

CARIN Community Meeting

December 10, 2019 | Baltimore, MD

Objectives

The CARIN community, made up of the CARIN Board, Affiliate Members, and Special Guests, met in Baltimore, MD to discuss workgroup progress and 2020 priorities, current federal activity on privacy, security and interoperability, to discuss the use of the CARIN Code of Conduct, opportunities to collaborate on price transparency and digital identity. The day prior to the Community Meeting the CARIN Alliance hosted its first Connectathon. More than 70 participants gathered to discuss and test the CARIN Blue Button 2.0 API Implementation Guide, and the Real-time Pharmacy Benefit Check Implementation Guide.

Key Discussion

Federal Perspective – Don Rucker, MD, National Coordinator for Health Information Technology

- Dr. Rucker discussed the importance of consumer directed exchange and the Office of the National Coordinator for Health Information Technology's (ONC) work to address information blocking in its proposed rule, "21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program," expected later this month.
 - He noted that there will be some allowable exceptions to the information blocking rules; those exceptions are regarding specific privacy and security harms. He reiterated that the rule is paired with the complementary CMS final rule, "Patient Access and Interoperability".
 - Dr. Rucker discussed the Trusted Exchange Framework and Common Agreement (TEFCA), and the progress made by The Sequoia Project, which is the recognized coordinating entity (RCE) responsible for overseeing the implementation of the TEFCA. He also discussed 'Bulk FHIR' which enables health care organizations to share bulk data. Finally, he underscored the net purpose is empowering the public to be active participants and decision-makers in their care.
- Dr. Rucker answered several questions regarding privacy and enforcement, Bulk FHIR, and the complementary CMS rule.

Leadership Perspectives – Aneesh Chopra, Care Journey

- Aneesh congratulated the CARIN Community on the progress made this year and called for diligence in strategically implementing of our current projects.
- Aneesh thanked the CARIN Community for their help in establishing a trusted and cross-sector alliance.
 - He invited our members to be as active as possible and to consider opportunities where the CARIN Alliance can be a vehicle for continued advancement of consumer directed exchange.
 - Areas where we may turn our attention including engaging on the proposed price transparency rule, improving provider director accuracy, bridging eligibility data with FHIR, developing a common language, particularly for shoppable services, and developing the business case for increased consumer access to their own data.

Consumer Advocate Story – Leslie Kelly Hall

- Leslie Kelly Hall spoke about the potential to improve health care safety and patient engagement by improving consumer access to their data.
 - She described her experience as a hospital administrator and noted that consumer access to data will push health systems to change how they capture and document health information. Further, that consumers who have access to their health information are empowered to actively participate in their care.
 - Leslie also shared her experience as a caregiver and how access to health records helped to identify medical errors, noting that consumers' access to their own health information can save their lives.

- She reminded the group that interoperability and consumer direct exchange are critical components of facilitating self-differentiation, self-care, patient, empowerment, and safety.
- Leslie noted that this work is not only a digital exercise, it provides life-saving access; data empowers patients and improves safety.

CARIN Alliance Accomplishments and Plans – Ryan Howells, Leavitt Partners,

- A status update was provided on CARIN Alliance activities including: development of the CARIN Blue Button 2.0 API (or Common Payer Consumer Data Set), updates to the CARIN Trust Framework and Code of Conduct, real-time pharmacy benefit check API, digital identity, and policy.
 - The CARIN Blue Button 2.0 API and the Real-time Pharmacy Benefit Check API will be balloted early next year. Some may recall that when the CARIN Blue Button draft implementation guide was announced at the White House in July 2019, 20 organizations volunteered to participate in real-world testing. To date, 14 of those organizations have actively participated among others; their efforts are appreciated. We hope to engage the remaining volunteers participate in the coming months.
 - The Digital Identity and Authentication workgroup is considering development of an industry-level framework for identity proofing, which will advance the ability to exchange data across systems electronically. This includes addressing trust and federation of ID credentials and addressing issues of consent and consumer matching through pilot testing.
 - The Policy workgroup continues to engage with Congress and the Administration on issues related to interoperability, consumer directed exchange and privacy, which has been a notable interest of Congressional members.
- The CARIN Alliance Board of Directors approved new 2020 activities. These include: actively expanding membership to include more patient advocacy groups, developing an electronic, centralized location for organizations to electronically attest to the code, work both in the US and with other countries on the code of conduct and trust framework to include a common approach to a privacy ‘nutrition label’ as well as other privacy design patterns, advancing and maturing the CARIN Commercial Blue Button and Real-time Pharmacy Benefit Check IG through the HL7 balloting process and production feedback, developing and piloting an approach for federating digital identities, and continued federal policy engagement.

