange. Currently, federal payment programs incentivize the transmission of the Common Clinical Data Set (CCDS) when transitioning the care of patients among healthcare providers.

While the CCDS contains information on many critical components of patient care—for example medications, problem list, and vital signs—this limited data set still omits key data elements contained in EHRs. Through the USCDI, ONC expands the set of patient information available for exchange each year with the intent of eventually reaching all health information.

For example, for the first stage of USCDI implementation, ONC proposes requiring the exchange of the full CCDS along with two additional data elements: clinical notes, including unstructured free text—such as clinician assessments and progress notes—and provenance that provides context around the origin of information (e.g. the date that information was entered and the physician’s name who entered it). Future versions of the USCDI, as proposed, would add family health history, diagnostic image reports, and other data.

As ONC finalizes the data elements in the USCDI, the agency should work with the RCE to consider the following:

- The USCDI currently does not require the use of certain semantic standards—e.g. vocabularies or code sets—for data elements, which could inhibit its integration and use by electronic data systems. As appropriate, ONC should consider providing additional guidance on the standards for healthcare providers and technology developers to use.
- For future editions of the USCDI, ONC should consider adding additional data elements including radiology images—not just the diagnostic image report—and food and environmental allergies if they are available in the EHR, to the emerging status data classes to evaluate their inclusion in the future.
- When EHRs contain data in structured and standardized formats, the data should remain in that format. This would prevent the conversion of structured data that can be used by computers for clinical decision support to a PDF, where computability of the information is more challenging. Even in scenarios where standards are not widely adopted, retaining the data in those structured formats will facilitate their use. When data are not standardized but deemed appropriate for inclusion in APIs, the information should still be accessible to clinicians and patients.
- ONC should examine whether health IT developers should enable access to the full longitudinal patient record available in an EHR or just a subset of time. Falling short of requiring access to longitudinal data could limit clinician and patient access to key information that could hinder their ability to obtain a complete picture of an individual’s

health and how it changes over time, especially for individuals with chronic diseases. However, challenges could emerge when accessing historical data outside a particular timeframe.

Conclusion

The development of TEFCA marks an important step in advancing interoperability so that patients and clinicians can have complete and accurate medical information on which to inform decisions. As ONC works with stakeholders and the RCE to finalize and implement TEFCA, we urge you to consider improvements to patient matching and use of data standards to further leverage this opportunity to enhance interoperability. Thank you for the opportunity to provide comments on a nationwide trusted exchange framework. Should you have any questions or if we can be of assistance, please contact me at 202-540-6333 or bmoscovitch@pewtrusts.org.

Sincerely,



Ben Moscovitch
Manager, Health Information Technology
The Pew Charitable Trusts

¹ Genevieve Morris et al., “Patient Identification and Matching Final Report,” February 7, 2014, https://www.healthit.gov/sites/default/files/patient_identification_matching_final_report.pdf.