

CPeH Summary and Talking Points:

Trusted Exchange Framework and Common Agreement

Public Comments Due February 20

NEW ACRONYM ON THE BLOCK: WHAT IS THE TEFCA?

The 21st Century Cures Act calls on the Office of the National Coordinator (ONC) to work with federal and industry partners to improve interoperability. Specifically, ONC is required to “develop or support a trusted exchange framework, including a common agreement among health information networks nationally.”

On January 05, ONC released the draft Trusted Exchange Framework and Common Agreement (TEFCA) for public comment. The TEFCA outlines a common set of principles and minimum terms and conditions for trusted exchange of health information.

WHY SHOULD CONSUMERS CARE?

CPeH has long advocated that interoperability must include individuals as equal partners in electronic access to and use of their own health information. Additionally, we believe that widespread electronic exchange of health information is a prerequisite for reimbursing value-based care and improving health outcomes. **The TEFCA holds promise to improve individuals’ ability to access and share their information electronically, as well as advance value-based care models.**

CONSUMER PRIORITY ISSUES (Taken from National Partnership comments)

- **We share ONC’s vision of an interoperable health system that empowers individuals** to use and share their electronic health information and enables providers and communities to deliver high-quality, patient-centered care. We support the TEFCA’s goal to build and maintain trust between stakeholders, including providers and patients, to further advance interoperability.
- **We support the prioritization of individual access** to electronic health information as a central component and prerequisite for delivering and paying for high-quality, value-based care.
 - Specifically, we believe individuals should be able to access their electronic data using application programming interfaces (APIs), as has been proposed for the Meaningful Use and Merit-based Incentive Payment System, and recently reinforced in the 21st Century Cures Act.
 - When available, APIs will let consumers choose from a range of apps that pull in health data from various health care providers and hospitals, helping form a comprehensive picture of their health and health care and facilitating information sharing.

- **However, the TEFCA is unclear about how individuals and their caregivers would access their own health data**, either directly or through apps acting on their behalf. To enable individuals to exercise their right of access under HIPAA, ONC should clarify how individuals connect to the exchange infrastructure.
- **We support the Principles for Trusted Exchange and offer several recommendations for implementing the principles in a person-centered manner.**

Principle 1 - Standardization

Adhere to industry and federally recognized standards, policies, best practices, and procedures.

Principle 2 - Transparency

Conduct all exchange openly and transparently.

Principle 3 - Cooperation and Non-Discrimination

Collaborate with stakeholders across the continuum of care to exchange Electronic Health Information, even when a stakeholder may be a business competitor.

Principle 4 – Privacy, Security, and Patient Safety

Exchange Electronic Health Information securely and in a manner that promotes patient safety and ensures data integrity.

Principle 5 – Access

Ensure that Individuals and their authorized caregivers have easy access to their Electronic Health Information.

Principle 6 – Data-driven Accountability

Exchange multiple records for a cohort of patients at one time in accordance with Applicable Law to enable identification and trending of data to lower the cost of care and improve the health of the population.

Recommendations:

- Qualified HINs must **not impede the ability of patients to access and direct their Electronic Health Information to designated third parties**, such as mobile health applications.
- Participants and Qualified HINs should **educate and train all staff members** on how to help individuals obtain electronic access.
- **Prohibit fees** for queries/pulls for individual access (which includes the right of an individual to access their information and have it sent directly to the third party of their choice).
- ONC should consider which stakeholders are best positioned to **provide consumer-facing educational information and tools**. Equipping patients with information about data privacy and security practice is vital as consumers increasingly manage their health data using smartphone apps and other electronic platforms that are not covered by HIPAA.
- Any QHIN that is not a Covered Entity under HIPAA **should publish and make available a notice of information practices**. It is important that information on a QHIN's data practices be available to the public to build trust between providers and patients.

WHAT IS THE USCDI?

ONC also released a draft U.S. Core Data for Interoperability (USCDI) for public comment.

The USCDI specifies a common set of clinical data classes that are required for interoperable exchange. Because Qualified Health Information Networks (QHINs) and their participants are required to be able to exchange the USCDI (when such data is available), the required data elements are important levers to secure and advance consumer priorities – for example, capturing data on sexual orientation or patient goals and priorities.