CARIN Alliance Code of Conduct – Aneesh Chopra, Care Journey

- Recent news reports about the sharing of health information, even as allowable under HIPAA, have surfaced important discussions about responsible use of consumer data, and what data use and disclosure consumers should have knowledge of and consent to. The group discussed how the CARIN Code of Conduct can be considered in this discussion.
 - The CARIN Code of Conduct was built on key principles of consumer choice, and the recognition that there should be a mechanism for clear agreements governing data use and disclosure between data holders, users, and consumers.
 - The group discussed whether the CARIN Code can be used for more use cases than the narrow use case for which it was developed – i.e. business to consumer (B2C) data exchange via consumer-facing applications – in light of recent concerns about data privacy.
 - Other potential applications of the CARIN Code discussed were consumer-facing applications that facilitate B2C and business to business (B2B) exchange data exchange, and consumer-facing application “controlled and managed” by covered entities or business associates – i.e. within HIPAA.
 - The group recognized that the key component of the code is that it underscores the importance of transparency to the consumer; the Code attempts to strike the proper balance between informed consent, and security and privacy. There was some agreement that the code could be adopted for other uses, but adaptation may be required. Further, the group noted the desire to revisit some of the Code’s tenets and clarify the language especially Section III a) and b).

- The group discussed the challenge of binding third party vendors to the principles of the code, as is expected when an organization signs it.
- The group wondered whether the Code could be required – e.g. a business could refuse to release information to a consumer-application that had not attested to the code to safeguard against data misuse. Others worried that this was not the intended use of the code and could be used as a justification for information blocking. This could unintentionally limit consumer access and subvert the benefits of consumer directed exchange.
- Finally, the group discussed enforcement of the code. The FTC will play a critical role in enforcement, but some noted State Attorney Generals may also have enforcement jurisdiction.
- The next steps are to refine and clarify the language in the code, so it is interpreted as intended, and to work on ways of communicating information about data use and disclosure in plain and understandable language to further informed consumer consent.

Price Transparency – Dave Lee and Ryan Howells, Leavitt Partners

- There is ongoing administrative and congressional activity on price transparency and privacy. Leavitt Partners staff and CARIN Alliance members have met or are meeting with sponsors of new consumer-facing privacy legislation, Energy and Commerce Committee leaders on the development of 21st Century Cures Act 2.0, the Committees of Jurisdiction on privacy policy options and with OCR and ONC on the operationalization of HIPAA Individual Right of Access and the Information Blocking Rules.
- We expect continued work on price transparency. It is an open question to what extent CARIN will continue or further engage on some of these issues. Some noted that the it is in the CARIN Community's interest to engage on these issues because they are important for price transparency and making claims data understandable and usable to consumers.

Digital Identity – Ryan Howells, Leavitt Partners

- CARIN is developing federation principles for digital identity and considering digital identity solutions pilots, including one with the Center for Disease Control and their work with State Vital Records offices. The CDC is considering a pilot in 2020 to develop a digitize the birth certificate process and allow third parties to access the information via an API. Please let Leavitt Partner staff know if you are interested in participating in this work.

Next Steps

- CARIN Alliance Members interested in participating in any of the existing workgroups are invited to reach out.
- We will not host a normal Q1 CARIN Community Meeting. Instead we invite CARIN Members to the Leavitt Partners DC Policy Forum on January 30, 2020. We will also host an informal open house during HIMSS for the CARIN Community. More information on both events to follow.
- The Q2 Community meeting will take place in April 2020. If organizations are interested in hosting the Q2 meeting, please reach out to Leavitt Partners staff.