



Interoperability MATTERS

an initiative of The Sequoia Project

February 2, 2024

Consumer Engagement Strategy Workgroup

Points of intersection with Privacy and Consent Workgroup



Assessing the landscape of consumer/patient needs, frustrations and experiences with accessing and using health data

Consumer Voices Workgroup
Report of Findings & Recommendations
July 1, 2023

the sequoia project

- 19 recommendations for accessing health records
- 7 recommendations for using health records
- 22 recommendations for sharing health records



JAMA Health Forum
Protecting the Privacy of Reproductive Health

HealthIT Buzz
The Evolution of Patient Access to Their Health

STAT
Breakthrough discoveries to end cancer
Needed: a new framework to make sure health companies play fair with patient data



Personal Access

All of my health information is readily accessible to me in one place when I need it

My patient portal makes it easy to find my visit reports, lab results, prescriptions and physician notes

* Portal improvements

I can access all of my health information from all of my physicians through a personal health hub of my choosing

* Interoperability/data exchange

HCP Access

All of my data is readily accessible to all of my HCPs through their EHR, regardless of their practice affiliation

All of my physicians have access to all of the data about me that I choose to make available through their office electronic health record

* Interoperability/data exchange

It's easy for me to share all of my data with providers, apps and researchers I choose

I am able to choose to not share specific types of health data with certain providers

Privacy and consent

Usability

I can understand my data and health information makes sense to me

My information is easy to read without straining my eyes

* Portal improvements

It is easy for me to see which of my lab values are out of range or if a specific test is negative or positive

My information is provided to me in language that is understandable to somebody without a medical degree

My information is accurate and its easy for me to correct inaccuracies

Awareness and Education

I understand my rights to data access, how and by whom my data is used and can advocate for myself and others

My provider makes it easy for me to understand my rights to data use and takes measures to ensure that I am able to exercise those rights.

* Portal improvements

My data access rights are clearly articulated in my patient portal and provider's office, so that I can see and understand them within the context in which that knowledge is relevant

* Patient notification and education

My provider and patient portal makes clear what data is and is not shared with other providers in that health system or other health systems