The CARIN Alliance
[Creating Access to Real-time Information Now through Consumer-Mediated Exchange]

CARIN Community Meeting Summary
January 26, 2017 **|** Washington, D.C.

Objectives
The CARIN Community, made up of the CARIN Board, Affiliate Members, and Special Guests, met to discuss priorities for 2017 with the goal of providing the Board with recommendations for a 2017 workplan. The group discussed progress being made on API implementation, consumer app development, and other key trends within government initiatives that happened since the last CARIN meeting in December, 2016. CARIN also reviewed annual anti-trust requirements before laying out 2017 plans.

Key Discussion
The CARIN Community reviewed 6 potential projects for 2017. The group will work on these projects throughout the year based on the resources available and guidance below.

Trust Framework
- CARIN could develop a set of guiding principles for exchanging data between patients, third-party applications, and EHRs as part of a trusted exchange framework
- Efforts in this space could involve: developing or refining a model privacy notice, developing the high-level principles for data exchange, and helping develop/clarify new or existing certification frameworks
- Leverage existing assets where they exist
- Group needs to continue to discuss the appropriate level of detail for the trust framework on topics such as certification, authentication, etc.
  - Group will schedule workgroup calls to review and discuss principles of trusted consumer data exchange

Individual Right of Access Best Practices
- CARIN examined the need to develop a set of best practices around how an individual could request access to their medical information
- AHIMA will be developing a framework for how individuals could request their health information. Target completion: Summer 2017
  - Group will provide feedback to the work AHIMA is doing

Demonstration of the Interoperable Meds list
- CARIN will be presenting at the HIMSS HX360 event and participating in the Argonaut Project's roundtable discussion on February 21st
  - Technology workgroup will focus on the agenda and demos for the HIMSS event

FHIR API Implementation Best Practices and Feedback for Consumers
- CARIN considered creating a technology forum for sharing best practices regarding the implementation of the vendor FHIR APIs
- Group discussed providing consumer and business feedback to the project roadmap for organizations like Argonaut and the FHIR foundation
- Activities for 2017 will focus on helping apps and providers become a conduit to get consumer feedback transferred back to data holders and proactively generate useful requirements as part of a feedback loop
  - Technology workgroup will help develop best practices in this space, but does not feel that diving in to the technical details is the right role for the alliance

Educating Consumers, Business, Providers, and HIM staff on CDEx
- While many open issues exist around education of rights, responsibilities, and capabilities related to CDEx, CARIN decided to wait until later in 2017 to begin educational activities once the APIs are installed
  - CARIN would like to leverage existing content from our consumer advocates where appropriate and look to each of the provider organizations to assist with that education later in the year

Longitudinal Health Record
- CARIN considered how to assist with the requirement in Cures that consumers have access to their longitudinal health record, which is not well defined. Discussions about clinical terminologies and semantic interoperability standards were thought best handled by SDOs.
  - CARIN will provide business and consumer feedback to the additional data fields that will be developed by groups like Argonaut, HL7, and the FHIR foundation

Next Steps

LP will get board input and approval for these priorities and then schedule workgroup meetings as appropriate.

Deliverable	Description	Suggested workgroup	Priority	Next Steps
Principles of trusted consumer-directed exchange	Describes the high-level principles to enable the trusted exchange of health data between consumers, apps, and providers	Trust Framework	High	LP to schedule a workgroup meeting to review draft set of principles
FHIR API implementation best practices and feedback	Technology forum for sharing best practices regarding the implementation of the vendor-based FHIR APIs	Technology	High	Group to discuss in an upcoming technology WG
Demonstration of an interoperable Meds list	Demonstrate during HIMSS and throughout the year the progress organizations are making implementing the FHIR-based APIs	Technology	Medium	Group to discuss in an upcoming technology WG
Individual Right of Access	Development of best practices and forms for individuals to request access to their health information	Adoption and Sustainability	Medium	Group to review AHIMA's draft deliverable
Consumer, Business, and Caregiver education	Remove the business barriers to CDEx and educate consumers, providers, and caregivers on CDEx	Adoption and Sustainability	Medium	Group will revisit in the 2nd half of 2017
Input to the longitudinal health record	Provide feedback to the SDOs regarding the Cures requirement to provide consumers access to their longitudinal health record	Technology	Low	Group will coordinate next steps with Argonaut at HIMSS
Cures regulatory policy	Provide a private-sector led vehicle for helping to define the regulatory policies associated with Cures	Policy	Low	LP to schedule monthly checkpoint call and look to increase frequency as new admin. gets in place