

About the CARIN Alliance

The [CARIN Alliance](#) is a non-partisan, multi-sector alliance convened by David Blumenthal, David Brailer, Aneesh Chopra, and former HHS Secretary Mike Leavitt. The Alliance is led by leading risk-bearing providers, payers, patients, health IT companies, and consumer-advocates who are working collaboratively with other stakeholders and leaders in government to overcome barriers in advancing consumer-directed exchange across the U.S.

Vision

Our vision is to rapidly advance the ability for consumers and their authorized caregivers to easily get, use, and share their digital health information when, where, and how they want to achieve their goals. Specifically, we are promoting the ability for consumers and their authorized caregivers to gain digital access to their health information via open APIs. This requires providers to share electronic health information with any application the patient chooses in a secure and trusted environment outside of HIPAA. To effectively exchange data outside of HIPAA, it requires the private sector to agree on specific principles for how data should be exchanged which is one of the priorities of the CARIN Alliance. ***In summary, we envision a future where any patient can choose any application to retrieve their health information from any provider, any time they want.***

Main Points

1. We are poised for a breakthrough in making information available to consumers.
2. All of the legal requirements are there.
3. What is needed is the regulations to make those requirements real and the resources (human and financial) to make those regulations effective.
4. The key agencies for making this happen are OCR – which needs to make enforcing HIPAA and 21st Century Cures a priority -- and ONC although there are things other agencies could do.
5. CMMI could provide valuable support by redirecting innovation resources to support this work on an expanded pilot basis.
6. We would encourage setting up goals and a timetable to have these agencies report back to the WH and the Secretary (once confirmed) on their progress.
7. Working with the CARIN Alliance will help assure this is an initiative that incorporates private sector views and needs.

6 Key Questions

We are trying to solve 6 key questions to reduce the friction experienced by providers and consumers when a consumer requests access to their health information.

1. How do we **user proof** individuals outside of the provider portal using a federated identity structure and existing or evolving open standards?
2. How do we securely **authenticate** individuals using advanced, multi-factor authentication (MFA) without the need for a UN/PW?
3. How do we record an **electronic patient request** to facilitate the delivery of health information to a third-party application?
4. How do we **record match** a patient's existing health information with identifying questions from the EHR that leverages data from installed FHIR resources?
5. How do we create a set of **trust framework** principles and open standards that allow for a robust marketplace of application endorsements and application endorsing organizations?
6. How do we rapidly develop more **open standards** to release more data to the consumer and their authorized caregiver?

Opportunities for Improvement

Attached are some ideas for how to improve interoperability in the US and provide health information to the consumer upon their request. These ideas also attempt to lower the administrative burden on providers.

Government's Role: What actions can CMS/ONC/HHS take to encourage interoperability (e.g., definition of meaningful use, information blocking, etc.)? What timeframe is realistic based on these actions and how can we accelerate that timeframe?

- Develop a consistent regulatory approach across agencies (FTC, FDA, HHS, ONC, OCR) that promote the ability for a consumer to access their health information

- Enforcement of the HIPAA right of individual access
- Implementation and guidance around the 2015 Edition Certified Health IT, especially the API module (ONC)
- Develop a regulation that creates a “safe harbor” for covered entities who want to share data with consumers
- Identify regulatory incentives to ensure the usability and interoperability of health IT APIs, i.e. encouraging, to the greatest extent possible, broad API conformity to technical specification such that third-party apps can be substituted and reused across and between health IT developer products without special effort
- Work with the Social Security Administration (SSA) to modify their SSA Privacy and Disclosure policy associated with the Federal Data Services Hub to allow third party commercial entities to access the API state exchanges use to identify that person exists; CMS should manage the data use agreement (DUA) (i.e., a digital version of the Consent Based Social Security Number Verification Service (CBSV) to identify (not authenticate) that a person with a given name exists)
- Help convene a public/private collaborative to co-create an open standard with the DMV for how they can, with your permission, digitally and remotely share your information with third parties (Real ID Act of 2005) (American Association of Motor Vehicle Administrators or AAMVA has a Driver’s License Data Verification Service (DLDV)
- Ensure HIEs are subject to the same requirements as other covered entities and allow data sharing directly with consumers

Technical standards and authentication: What is needed for full industry support, alignment, and adoption? What approaches/technologies can we use to verify identities (e.g., fingerprint scanning)? Will this vary by vendor or provider?

- Promote and help fund additional efforts like HL7, the Argonaut Project, and the HL7 FHIR Foundation who are focused on developing industry standards for exchanging health information
- Technical standards and interoperability needs to be defined in terms of a patient centric digital health information system connecting all the moving parts, not just EHRs.
- Promote and incentivize the use of the FIDO Alliance open authentication standard with EHR vendors and third-party applications
- Request or incentivize EHRs, providers, and other health care organizations to publish their FHIR end points publicly in a centralized location
- When patients request their health information, the user should be allowed to adjust the frequency which they receive their data
- Encourage health IT vendors to securely expose more granular data via APIs---improving the usability and interoperability of EHR data for both patients and providers
- When customers are requesting access to their electronic health information via the APIs, there should never be a charge to the application or the consumer
- Help convene or fund a multi-sector, public/private collaborative to develop an open standard utility for record matching a patient’s existing health information outside the patient portal using data from installed FHIR resources

Patient and physician engagement: How do we focus the solution to encourage participation (e.g., campaign around demand) and overcome obstacles, and address any issues such as HIPAA compliance?

- Promote current understanding among provider and patient/consumer communities of what information sharing is allowed under HIPAA; reinforce what is possible under current law
- Measuring a patient’s experience regarding access and use of the patient’s digital health information to promote patient engagement
- Increase demand from providers by supporting advance payment and delivery system models that excel with support of interoperable health information.
- Direct the Office of Civil Rights to develop additional educational campaigns that explain HIPAA privacy regulations using stories, vignettes, and other scenario-based examples.
- Encourage health IT vendors to proactively engage with their provider customers about the opportunities, considerations, and best practices when using new EHR functionality, i.e. APIs and Patient Generated Health Data (PGHD).
- Direct CMS to adjust MIPS program components and scoring, e.g. Improvement Activities and Advancing Care Information measures, such that providers are rewarded for utilizing a wider range of health IT not specifically tied to certified EHRs, i.e. telemedicine, remote patient monitoring, and provider/consumer facing apps.

Public/private partnership: How do we encourage private sector innovation? Can the government help to jump start with claims or other data? Who do we need to have on board; how do we best engage with the broadest possible group?

- Use the ONC's roadmap that will be released later this year as a starting point to work collaboratively with industry regarding the development of open industry standards to create a 'single, longitudinal record' as required in 21st Century Cures that will include at a minimum: clinical physician notes (unstructured or semi-structured), claims (Blue Button API for Parts A, B, and D), radiology reports, diagnostic data, and more.
 - All of the data that is currently being provided in the patient portal should be provided to the consumer via an API
 - All of the reporting data required by federal law should be required to be provided by APIs to the consumer
- Use the savings from disbanding the mandatory bundled payment programs within CMMI to fund a health IT innovation fund to help solve interoperability and patient-centric, digital health models that promote the learning health care system

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