

Consumer-Directed Exchange Pledge

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 any 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, unless otherwise permitted by law. Information should be clearly spelled out regarding how the application will access, use and share the data on the consumer's behalf.

WE BELIEVE data provenance should be provided where possible to identify who originally supplied the data, who made changes to the data, and when those changes were made.

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.

If you would like more information on how to get involved, please visit www.carinalliance.com or www.hcttf.org

