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

CARIN Community Meeting
May 28, 2020 **|** Virtual

Objectives

The CARIN community, made up of the CARIN Board, Affiliate Members, and Special Guests, met virtually to discuss the CMS Patient Access and Interoperability rule, the ONC Information Blocking Rule, progress on the Common Payer Consumer Data Set (CPCDS) and the CARIN Blue Button Implementation Guide (IG), and ongoing efforts to aid the national response to COVID-19 through consumer engagement with public health agencies. We closed out the day discussing progress on CARIN Alliance Workgroup progress.

Key Discussion

General Announcement – Ryan Howells, Leavitt Partners
- Ryan Howells announced the launch of the My Health Application website (myhealthapplication.com), which catalogues applications that have self-attested to the CARIN Code of Conduct.
- My Health Application is intended to provide consumers and caregivers a resource to learn about apps that self-attest the CARIN Code of Conduct.
- If you represent an application that attests to the CARIN Code of Conduct and wishes to be listed on My Health Application, please enter your info on the website form: https://myhealthapplication.com/list-your-app. If you would like to update your listing, please email Leavitt Partners staff. There is no fee to be included on the website.
- Ryan thanked the 1upHealth team who helped develop My Health Application, and applications which have self-attested and listed themselves on My Health Application. The CARIN Alliance will have maintenance responsibility going forward.
- The CARIN Alliance and Leavitt Partners are not endorsing applications by listing them, our focus is providing consumers with transparent information about applications terms and conditions and privacy policies so they can make informed decisions which align with their preferences.

Leadership Perspectives – Aneesh Chopra, Care Journey
- Aneesh welcomed the CARIN Community to the meeting and congratulated them on the progress made to develop the CARIN Blue Button IG. He discussed shifting our path from defining the standards and policies to govern consumer directed exchange, to implementation.
  - He urged application developers and data holders to work together and lead implementation. In 2021, health plans will be responsible for implementing R4 version of FHIR and adhering to the new CMS Patient Access and Interoperability and ONC Information blocking rules. CARIN Community is an opportunity to focus on the practical aspects of implementation ad adherence including discussing challenges and drive adoption.
- Aneesh also encouraged the CARIN Community to consider how they can support the domestic COVID-19 emergency response. Applications may have a role in addressing data gaps amidst the public health emergency, and support public health authorities so they have data tools and resources to effectively respond to COVID-19.

Consumer Advocate Story – Liz Salmi
- Liz spoke about the importance of empowering regular people through access to their own personal health information, and the opportunities and challenges associated with new CMS and ONC interoperability rules.
  - Liz described her experience living with cancer and the value of having her personal health data made available to her.
  - She reminded the group that consumer preferences about accessing and using their own health data is evolving in the age of connectivity. For this reason, the CMS and ONC Interoperability rules are exciting; they will enable regular people to steward and use their own data in line with their individual preferences.

- o Liz congratulated the CARIN Alliance for the work to advance consumer directed exchange and to develop the CARIN Trust Framework and Code of Conduct. However, she called on the group to be mindful of accountability. Liz reminded the group that consumers' digital literacy and their preferences are evolving as they are exposed to more and more of their own data. Self-attestation is an important step, but there should be mechanisms to ensure that applications which claim to attest to the code are adhering to that agreement.
- The CARIN Alliance members applauded Liz for sharing her story and thanked her for speaking. The group discussed the importance of balancing innovation and the cost of complying with certification or validation. The group also asked Liz about her experience with the Open Notes movement and how providers are responding to making their clinical notes available to consumers. Anyone interested in learning more about Open Notes and associated research are encouraged to reach out to Liz directly: lsalmi@bidmc.harvard.edu.

Topic #1: CMS Patient Access API
- The CMS Patient access rule is final; the group discussed the requirements of the final rule and clarifications on several common questions.
  - o Health plans are not required to use the CARIN Blue Button IG to be compliant the claims and encounter requirements. But if they don't use the CARIN Blue Button IG, health plans need to publish all of their technical API documentation and find applications who are willing to customize their interfaces to connect to a health plan who doesn't use the CARIN Blue Button IG.
  - o Under the Patient Access API, upon the member's request and where available, the member's current health plan must provide the claims / encounter information from the member's current health plan and the clinical USCDI information that the current health plan maintains with a date of service on or after January 1, 2016 in a FHIR R4 API format. The plan must also make available current formulary or preferred drug list information, as applicable. MA organizations with MA-PD plans must also make available the current member's pharmacy claims with a date of service on or after January 1, 2016. Payers are only required to send clinical USCDI information they have in their systems for payer-to-payer data exchange.
- Members noted that one of the key values of the CARIN Alliance is that consumers should be empowered with more data with less friction. While some data holders may be concerned that consumers are sharing their data with others, this is irrelevant; patients should receive their data. Please let CARIN/LP staff know how the CARIN Alliance can support members implementing the requirements in the CMS Patient Access rule.

TOPIC #2: COVID-19: Consumer Engagement with Public Health Emergencies
- Representatives from Apple and Google discussed their work to develop an exposure notification API, which alerts people when they have been exposed to someone diagnosed with COVID-19. This product is to complement traditional public health contact tracing efforts, not replace them.
  - o Apple and Google clarified that public health authorities requested help to scale contact tracing using mobile devices.
  - o The benefits of the solution proposed is that it can reduce the number of resources needed to control the pandemic, decrease the time between an exposure and notification of the exposure, and account for the completeness of contact tracing data.
  - o Google and Apple reviewed the technical specifications of the exposure notification API and clarified how state public health authorities maintain oversite over the use of the technology. The exposure notification system is built on non-identifiable Bluetooth signals; this approach is privacy preserving. Further, the technology is configurable; the API facilitates the sharing of anonymous Bluetooth beacons and notifications and the rest is determined by the Public Health authority. Public health authorities select the application which will facilitate exposure notification in their state, and can

control the factors and criteria which lead to an exposure notification, what information is provided and outlines the next steps users in their states should take.

