

# The CARIN Alliance

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

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## Meeting Summary | July 7, 2016 | Washington, D.C.

**Purpose:** On July 7, 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 continue the conversation on an opportunity to collaborate on ways to move forward on a national strategy to implement consumer-mediated health information management and exchange. As a follow-up to the inaugural meeting on May 26, 2016, this meeting focused on what the alliance is trying to achieve, the barriers that exist in consumer-mediated health information exchange, and what the group can do to remove those barriers. The discussion focused on activities the group can start now to make progress and on the vision for the alliance going forward.

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

- Administration officials (ONC, OCR, CMS, 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 alliance reached consensus on key activities and strategies the group can focus on going forward. The group wants to be action oriented and find ways for consumers to get, share, and use, their data as they need it. While an official vision was not finalized, the group is moving forward to create that and finalize the structure of the alliance.

Additionally, the meeting participants identified 3 near term (30-60 day) activities as well as longer-term goals and workgroups that can be formed to achieve the alliance's mission.

### Major Discussion Themes

- **Understanding the Problem** – Across the group, there was clear consensus that consumers do not currently have ready access to useable information about their health or their full health records. Participants stressed that there is vehement agreement that consumers, and their caregivers, should have this information and be able to send it when and where they want. The group feels it is important to find common ways to share this data in ways that are useable for both providers and patients. The alliance will focus on finding ways to make this vision happen.
- **Urgency** – Participants in the group stressed the importance of acting quickly given the risks to patients and the system in not acting. Urgency has been escalated particularly with the upcoming lame duck Congress and change in administration. At the meeting, government representatives expressed support to remove as many barriers as they could to make good on a future vision where consumers are at the center of the data exchange process. The group believes the time is now to influence policy, regulations, and culture around exchange.

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- **Culture Change** - The group discussed the challenges of current organizational culture and patient-provider relationships as a reason consumer mediated exchange has not been taken up in larger numbers. In order to change this, providers and hospital systems need to deeply embrace the future where consumers drive access to their data. One suggestion to start this culture shift was for leaders within each hospital to attempt to access their records and figure out where bottlenecks are. The group was interested in furthering the National Partnership for Women and Families project around data exemplars to do this.
- **Technology** - In many cases, the group believes the necessary technology to change the way information is shared exists now, but there may be unclear standards to allow for the sharing of information. One of the ways the group would like to address this is to continue to push for the use of open APIs and fire APIs. This allows for greater access to the data through different platforms. The group also understands that it will be key to clarify privacy questions both to protect the consumer's information and the security of the systems this data is shared in. Representatives from the government expressed that there are not large-scale HIPAA concerns around this and that any that exist can be clarified.
- **Advocacy and Education** – The group felt that at present, there is a lack of understanding by many providers, patients, and lawmakers about the technology opportunities that exist to encourage consumer-mediated exchange. There was conversation around the importance for CARIN to advocate and educate these communities about what they can do to help support the CARIN mission. Similarly, education with patients and providers will be important to motivate people to use the new systems and technology CARIN will work to incentivize.
- **Business Cases** - Going forward, CARIN needs to work to develop businesses cases and examples to test out consumer-mediated exchange. The idea of working on this exchange for a sub-set of CCD, such a medication lists, is one proposal. Others were identified by the group and are outlined in the future opportunities.

### Vision and Goals

The group began to work through a vision for CARIN. The group wants to ensure the vision considers the following:

- Consumer-mediated exchange needs to be about more than access – information needs to be easily useable, moveable, and helpful
- Focus will be on the consumer/patient and not on provider to provider interoperability
  - Consumer's agents or caregivers also need to have access
- Vision and mission should drive the industry to innovate and create new technical solutions
- CARIN should utilize technology to strengthen the provider-patient relationship

Topics for further discussion:

- The group will reconsider the name for consumer-mediated exchange as CME is often thought of as continuing medical education
- There is an outstanding discussion on how to handle patient-generated data as part of the health data included in CARIN's mission

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- The alliance will consider how to address the two-way flow of information between patients and providers
- At future meetings, the alliance will look to lay out what success looks like for CARIN

### Near-Term Opportunities

Before the next meeting of the full alliance, the group will begin working on the following near-term opportunities:

#### 1) Data Exemplar Project with the National Partnership

*Opportunity:* Determine the experience of a patient in each organization's system when they access their own consumer health information and what could be done to improve the process. We will use this strategy to highlight the positive impact of sharing useful, actionable data with patients, including improvements in patient/family engagement, patient experience, clinician experience, other quality and financial metrics, and overall system culture. The focus will be to create positive examples that show how this can be manageable and adaptable to various settings. The process will involve organizational leadership, clinicians, patients and families.

A Data Exemplar is an organization that commits to a short term effort to make data access and use for patients easy, automated and routine. In addition:

- Exemplar partners would agree to assess their current processes and develop a first-hand understanding of their patients' experiences when requesting and compiling their health data.
- Exemplars would agree to involve patients and families in the process of identifying solutions and implementing change.
- Exemplars would agree to share insights and lessons learned, and inform our efforts to spread promising practices.

#### 2) Assessing the impact of CMS' APM regulations

*Opportunity:* As CMS continues to propose regulations related to MACRA, APMs, and MIPS, develop a strategy for responding to those regulations during the NPRM process to ensure the liberation of patient data will not be curbed.

#### 3) Hackensack technology partnership

*Opportunity:* Develop an ecosystem of providers in the tri-state area who will begin to share data across organizations. Develop a case study regarding how Hackensack implemented their solution. Work with other interested organizations on how Hackensack was able to build accessible consumer health information using the FHIR APIs.

### Next Steps

The group is energized around the idea of moving quickly to make progress on this important issue. Leavitt Partners will be following up with each participant to get feedback on the meeting, areas participants are interested in getting involved in, and will discuss the structure of the alliance going forward.

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In order to officially form the alliance, Leavitt Partners will be working to capture the vision, mission, governance structure, etc. for the group and will be discussing this with each participant as well. After these conversations, the group will reconvene. Concurrently, Leavitt Partners will be working to help structure workgroups around some of the key activities discussed at the meeting.

Action Item	Responsible Party	Timeframe
Distribute meeting notes and action plan from the July 7 discussion	Leavitt Partners	Week of July 11
Continue reaching out to Hill staffers and announce the formation of the alliance	Leavitt Partners	July / August 2016
Receive feedback from CARIN participants on the meeting, notes, & next steps	Leavitt Partners CARIN participants	August 2016
Begin to finalize charter and membership agreements for CARIN alliance participation	Leavitt Partners	August 2016
Set up workgroups around key activities	Leavitt Partners	August 2016