

CARIN Community Meeting September 12, 2019 | Chicago, IL

Objectives

The CARIN community, made up of the CARIN Board, Affiliate Members, and Special Guests, met in Chicago, IL to discuss workgroup progress, current federal priorities on consumer directed exchange, to discuss the use of the CARIN Code of Conduct and prepare for the HL7 Connectathon testing of the Common Payer Consumer Data Set and Real-time Pharmacy Benefit standards.

Key Discussion

Leadership Perspectives – Aneesh Chopra, Care Journey

- Aneesh noted that the CARIN Alliance is moving from concept to production. This brings exciting opportunities and challenges. Our goal will be thoughtful and strategic implementation of the CARIN Alliance work, and we invite our members to be as active as possible in advancing the CARIN Alliance priorities.

Patient / Caregiver Story – Dave deBronkart

- Dave deBronkart spoke about the importance of equipping patients with their health data and providing them access to tools for care management. He described his experience navigating the health care system through his cancer diagnosis and treatment and difficulties accessing his own information. He provided insight into how data access equipped him to manage his care and achieve health and well-being.
- The World Bank defines empowerment as increasing capacity to make informed choices, to take informed action, and produce effective outcomes. Sharing data with consumers empowers them and enables them to be partners in their care. This should be the goal of every organization participating in the CARIN Alliance.

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, Post-acute care API (managed by MITRE), digital identity, and policy.
- A recap of the joint CARIN Alliance, Centers for Medicare and Medicaid Services (CMS), and Office of the National Coordinator (ONC) Digital Identity Summit held on June 4th was discussed. More than 30 organizations came together to discuss the challenges associated with identifying and authenticating users of person-centric mobile technologies and federating consent to share identity and consent across systems. Next steps are to investigate a proof of concept and explore opportunities to develop and implement a pilot project.
- The group discussed the CARIN Blue Button 2.0 API, testing for which was announced at the White House Developers Conference in July 2019. The group discussed opportunities to advance this work including collaborating on implementation and the upcoming HL7 Connectathon.
- Because of the CMS proposed rule, the group discussed opportunities to map source systems to FHIR, or source systems to X12 to FHIR. It's anticipated X12 will their official mapping to FHIR by the end of 2019.
- The group also discussed the opportunity to collaborate on a centralized app registration utility 'playbook' that enables the application community to access all HL7 FHIR client end points, but allows covered entities to determine whether they release data or not to each app.
- The CARIN Alliance Board of Directors will be determining the slate of 2020 projects in the months ahead. There are still opportunities to develop policy, utilities to register applications, ways to progress digital identity, and metrics to advance consumer-directed exchange. Community recommendations for the Board to consider are welcome.

CARIN Alliance Blue Button draft implementation guide – Amol Vyas, Cambia and Ryan Howells, Leavitt Partners,

- Testing for the CARIN Alliance Blue Button IG was tested at the HL7 Connectathon in Atlanta from September 14-17 was discussed. Amol asked CARIN community members to stand up FHIR servers with data that complies with the CARIN BB IG, and help test the IG. This will help identify where improvements can be made.

CARIN Alliance Real Time Pharmacy Benefit Check – Pooja Babbrah, Point of Care Partners and Ryan Howells, Leavitt Partners

- Pooja described the focus of the RTPBC API, which is to create an IG that will enable consumer access to drug pricing information based on their coverage and cash-discounters as well as their location.
- The group discussed considerations for RTPBC API, including the importance caregiver access to this information, non-medical switching, and others.
- Any plans that are interested in engaging in the RTPBC API development should reach out to Leavitt Partners staff, and join the RTPBC workgroup.

CARIN Alliance Code of Conduct - Ryan Howells, Leavitt Partners and Dave Lee, Leavitt Partners

- The group discussed the intended use of the CARIN Code of Conduct and potential evolution of the Code to advance different use cases. The group talked about the code as an educational tool which surfaces important summary data elements when patients are making decisions about their data.
- The group also emphasized the need to adopt the code as part of their existing application registration process to enable the entire industry to use the same set of baseline principles.
- The group talked about a palatable and effective way to share the results of the application questionnaire with consumers so they are well informed but not fatigued by decision making.
- The group discussed a ‘nutrition label’ concept that involved displaying a higher-level, graphical version of the application’s answers to the questionnaire but also includes the ability for the consumer to dig into the details regarding how each application uses their data. Easy to understand + full transparency.
- The Code of Conduct group continues to build out the Code of Conduct questionnaire. The questionnaire advances the Trust Framework and provides more information about how applications comply with the Code of Conduct. We invite CARIN Alliance members to provide comments on the questionnaire: (<http://bit.ly/CARIN-Trust-Framework>). The CARIN Alliance has drafted an initial set of questions. We invite CARIN Alliance members and others to provide comments on the questionnaire: (<https://bit.ly/2kv6FXp>).

Public Policy Update on Consumer Privacy Initiatives

- Members discussed consumer privacy issues and public policy developments.
 - The Office of Civil Rights issued its first fine for a violation of the right of access provision of the Health Insurance Portability and Accountability Act (HIPAA). This shows OCR is committed to individual right of access.
 - Congressional staff in both the Senate and House are interested in privacy issues. Staff continue to develop their thinking on privacy and security in relation to health applications and consumer data.
 - Recently, agencies are considering proposed revisions to 42 CFR Part 2 to increase data sharing about patients with substance abuse disorders.
 - The CMS final rule, “Patient Access and Interoperability,” and the ONC final rule, “21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program,” are not until late Q4.

Next Steps

- Please review the CARIN Code of Conduct Questionnaire and provide any feedback.
- CARIN Alliance Members interested in participating in any of the existing workgroups are invited to reach out.
- The Q4 Community meeting will take place in December 10th. Additional details will follow.