- It was clarified that applications that use the exposure notification API cannot request access to location data.
- Additional information about this presentation is available in the meeting slides.
- Applications which can support the exposure notification API are encouraged to contact their state public health authorities. CARIN staff will help facilitate as possible

- Mike Wilkening, Special Advisor on Innovation and Digital Services, Office of Governor Gavin Newsom, State of California, and Nick Lucius, Chief Data Officer, Office of the Mayor, City of Chicago, discussed how their state and city, respectively, are responding to the pandemic and how the CARIN application community can help.
  - Mike and Nick shared that their state and city have focused on scaling contact tracing and testing capacity, which includes modernizing the public health infrastructure and deploying technology solutions to support these efforts.
  - They discussed the difficulty in managing the massive flow of data being collected through contact tracing and testing, but that this information is essential to inform targeted testing and interventions in communities where the pandemic is having the largest impact.
  - Both felt that there is a role for consumer facing applications in these efforts. If individuals are engaging with applications and platforms and are voluntarily sharing their information, it can be useful to public health agencies. While traditional contact tracing will continue, they believe applications can help facilitate connections to hard to reach populations.

CARIN Alliance Workgroup Progress Updates – Ryan Howells, Leavitt Partners
- A status update was provided on CARIN Alliance activities including updates to the CARIN Trust Framework and Code of Conduct, CARIN Digital identity Federation Trust Agreement Framework, and plans for a 2020 state Medicaid Roadshow.
  - Ryan reviewed the 3 phases of the CARIN Voluntary Code of Conduct, and provided updates from the Workgroup:
    - The first phase is foundational and calls on application developers to self-attest to the principles in the CARIN Code of Conduct. To support self-attestation to the code, the workgroup has developed a draft process for updating the CARIN Code of Conduct on an annual basis. This includes gathering and incorporating input from the broader community.
    - The second phase is a questionnaire, which calls on application developers to complete a questionnaire and attest to how they use, manage and secure consumers' health information. The workgroup has developed a draft detailed 'nutrition label,' which presents questionnaire responses in a consumer-friendly way. The nutrition label is intended to help consumers compare and identify applications which adhere to practices in line with their preferences. Next, CARIN/ LP staff will be engaging with patient groups and consumer advocates to seek their input on the usability of the nutrition label.
    - The third phase is a validation phase in which multiple, independent certifiers validate application's adherence to the CARIN Code of Conduct. CARIN/ LP staff have engaged in initial conversations with 2 independent validation organizations to develop an application verification and validation program based on the CARIN code of conduct.
    - CARIN Alliance members asked about enforceability for violating self-attestation; any app attesting to the Code of Conduct can be held to those commitments by the FTC. Further, state consumer protection authorities may be able to act, depending on the scope of their authorities. This is intended to be the initial mechanism of enforcement.

- o The Real-time Pharmacy Benefit Check (RTPBC) API was balloted early this year and the group is working on reconciling comments from the HL7 balloting process. For those interested, the CARIN RTPBC IG is available here: http://hl7.org/fhir/us/carin-rtpbc/2020Feb/
  - The target date for testing the API among CARIN members, which include 5 large PBMs, is Fall 2020.
  - Finally, the group is considering how to make the information more user-friendly.
  - Ryan reminded the group that CMS' recent proposed rule related to technical changes for PY 2021/2022 would require plans to have a RTPBC tool to facilitate business to consumer data sharing, which the CARIN RTPBC API is intended to do.
  - o The Digital Identity and Authentication workgroup is working on development of an industry-level framework for digital identity federation, which will advance the ability to exchange personal health information across systems electronically.
    - A CARIN digital identity tiger team, which consists of a smaller group of CARIN ID & Authentication workgroup members, is collaborating on a draft set of open contractual terms and conditions which establish trusted policies to support federated digital identity.
    - Ultimately, the principles CARIN will develop would point to third party organizations to certify identity providers.
    - Related, the CARIN Alliance has announced a relationship with Carequality to work closely to integrate this work into their agreement and hopefully, include in the TEFCA.
- Ryan also shared several updates:
  - o The CARIN Alliance is supporting the release and roll out of mobile driver's license (mDL) across several states. The mobile driver's license is a true credential.
  - o CARIN has also been invited to participate in the World Economic Forum's Digital ID Coalitions Network. The networks purpose is to advance global activities toward digital identities that put the user interest at the center: e.g. they are fit for purpose, inclusive, useful, secure, and offers choice to individuals. Other representatives involved include: Smart Africa, multiple global financial services firms, Canada, European Commission, Open ID Exchange, U.K., Singapore, Mastercard, Finland, Germany, Ireland, Norway, and others.
  - o Finally, this summer and vall, CARIN/ LP staff will host state Medicaid listening sessions with CMS and HL7 to support state Medicaid agencies' technology infrastructure modernization and FHIR adoption. Currently, state Medicaid agencies lag behind the commercial sectors adoption of FHIR. The purpose of this listening session is to understand the challenges state Medicaid agencies face and help develop consensus-based solutions to support states' implementations.

Next Steps

- CARIN Alliance Members interested in participating in any of the existing workgroups are invited to reach out.
- The Q3 Community meeting will likely be virtual. Dates will be communicated shortly.