

About the CARIN Alliance

The CARIN Alliance is a multi-sector collaborative convened by [Leavitt Partners](#) and more than 80 stakeholders, to advance the adoption of consumer-directed exchange across the U.S. Working with both the public and private sector, the group seeks 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. We envision a future where any consumer can choose any application to retrieve both their complete health record and their complete coverage information from any provider or plan in the country. For more information, please contact the alliance via the CARIN Alliance [website](#) or [Twitter](#), [YouTube](#), or [LinkedIn](#).

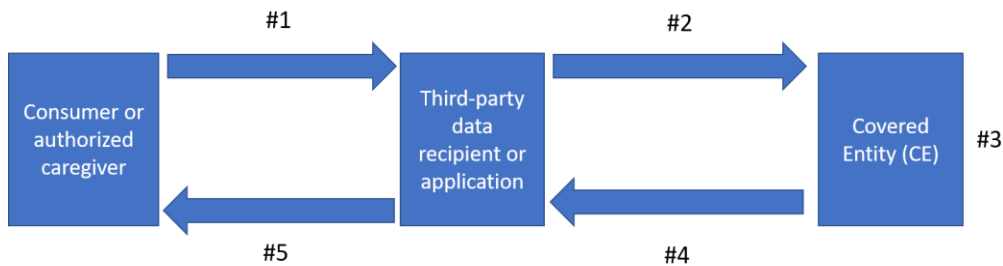
Vision

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 HL7[®] FHIR[®] APIs, OpenID Connect, and OAuth 2.0. ***In summary, we envision a future where any consumer can choose any application to retrieve both their complete health record and their complete coverage information from any provider or plan in the country.***

What is consumer-directed exchange?

Consumer-directed exchange occurs when a consumer or an authorized caregiver invokes their HIPAA Individual Right of Access (45 CFR § 164.524) and requests their digital health information from a HIPAA covered entity (CE) via an application or other third-party data steward.

The principles and best practices are primarily focused on the following process:



Step #1: Consumer makes a request under their individual right of access (implied or explicit)

Step #2: Consumer names an application to be their data steward

Step #3: Covered entity adds requested data to API server

Step #4: Covered entity authorizes application with token that is associated with the consumer

Step #5: Application queries covered entity API server for data

The Alliance believes and understands the following:

- Current law requires that electronic provider-to-consumer health information exchange is provided when requested by the consumer.
- Consumer-directed exchange supports sharing of personal health information with non-covered entities which are not regulated by HIPAA and thus not subject to the same privacy and security rules as providers, plans, and clearinghouses. Therefore, no covered entity should require third-party apps acting on behalf of

the individual to sign a business associate agreement. Consumer data protection guidelines fall under the jurisdiction of the Federal Trade Commission (FTC).

- Consumers and their authorized caregivers should easily be able to receive their API-accessible electronic health information from any provider at no charge. The remaining health information should be provided in a format that is readily producible by the covered entity and easily accessible by the consumer.
- One of the most important issues to solve is the ability to identity-proof and authenticate individuals securely, consistently, and in a trusted way across systems and to map them to their existing identifiers.

To achieve our goals, the Alliance meets regularly and performs its work via regular teleconference calls and in person meetings through a set of workgroups which are organized as follows:

- **CARIN Community meetings**
 - Purpose: Regular meetings with the [CARIN Community](#) (which includes everyone in CARIN) to collaborate and inform
- **CARIN HL7® FHIR® IG for Blue Button® IG (<https://build.fhir.org/ig/HL7/carin-bb/>)**
 - Purpose: Development, balloting, publishing, and maturing the CARIN FHIR IG for Blue Button within HL7 which includes payer claims data
- **CARIN HL7® FHIR® IG for Digital Insurance Card (<https://build.fhir.org/ig/HL7/carin-digital-insurance-card/>)**
 - Purpose: Development, balloting, publishing, and maturing the CARIN FHIR IG for Digital Insurance Card within HL7 which includes membership ID card information
- **CARIN HL7® FHIR® IG for Consumer-facing Real-time Pharmacy Benefit Check (<https://hl7.org/fhir/us/carin-rtpbc/2020Feb/index.html>)**
 - Purpose: Published the CARIN FHIR IG for Consumer-facing Real-time Pharmacy Benefit Check within HL7 which includes membership ID card information
- **Policy workgroup**
 - Purpose: Provide a forum to discuss and [draft public comments](#) to federal policy makers related to policies impacting consumer-directed exchange
- **Digital ID & Authentication**
 - Purpose: Discuss ways to both implement and federate a [NIST 800-63 IAL2 digital identity credential](#) in health care which includes discussing how minor's identity and the personal representative use cases should work and the creation of the [CARIN Credential Policy](#)
- **Trust Framework and App Registration Guide**
 - Purpose: Develops the business policies associated with consumer-directed exchange including the [CARIN code of conduct](#), [application registration guide](#), [MyHealthApplication.com](#) application website, and a privacy policy [UX design best practices](#) website for application developers (awarded a [FAST Company World Changing Idea – Honorable Mention](#))
- **HHS XMS Digital Identity Federation Proof of Concept**
 - Purpose: Develop a technical and policy architecture that would support the federation of a NIST 800-63 IAL2 digital identity credential via the CARIN Alliance Digital Identity Federation Proof of Concept and [report](#)

For a complete list of the organizations involved in the CARIN Alliance, please visit our [website](#). For more information, please contact the alliance via the CARIN Alliance [Website](#) or [Twitter](#), [YouTube](#), or [LinkedIn](#).