

CARIN Community Meeting Summary

July 27, 2017 | Chicago, IL

Objectives

The CARIN community, made up of the CARIN Board, Affiliate Members, and Special Guests, met to discuss progress on the Trust Framework and other key goals for 2017 and hear from ONC National Coordinator, Dr. Rucker as well as a caregiver to remember the central mission of the CARIN Alliance. The CARIN Community will meet next on October 24th in a location that is being finalized.

Special Guest Presentations

ONC Perspectives

Dr. Donald Rucker, National Coordinator for Health IT, ONC

Dr. Teresa Zayas-Caban, Acting Chief of Staff and Chief Scientist, ONC

- ONC is focused on implementing 21st Century Cures requirements in the coming year
 - Dr. Rucker believes that defining what interoperability and information blocking entail will be big questions for the ONC to work on answering along with how to define Open APIs
 - ONC is interested in comments around topics such as: standardization, transparency, non-discrimination, patient safety, access, choice, and general commentary
 - ONC will work with OIG on questions around information blocking and is looking to release guidance on that topic soon
- ONC sees its mission as making what we have for health IT more useable and making any new products or services integrate with existing systems and tools
- ONC will focus on three use cases related to their work on 21st Century Cures and the development of a common agreement / trust framework:
 - First, patients can access their health information electronically without any special effort.
 - Second, providers and organizations accountable for managing the health of populations can receive necessary and appropriate information on a group of individuals without having to access one record at a time (bulk accountability)
 - Third, the health information technology (health IT) community should have open and accessible application programming interfaces to encourage entrepreneurial, user-focused innovation to make health information more accessible and to improve electronic health record (EHR) usability.

Key Discussion

The CARIN community received updates on key activities for the CARIN Alliance since the last meeting.

New Members

- Cerner, Aetna, Medfusion, and Crimson Tide are new members of the CARIN Alliance and shared their perspectives on the importance of consumer directed exchange

CARIN Alliance Use Cases

- The CARIN Alliance is focused on two key use cases
 - **Use Case #1** – Individuals or their authorized caregivers invoking their individual right of access to electronically transmit their health information to a third-party application of their choice
 - The Alliance is supportive of AHIMA's efforts to develop an individual right of access [form](#). The Alliance is working to modify the fields in the form to be used in the electronic world to further this use case.



The CARIN Alliance

Creating Access to Real-time Information Now through Consumer-Directed Exchange

- The Alliance will also work to find ways to ensure caregivers are linked to patients for information sharing when one invokes their individual right of access
 - **Use Case #2** – Upon invoking their right of access, facilitating the data exchange between the consumer-controlled application and the EHR
 - The Alliance is working on a preferred technology workflow for how to do this
 - The CARIN community noted that there are points of friction with connecting to API endpoints today and there is a growing need to reduce those over time

Trust Framework

- The CARIN Alliance is working with the ONC and other trusted exchange frameworks to develop a common agreement for trusted exchange as required by 21st Century Cures
- The CARIN community reviewed critical barriers that exist to achieve trusted exchange for consumer directed exchange, which include:
 - User Authentication
 - In person and remote ID Proofing
 - A methodology for uniquely identifying patients and their authorized caregivers within and across systems
 - Regulatory uncertainty around requirements for open APIs and information blocking definitions
 - Consumer and provider education regarding the requirement that patients have the right to access their health information from their providers ‘without any special effort’
 - Sharing data with the patient despite the fact it may be outside the physician workflow
 - Lack of trust between entities within the health care ecosystem
 - The process for registering, endorsing, and certifying applications

Technology Work Group

- The CARIN community reviewed the current workflows around CDEX and addressed open questions around authentication and validation

Policy Work Group

- The CARIN board decided to move forward commenting on the MACRA/MIPS Proposed Rule to encourage the use of 2015 Edition CEHRT because of its use of APIs to enable patient access
- The CARIN board decided to submit comments on the ONC Trusted Exchange Framework activity

Update on 2017 Priorities

Deliverable	Progress
Principles of trusted consumer-directed exchange	Phase I – 12 Principles Phase II – Preferred technology workflow Phase III – 11 Major Topics
FHIR API implementation best practices and feedback	Bi-weekly technology workgroup
Public demonstrations of how the FHIR APIs work in production	February – HIMSS HX360 April – Health Datapalooza October – Health 2.0
Individual Right of Access best practices	July – AHIMA publication Q3 – CARIN specific publication
Consumer, Business, and Caregiver education	On hold until 2 nd half of 2017
Business and Policy input to the longitudinal health record	Ongoing dialogue
Cures regulatory policy	ONC 21 st Century Cures Trusted Exchange Framework and Common Agreement work