

The CARIN Alliance

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

CARIN In-Person Meeting Summary | September 12, 2016 | Washington, D.C.

Objectives

- Organize CARIN by establishing:
 - A governance and consensus approach
 - Workgroup strategies, activities, and priorities
 - Current membership
 - Current participants while confirming there is a desire to add affiliates (vendors and others) in the future
- Agree to work products being published as a “common-good”
- Focus on a limited set of significant, signature projects
- Ensure continuous alignment with similar government initiatives including: the ONC Interoperable Meds List, CMS Medicare ‘Blue Button’, NIH Sync 4 Science (S4S), and Medicaid T-MSIS

CARIN Formation

Membership Update

- Leavitt Partners is working with each participant organization who would like to become members of CARIN to draft a membership agreement
- CARIN is open to adding members through the rest of 2016 and will likely cap the board at 20-25 organizations by the start of 2017
 - Vendors and other affiliate organizations who want to join may be able to join as affiliate members, subject to board approval

Review and Approval of CARIN Charter

- The group reviewed, updated, and approved the CARIN charter
 - It was suggested to insert the phrase “widespread consumer access, education, and demand for CDE”
 - The change was approved unanimously by the group
 - The charter will be the guiding document for the alliance moving forward

Government Updates

Medicaid Update

- CMCS provided an update on CMMI’s Accountable Health Communities project and the T-MSIS Medicaid data initiative
 - 72M Medicaid beneficiaries; 50% are kids; majority of pregnant women in the U.S.
 - At present, there is broad state data becoming available through the Amazon cloud including: eligibility, primary language, provider information, non-traditional providers, all encounter data including costs, data on the managed care plans themselves, third party liability (i.e., Medicare-Medicaid payer mix, VA)
 - 17 states are currently live; most of the rest will be live by the end of 2016
 - CMCS is working on a data sharing plan with other government agencies and other commercial entities (i.e., data mare, PUF file, etc.)
 - Data exchange efforts are a key part of the Accountable Health Communities project

The CARIN Alliance

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

- Ultimately, the vision is to also include social determinants of health as part of the data exchange
- The goal of the Accountable Health Communities initiative is to link community and other social determinants of health with traditional data sets. There may be an opportunity to include the Accountable Health Communities initiative with the work we are doing within CARIN.

ONC Update

- ONC provided an update on ONC activities, specifically around the Interoperable Meds List effort
- ONC also discussed the role CARIN can play in moving the effort forward, noting that CARIN:
 - Can go to a level of specificity and technical specs that the federal government cannot do, especially around implementation specificity
 - Can be a vehicle for developing an ongoing testing lab for the project
 - Might consider publishing what is learned and to help the industry identify gaps that could be resolved by industry or the ONC

White House Update

- Provided an update on current efforts including Sync for Science and voiced support for the data exemplars work
 - The Meds List initiative is also a top priority for the White House

Additional HHS Update

- ONC discussed the importance of establishing a trust framework as a pre-cursor to the activities we would like to implement
 - Internet commerce can be a good example of an ability to designate which sites are able to be trusted, similar to how to know which apps can be trusted
- CMS discussed the Blue Button initiative and how important it is to understand that patients have an absolute right to their data
 - There are open trust framework questions related to how patients can designate certain apps or machines to access their information

Workgroup Discussion

Workgroup Framing

- CARIN member organizations can join one or all of the workgroups
- Different individuals from each member organization can be members of different workgroups
- Workgroups will focus on signature projects and will try not to duplicate other efforts
- Final work products will be a “public good” and put in the public domain through a CARIN document library, website, or other mechanism

Policy Workgroup

- The workgroup will need to quickly determine quickly which Congressional policy vehicles and opportunities to pursue
- The workgroup will consider legislative approaches to improving CDE usage
 - This may involve a focus on getting more specific in regulation and legislation to account for gaps that currently exist due to existing broad policies

The CARIN Alliance

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

- During the meeting participants noted three specific initiatives that the workgroup should consider:
 - Three initiatives for the House Energy and Commerce Committee to consider regarding open API issues in 21st Century Cures: standards development, restrictive terms and conditions, and expanding the CCD
 - MACRA's requirement for a care plan can be an opportunity here
 - Privacy and security are concerns within CDE, even though the White House and ONC have said that patients have a right to their data
- Interested parties will prioritize activities as part of their first workgroup meeting

Adoption and Sustainability Workgroup

Group discussed a few key categories to consider when looking at projects in the adoption and sustainability workgroup. They include:

- Engagement (awareness, education, incentives, best practices)
 - Physician
 - Consumer
 - Organizational
- Business project simplification
- Financial / economic costs & revenue
 - Capital expenses
 - Operating costs (education, patient communication, etc.)
 - Revenue opportunities
- Trust frameworks continue to be a priority for the workgroup before there can be widespread use of CDE
- The workgroup is interested in pursuing the Data Exemplars project that the National Partnership for Woman and Families has started
- Determining effective business case principles and examples for CDE will be an important effort of this workgroup
- Consumer access to health information can mean different things to different consumers
 - There will need to be a way for information to be useable, transformable, and adaptable in to any app a consumer would want – ie: different language, visual representation of information, etc.
 - It will also be important that information fed into apps is shared in a way that is understandable for consumers and not too technical
 - The workgroup may also consider including notes in the full health record that gets shared
- The workgroup may also address use cases that are a good test for CDE and the trust framework
 - Using FDA cleared devices and connecting those can be a challenge
 - There is a consideration to use a use case of adding a new designated caregiver to become a credentialed user and have access since this would not have regulatory concerns
 - The idea of the framework is that a system or app should be able to identify that a patient requesting information is known to them and also identify that the patient has authorized that specific machine or app to get access to that information
- Key Question: What are the **principles** we should consider in evaluating projects? We need to first get the evaluation criteria correct.

The CARIN Alliance

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

Technology Workgroup

- CARIN can become a place to do testing of Oauth, FHIR, APIs, CDAs, standards, Meds List work, CDE apps and other projects
 - CARIN technology labs can help to fill holes and go from functional specs to the level of specificity that is needed
- The workgroup will consider how to get access for patients to their entire record (and define that) so that the information shared is beyond just the CCD
- The workgroup will look at how to define how to break through walls of information blocking and determine what is being shipped across that wall to patients in a way that is meaningful and useful to the patient
- Discussion of the following specific workgroup activities
 - Form guiding principles for CDE technologies
 - Tip of spear activities:
 - Oauth 2.0
 - API
 - FHIR
 - C-CDA
 - CARIN Meds lab
 - Work with others semantic interoperability
 - Develop a roadmap for a full interoperable “designated record set”
- Special Project idea: CDE Trust Framework
 - Cross-cutting across three workgroups
 - Create recommended framework

Conclusion

Next Steps

- Our next in person meeting will be tentatively scheduled for early December. The group is discussing making the next in person meeting a members-only meeting to discuss their 2017 strategy for execution and growth.
- The group will target having a public event in the first quarter of 2017 to demonstrate their progress to date and provide an opportunity to engage and collaborate with new participants
- Leavitt Partners will reach out to each participant to understand which workgroup each participant would like to join
- Agendas for the new workgroups and dates will be circulated shortly
- High-level, high value use cases will be developed to ensure CARIN is focusing on ways to make data more accessible to consumers