

### CARIN Community Meeting

December 13, 2018 | Los Angeles, CA

#### Objectives

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The CARIN community made up of the CARIN Board, General Members, and Special Guests met to discuss Workgroup progress, receive an update regarding the CARIN Code of Conduct, discussed the need for additional group engagement and broadening alliance and community membership, and heard patient stories. Attendees also received an update on end of year progress and 2019 priorities.

#### Special Guests

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##### *Patient / Caregiver Story – Stacey Tinianov, Patient Advocate*

- Stacey Tinianov shared her story about the challenges that her mother and she faced when trying to share their health care records.
- She expressed her support for the work that CARIN is undertaking to help future patients encounter fewer barriers when accessing their health records.

##### *Patient / Caregiver Story – Lonnie Rae, Medal*

- Lonnie Rae shared her story about a health care condition she recently recovered from that showed how harmful the current lack of interoperability can be for patients.
- Lonnie explained how critical interoperability is for improving patient outcomes and how the work that CARIN does will help move the health care industry towards solving the interoperability problem.

##### *GetMyHealthData – Katie Martin and Erin Mackay, National Partnership for Women & Families*

- Erin Mackay discussed the GetMyHealthData program, which is designed to help patients and families access and use their health information and make the most out of online access by making clinical notes easier to access.
- They believe that clinical notes are important data that can really help a understand their conditions and what care they might need.
- They also created a patient portal help desk designated to answer patient questions. The patient help desk consists of four full time employees who work to answer help tickets that are submitted by patients. These questions often involve: technical, administrative, billing, upcoming appointments, clinical questions related to what the results mean, and corrections/updates to their records.
- They are looking ahead to consumer directed exchange by engaging consumers online and approaching information as a way to enhance patient engagement while setting appropriate expectations.
- They also believe that you must meet people where they are as not everyone may want to engage with the data in the same way.

### Key Discussion

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#### New Members

- Blue Cross Blue Shield Association is new members of the CARIN Alliance.

#### 2018 Year in Review & 2019 Draft Strategic Initiatives

LP discussed 2018 achievements and upcoming 2019 priorities and publications for the overall Alliance and the individual Workgroups.

- Trust Framework Workgroup
  - The Code of Conduct was recently released to the public and was picked on social media by 198 organizations with a potential audience of 8.4 million people.
  - The Trust Framework Workgroup will release the framework draft/Code of Conduct in three phases:
    - Phase I (Foundational, CARIN Code of Conduct; COMPLETE): The Workgroup released the Code of Conduct to the industry for review and comment
    - Phase II (Questionnaire, Q1; In Process): The trust framework workgroup will develop a set of questions regarding how the apps will use the health data); and
    - Phase III (Validation, Ongoing): The CARIN Alliance will work with third party certifiers to validate the application vendor's self-attestations).
  - CARIN will look for opportunities to share the Code of Conduct with patients via webinar or presentation to help patients better understand what the Code of Conduct entails and to get patient feedback.
- Health Plan Workgroup
  - The Common Consumer Payer Data set will be finalized by the end of December. Once finalized, the Workgroup will work with the Da Vinci Project and Cambia to create an Implementation Guide. The goal is to complete this work in late Q1 2019.
- Real-Time Pharmacy Benefit Check
  - The Workgroup will finalize a work plan for 2019 and partner with a point of care partner (HL7/NCPDP) and respond to the Part D proposed rule, which included some real-time pharmacy benefit check requirements.
- Post-Acute Care
  - We continue to pursue additional opportunity to establish Post-Acute Care Workgroup. Specifically, we will be drafting a proposed work plan for collaboration with MITRE and CMS for activity in early Q1.
- Policy Workgroup
  - The Workgroup has developed a document on the benefits of APIs and is passing their recommended document up to the board. It will respond to a number of proposed rules in Q1, including: Part D, information blocking, patient access and interoperability, and the HIPAA RFI.
  - CARIN will continue to engage with and keep Congressional staff updated on CARIN work.
- ID Proofing & Authentication Workgroup
  - The Workgroup will draft an implementable framework for specific identification challenges, which will be presented to ONC and Pew in Q1 at a summit convened by ONC. The Workgroup will also discuss opportunities to engage with LogIn.gov on authentication possibilities for Blue Button 2.0, Healthcare.gov, health plans, and EHRs.

- Technology Workgroup
  - The Workgroup is creating a document on security of APIs and best practices for enabling API access for covered entities.
- CARIN Health Care Conferences and Events
  - CARIN will be present at a number of health care conferences and events in 2019 including the HL7 Workgroup meeting in January in San Antonio, TX, the CMS Interoperability Summit, and HIMSS.

### Opportunities to Collaborate

- *Meg Doerr, Sage Bionetworks*
  - Meg Doerr explained how Sage Bionetworks has developed an informed consent processes to help patients easily understand their health record information and have released a document called the [Elements of Informed Consent](#) which lays out the principles
  - Using the Elements of Informed Consent, they write all their information so that it can be broadly understood by all levels of literacy and education. They also translate the information into foreign languages using the same approach. They have found that patients have 90% comprehension rate when reading the information using this approach.
  - Sage believes that compliance and terms of service is something that should be created from a consumer lens so that the patient truly understands what they are agreeing to.
  - Sage believes that CARIN should include principles from the Elements of Informed Consent document in the CARIN Code of Conduct so that patients fully understand what is covered by the framework.
  - CARIN Members were supportive of including the best practices of informed consent into the Code of Conduct.
- *Cynthia Grossman, Faster Cures – Milken Institute*
  - The mission of Faster Cures is to accelerate faster cures for patients through increased data sharing and they created Healthdatabasics.org to make it easier to access data.
  - They believe that patient trust erodes the further away from the physician you go, so there is a need to work to improve trust. They see 5 areas that need to be improved:
    - Transparency
    - Control
    - Agency (self-efficacy)
    - Privacy
    - Ethics
  - Faster Cures feels that informing patients can be hard to implement at an organization level, which is why they want to look at how to improve this process.

### Next Steps

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- Finalize and release the CARIN Code of Conduct in Q1 2019 and begin working on the set or reportable questions for how apps use the data.
- CARIN members will review and provide feedback on the API standards policy and will look to finalize it prior to HIMSS.
- Invite Sage BioNetworks to discuss more about their successes around consumer-readable consent frameworks in an upcoming Trust Framework meeting
- The Q1 2019 Community Meeting will take place in Washington, DC on March 13