The CARIN Alliance

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A consumer can share their data with anyone

**Must** Share vs. **May** Share

No Legal Agreements Needed

**HIPAA**

**Covered Entity**

**Consumer API**

**FTC**
VISION

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, the undersigned, are a group of multi-sector stakeholders of leading providers, payers, health IT companies, EHR companies, consumer platform companies, consumers, caregivers and others focused on advancing consumer-directed exchange across the U.S. We are working collaboratively with other stakeholders and leaders in government to overcome the policy, cultural, and technological barriers to advancing consumer-directed exchange.

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 the open APIs required under the MIPS Advancing Care Information measure to Provide Patient Access. This measure requires providers to share electronic health information with any application the consumer chooses. 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.

Our Pledge

We believe consumers, or their authorized caregivers, have a right to access, receive, and share their available digital health information with any third-party data steward they authorize in a readily producible format they request, in as close to real-time as feasible, and at no cost. Data blocking is not acceptable.

We believe covered entities have a responsibility to provide consumers or their authorized caregivers access to share their digital health information with any third-party data steward they choose once the consumer makes a request to do so.

We believe covered entities need to ID proof and authenticate the individual consumer or their authorized caregiver requesting access to their digital health information via a third-party application before providing access.

We believe consumers should be able to know what personal information has been collected about them, the purpose of its use, who can access and use it, and how it is shared. We also believe consumers should be informed regarding how they may obtain access to information collected about them and how they may control who has access to it.

We believe personal data should not be disclosed, made available, or otherwise used for purposes other than those proactively specified by the consumer. Information should be clearly spelled out regarding how the application will access, use and share the data on the consumer's behalf.

We believe robust safeguards should protect personal data against such risks as loss or unauthorized access, use, destruction, annotation, or disclosure.

We believe data stewards in possession of personal health data should be held accountable for implementing these principles. We do not believe covered entities should be involved in the oversight of third-party applications.

We believe meaningful remedies must exist for all participants involved in consumer-directed data exchange to address security breaches, privacy, or other violations incurred because of misuse of the data by the application.

We believe data stewards should have the ability to obtain endorsements and certifications from independent, market-based organizations.

We believe health IT developers should actively seek ways to expand the set of consumer data available for electronic access and exchange with individuals, caregivers, and clinicians. Ultimately, machine-readable data should be expanded to ensure the entire health record is available electronically to the individual requesting it.

Call to Action

We call on all public and private health care stakeholders to join with us in supporting electronic, third-party access to a consumer's complete longitudinal health record and coverage information to allow 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.
Participating Organizations

- 23andMe
- AMA
- Aetna
- AHIMA
- Alliance for Nursing Info. (ANI)
- Allscripts
- American College of Surgeons
- Apple
- b.well
- BCBSA
- Cambia Health Solutions
- CareEvolution
- Caregiver Action Network
- Cedars-Sinai
- Center for HC Interoperability
- Cerner
- DaVita Healthcare
- Electronic Health Records Association (EHRA)
- Everything Benefits
- Foothold Technology
- Health Care Transformation Task Force
- HL7 | Argonaut | FHIR Foundation
- Humana
- ID.me
- Indiana HIE (IHIE)
- LifeMedID
- Marshfield Clinic
- MyPatientLinks
- MedFusion
- Medial Research
- Medical Home Network (MHN)
- Microsoft
- NATE
- National Partnership for Women and Families
- New Jersey Innovation Institute
- New York Presbyterian
- Pfizer
- Sequoia / Carequality
- Stacey Tinianov (Patient Advocate)
- The Broad Institute
- Trinity Health
- UCSF
- UPMC
- Velatura
- Videntity

Government Partners: ONC, OCR, FTC, CMS, HHS, VA
2018 Workgroup Focus Areas

• Policy and Regulatory
  Develop policy and regulatory recommendations for consumer-directed exchange in order to harmonize relevant policies and regulations across government agencies

• Consumer ID and Authentication
  Develop a set of best practices and principles for implementing IAL2 and AAL2 within health care in response to the TEFCA

• Trust Framework
  Develop a set of trust framework principles, enforceable code of conduct, self-attestation questions, and certifying bodies for exchanging data outside of HIPAA

• Health Plan and Real-time benefit check (RTBC)
  Develop a common payer data set and corresponding FHIR implementation guide for the agreed upon set of FHIR resources that payers will display to consumers and make RTBC available to consumers

• Technology
  Technology related questions and issues associated with consumer-directed exchange along with an opportunity to demonstrate consumer-directed exchange functionality publicly
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