

Interoperability and Custodianship

Empowering consumers and clinicians with responsible data use

A connected, informed, and effective health care system relies on data, actionable insights, care coordination, and value to enable innovation and advance high-quality care. Investments to modernize health care infrastructure, increase utilization of data and information, and deploy proven technology solutions are necessary to empower consumers and care providers, reduce costs, contribute to better health outcomes, and improve the consumer experience.

Interoperable Health IT Enables Clinicians to Improve Care Coordination

In order to effectively coordinate patient care with providers from other facilities and health systems, clinicians need integrated access to relevant clinical information about their patients from other health IT systems. Achieving interoperability has been challenging, with only 18 percent of hospitals using data from outside sources for patient care on a regular basis. A meaningful barrier is not having information available to view in the electronic health record (EHR) as part of a clinicians' workflow.

Solutions to enable clinicians with interoperable health IT include:

- Incent providers to use EHRs and demonstrate improved clinical quality and health outcomes to facilitate the shift to value-based care.
- Advance interoperability and end information blocking by requiring EHR technologies to both accept and send standardized information, enabling medical information to be seamlessly integrated into the clinical workflow.
- Define clear and unambiguous types of fees EHR vendors may charge for standardized data access, set limits on fees, and prevent recurring per-transaction fees for data.
- Promote the transfer of electronic notifications by hospitals to primary care providers and health plans upon patient admission and discharge.
- Create a public-private collaboration for a national health information exchange.



63% of Americans
do not know where their
medical information is stored



Less than 1/3
of office-based physicians
can integrate health information
received electronically into
their health IT system

Responsible Health Care Data Use Protects Consumer Privacy

Consumers have long benefited from the protections of Federal and State health care data privacy and security laws. Efforts to advance interoperability must not sacrifice these longstanding safeguards, such as the protections in the Health Insurance Portability and Accountability Act (HIPAA). Consumers have an expectation of trust in institutions that access and use their health care data, and should expect any entity using this data to:

- Use data for the purposes of improving personal health, advancing health system performance, and new discovery.
- Protect data at the highest standards.
- Offer a clear description of how health data is used and protected, versus a long and complicated end user license agreement.

Policies to ensure responsible health care data use and the protection of consumer privacy include:

- Establish uniform State or Federal requirements to streamline conflicting laws concerning individual consent for the access, use, and sharing of personal health care data.
- Remove Federal limits prohibiting providers from receiving data on an individual's mental health treatment history in EHRs to facilitate enhanced care coordination.
- Establish uniform and responsible data-use, privacy and security requirements for health apps, prevent sensitive health data from flowing to non-regulated apps, and allow health plans the ability to deny Application Programming Interface (API) access to third party applications that do not meet the health plan's standards for appropriate uses of health data.
- Establish a well-defined, appropriate, and relevant-to-consumer dataset that plans can share via APIs that factor in concepts such as intended purpose, relevance of the data, standards maturity, and sensitive data classes and consent considerations.
 - Do not require the dataset to include proprietary data or data which could be reverse engineered to determine proprietary data such as negotiated rates between payers and providers.



91% of consumers

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