- **We support the addition of data provenance and clinical notes** to the Draft USCDI Version 1 Data classes; these data are critical pieces of information about individuals' care and health that are necessary for safe and effective transitions of care. Data provenance, an indicator of who collected the data elements, is essential for greater collection and use of patient-generated health data as part of clinical care. Clinical notes, which include detailed provider impressions and plans, and are particularly valuable to patients and families.
- **We are concerned with the proposal to delay data classes that are important to patients and families, particularly social determinants of health** (social, psychological and behavioral data) until 2021 or later. We disagree that these are “emerging data classes,” as technical specifications are already available for most of the data classes listed. We also disagree with the statement that “their overall priority for [promotion] is unclear” – there is substantial evidence to support the importance of collecting information about the social determinants of health to provide high quality, comprehensive care.
- **We suggest accelerating the adoption of multiple data classes.** The proposed timelines for many data classes are inadequate to meet the information needs of consumers, or providers participating in new models of care. In particular, we would like to highlight those data classes below as candidates for accelerated adoption:
 - Cognitive status
 - Discharge instructions
 - Functional status
 - Gender identity
 - Care Team Members Contact Information
 - Care Team Member Roles/Relationships
 - Individual Goals and Priorities
 - Advance Directive
 - Disability Status
 - Personal Representative
 - Social, psychological, and behavioral data*
 - Reconciled Medication List

Proposed Version / Timeline	Data Class	Description	Technical Specifications
Version 2 / 2019 Candidate Status	Cognitive Status	Cognitive function, including a person's current and baseline attention, orientation and ability to register and recall new information and an individual's mental status.	Yes (FHIR and C-CDA)
	Discharge Instructions	Any directions that the patient must follow after discharge to attend to any residual conditions that need to be addressed personally by the patient, home care attendants, and other clinicians on an outpatient basis.	Yes (FHIR and C-CDA)
	Functional Status	Functional status data includes a person's current and baseline performance completing activities of daily living (ADLs), such as eating, bathing, walking, stair climbing, and may address altered gait and balance and decreased range of motion.	Yes (FHIR and C-CDA)
	Gender Identity	Gender identity refers to a person's self-perception as male or female, and may not be congruent with one's birth sex (or administrative gender).	Yes (FHIR)
Version 3 / 2020 Candidate Status	Care Team Members Contact Information	Identification of contact information for each care team member as it relates to the patient.	Yes (FHIR and C-CDA)
	Care Team Member Roles/Relationships	Identification of roles/relationships for each care team member as it relates to the patient (e.g., provider to patient, provider to provider).	Yes (FHIR and C-CDA)
Version 4 / 2021 Candidate Status	Individual Goals and Priorities	Attribute within Goals that describes the intended health objective(s) set by an individual with a specific end point, for example, weight loss, restoring an activity of daily living, exercise goal, prevention based activities etc.	Yes (FHIR and C-CDA)
No timeline / Emerging Status	Advance Directive	A legal document that states the kinds of medical care a person does or does not want under certain specific conditions.	Yes (FHIR and C-CDA)
	Disability Status	A physical or mental impairment that substantially limits one or more of the major life activities of such an individual. Y	Yes (FHIR and C-CDA)
	Personal Representative	A person allowed access to protected health information on behalf of an individual they are representing, such as a child's parent or legal guardian, or a family member providing care for an aging relative.	Yes (FHIR)
	Social, psychological, and behavioral data*	Conditions in the places where people live, learn, work, and play that affect a wide range of health risks and outcomes.	Yes (FHIR and C-CDA) except Veteran's Status
	Reconciled Medication List	Attribute within Medications that lists all the medications that the patient is taking, reconciled with allergy intolerances and problem list, as well as prescribed dosage, instructions, and intended duration.	Yes (FHIR and C-CDA)

*Includes Education, Overall Financial Resource Strain, Social Connection / Support and Isolation, Exposure to Violence, Employment Status, Depression, Stress, Physical Activity, Alcohol Use, Veteran's Status / Military History.

Table adapted from: [Draft U.S. Core Data for Interoperability \(USCDI\) and Proposed Expansion Process](#). (2018, January). The Office of the National Coordinator for Health Information Technology.