

### CARIN Community Meeting

September 26, 2018 | Salt Lake City, Utah

#### Objectives

---

The CARIN community, made up of the CARIN Board, General Members, and Special Guests, met to discuss workgroup progress, the challenges currently faced from leading application developers to accessing consumer health records, learn more about consumer attitudes from the recently published HINTS survey, and discuss the launch of the CARIN Code of Conduct. Attendees also discussed the need for additional group engagement and broadening alliance and community membership.

#### Special Guests

---

##### *Leadership Perspectives – Governor Michael O. Leavitt, Leavitt Partners*

- Governor Leavitt expressed his sincere gratitude to the entire Community for what they are doing to advance a consumer's ability to access their electronic health information.
- He discussed the need for active outreach by CARIN to share our story more broadly.
- He also suggested CARIN find opportunities to convene C-suite representatives to discuss the strategic business opportunities that exist by engaging consumers more directly with copies of the health information
- He also noted that the CARIN community should "evangelize the effort" by explaining why we need more organizations to participate.
- He encouraged CARIN to continue to advertise our progress through press releases and conferences especially after the completion of major deliverables and accomplishments

##### *Patient / Caregiver Story – Bruce Fryer, Management & Product Consultant, Fryergroup LLC*

- Bruce Fryer shared his story about the challenges he faced when trying to with access his brother's health care records
- He noted that the work CARIN is doing will address many of the issues that he faced so that future patients will encounter fewer problems when attempting to access their medical records

##### *HINTS Annual Survey – Vaishali Patel, Office of the National Coordinator for Health Information Technology*

##### *Erin Mackay, National Partnership for Women and Families*

- Vaishali Patel and Eric Mackay shared some of the findings from the HINTS survey.
- Some of the key findings were:
  - 3 in 10 individuals offered access to their medical records and viewed them at least once in the past year
  - Nearly ¼ of caregivers accessed their care recipient's online medical record at least once within the last 12 months
  - 4 in 10 smartphone/tablet owners have a health or wellness app

##### *Online Records Request Demo – X4 Health*

- Christine Bechtel demoed an online "request for records" portal using a consumer's individual right of access which included the ability to have information sent to the patient or caregiver, ability to select the types of records, deadlines to receive them, whether to link to an app or enter your app via email, and upload a supporting document like a power of attorney
- The portal is secured by a cell phone authentication code, visual validation of a driver's license or gov't ID via taking a picture and including it in the request, and a docusign signature
- Some providers are accepting driver's license and photo copies of birth certificate as a form of authentication; None of their beta users (consumers) have balked at sending their driver's license to them
- An electronic signature is often accepted but some providers are still requesting hard-copy signatures

- X4 started by using DocuSign, but found that many providers won't take it
- Many consumers had to sign, scan, and send a hard copy back to the provider
- X4 Health currently has 20 organizations that are participating, with plans to increase the number soon. The full website is available here: [www.healthrecordwizard.com](http://www.healthrecordwizard.com)

### Key Discussion

---

#### New Members

- Facebook, GoodRx, and Blue Cross Blue Shield of NC are new members of the CARIN Alliance

#### CARIN Business and Policy Trust Framework

- LP walked through the three stages of the business and policy trust framework that includes the CARIN Code of Conduct. The phases of the Trust Framework include:
  - **Phase I** – CARIN Code of Conduct which outlines a set of consensus-based, voluntarily adopted set of principles for how health care data should be handled by third-party applications outside of HIPAA
  - **Phase II** – A set of self-attested questions third-party application developers answer which relate to the CARIN Code of Conduct and includes questions from the ONC Model Privacy Notice
  - **Phase III (future)** – Independent certification of third-party applications to verify the application vendor's responses to the self-attested questions along with other functionality important to the consumer
- The CARIN Code of Conduct is built on three key principles:
  - Informed, Proactive Choice: Well informed consumers who make an intentional decision is the best way for consumers to direct their health information
  - Application Attestation: Applications should attest to and be held accountable for a set of structured, consistent, and reportable responses regarding how they plan on using consumer's data
  - Purpose Specification: Consumers should have the ability to specify the purposes in which their data can be used by an application
- The Code of Conduct will include three-pronged implementation approach over the next few months as follows:
  - **Phase 1** – The foundation phase, where app developers and other members of the health care ecosystem provide feedback and agree to the principles of the CARIN Code of Conduct began at the September Q3 Community meeting and will conclude in the October/November timeframe
    - During this phase, the CARIN Community and health care ecosystem will be able to provide comments to the CARIN Code of Conduct
    - Following a public comment period, the Code of Conduct will be finalized and will be launched with a joint press release by multiple organizations who agree to the principles
  - **Phase 2** – The CARIN Trust Framework workgroup will develop in parallel a set of self-attested questions for application vendors to explain how they are using the consumer's health data. This will also take in place in Q4 2018.
  - **Phase 3** – The final phase involves reaching out to multiple application aggregators (e.g., iOS, CMS, Android, SMART, EHR vendors, etc.) and request their help to implement the Code of Conduct

#### Consumer-Facing Application Perspectives

- Three themes emerged from the consumer-facing application vendors who are requesting health care data on behalf of an individual:

- Wrong Implementation – The policy is right and the technology works but there is a misunderstanding or misalignment between the EHR manufacturers and the app developers on what is needed
  - Policy doesn't exist – What the consumer is requesting through the application doesn't exist in electronic form and the policy doesn't yet exist to release the data
  - Grey Areas – There is a grey area in how providers or others are interpreting the regulation or policy that is inhibiting the application vendors from accessing the data
- EHR Perspective
    - EHR vendors are distinguishing between organizations building workflow improvement apps (provider-facing and fee-based) and those who are building applications to allow consumers to access their health information (consumer-facing and non-fee based)
    - Most EHR organizations can and/or will provide reusable tokens for their app vendor partners
    - Dynamic Client App registration is going to become the norm for consumer-facing applications
    - EHRs have and will continue to publish their FHIR end points to ensure they are discoverable

### Next Steps

---

- Review the CARIN Code of Conduct and provide feedback to the CARIN LP team in October
- Discuss whether CARIN should create a guidance memo where CARIN members could define API best practices which would help providers and their general counsel operationalize the APIs
- Work with innovative HIEs like UHIN and IHIE to discuss how patient data could be made available regionally
- Schedule a C-suite event to discuss strategic opportunities related to consumer-directed exchange
- Develop a press release promoting the CARIN Code of Conduct and let the CARIN LP team know if your organization would like to be included
- **The Q4 Community Meeting will take place in Los Angeles on December 13**