

The CARIN Alliance

[Creating Access to Real-time Information Now through Consumer-Mediated Exchange]

Meeting Summary | 26 May 2016 | Washington, D.C.

Purpose: On May 26, 2016, David Blumenthal, David Brailer, Aneesh Chopra, & Leavitt Partners co-convened a multi-sector group of industry leaders – including consumer/patient advocates, providers, purchasers, payers and regulators from across the health care ecosystem – to discuss the opportunity to collaborate on ways to move forward on a national strategy to implement consumer-mediated health information management and exchange.

Attendees: Over 45 participants representing the following sectors attended the meeting:

- Administration officials (ONC, OCR, and the White House)
- C-level executives from large hospital and integrated delivery systems
- Health care professional organizations
- Major consumer and family care giver advocacy groups
- Payer organizations
- Physician groups
- Purchasers
- Other industry and technology leaders

Outcome. After a robust discussion, the group reached a consensus to convene an alliance to incorporate input into meaningful action items and specific deliverables to advance consumer-mediated exchange in order to improve access to complete, accurate, and timely health information when, where, and how it is needed by all parties.

Major Discussion Themes.

- **Reasons for Gathering.** Participants came together with a shared sense of the importance of developing and deploying a consumer-mediated approach to health information management and exchange in the U.S. The movement to value-based care is acting as a key enabler in moving consumer-mediated information exchange into becoming more of a priority for providers, institutions, and other entities.
- **Importance to consumers/patients.** Several participants told stories about how they and their loved ones have suffered because of a lack of timely access to health records. Such accounts resonated widely with attendees and the group shared a sense of obligation to do better by the consumers/patients we all serve.
- **Urgency.** The group agreed the time to drive advances in this area is now. The spread of APIs, emergence of FHIR and other standards, strong support from the current administration, bi-partisan nature of the topic, and in-flight legislation on the Hill all point to the need to act.
- **Opportunities.** The group discussed opportunities to drive change by: leveraging value created by the ACA and value-based care contracts, focusing on ways to change cultural norms preventing the free-flowing access to patient data, leveraging consumer rights to data enabled by the OCR, leveraging emerging technologies, and “learning by doing” – acting to move data using consumer mediated exchange models & sharing best practices.
- **Barriers.** The group discussed various barriers including: culture (we lack a consumer-centric culture); consumer/patient preferences; competing provider priorities; concerns about privacy, cybersecurity, and HIPAA violation risks; widespread misunderstanding of patient access rights and provider

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obligations to provide data upon request; EHR implementation “exhaustion”; risks that vendors are creating proprietary software/API barriers which could limit free flow of information; lack of clear guidelines for what constitutes an “allowable” app to access an EHR or API on behalf of a consumer; physician concerns including data-overload, workflow issues, concerns about accuracy and reliability of data, and lack of resources; lack of clarity regarding standards; lack of standardization of EHR Continuity of Care Documents (CCDs) and formats; lack of business models and incentives needed to drive investment; difficulty getting Congress to act; challenges of any small group to move the needle in Congress; lack of private-sector leadership.

- **Strategies.** The group discussed various strategies for advancing consumer-mediated exchange and expressed a strong bias for action. Some major themes that were discussed include:
 - *Action-oriented strategies*
 - **Platform for Action.** Could CARIN provide a platform for “learning by doing” by the members?
 - **Culture-Change.** What actions could be taken to drive consumer-centric culture change?
 - **Consumer Access Tests.** What real-world experiences could be facilitated to help the industry better understand what happens when consumers request their data? What are the consumer-focused use cases that could be performed to link EHR APIs?
 - **Benchmarking Surveys.** Could a national survey be done to benchmark provider use of consumer-mediated exchange?
 - *Policy-related strategies*
 - **Guidance.** What additional clarification or guidance needs to be provided to help the industry adopt consumer-mediated health information exchange? Could we work with HHS to clarify rules regarding data access by consumers and third parties and to disseminate information regarding provider obligations?
 - **Education.** What education needs to be done with the industry and on the Hill regarding this issue?
 - **Federal and state law.** How can we better standardize HIPAA waivers and educate legal counsel on the distribution of a patient’s medical information? How does current state law interact with federal law regarding this issue?
 - *Practice related strategies (development of best practice recommendations)*
 - **Cultural:** What incentives or other information needs to be provided to break through the barrier of cultural norms that prevent the flow of medical information between providers, patients, and care givers? Can providers begin to request patient-mediated longitudinal access to medical information?
 - **Technical:** How can this group help expedite open API standards in the industry? What additional data standards or contracting parameters need to exist to help make that happen? What is the role of patient-generated health data?
 - **Business:** What is the business model, economic framework, and financial model to help consumer-mediated health information exchange grow? What does the return on investment look like for organizations who are early adopters?

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Next Steps

The group is scheduled to meet again on July 7th, 2016 in Washington D.C. where we will develop a framework and strategy for moving forward.

In addition to moving forward to create an alliance, the group also supported notifying people in the administration, Congress and elsewhere that “a group of national leaders are organizing a new multi-sector alliance to lead in advancing consumer mediated exchange in the U.S.” With respect to adding other participants, there was openness to think about who else should be at the table.

Action Item	Responsible Party	Timeframe
Attend the ONC meeting May 31 – June 2 to socialize the group’s formation	Leavitt Partners CARIN participants	May 31 – June 2
Distribute meeting notes and action plan from the initial May 26 discussion	Leavitt Partners	Week of May 30 th
Begin reaching out to Hill staffers and announce the formation of the alliance	Leavitt Partners	June / July 2016
Receive feedback from CARIN participants on the meeting, notes, & next steps	Leavitt Partners CARIN participants	June 2016