



Interoperability MATTERS

an initiative of The Sequoia Project

Consumer Voices

The Sequoia Project Elevating Consumer Engagement



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Invitae

A defining moment

Healthcare and health IT are tasked with transforming **Information Blocking to Information Sharing** for the most important Stakeholder...

...the **people** that are patients, their representatives, and an estimated 55 million caregivers in the U.S.



The Sequoia Project is seeking to advance this transformation through our Consumer Voices workgroup.

Individual right of access... in the form and format requested

- This right was established by HIPAA in 2000!
- We needed standards, technology, regulations and industry willingness.
- We advanced with HITECH through patient portals, but no two portals are alike.
- 21st century Cures Act, non-blocking rules, and FHIR APIs should fully enable this right a mere 22 years later.



“It’s time to embrace
the consumer’s
role in health
information”

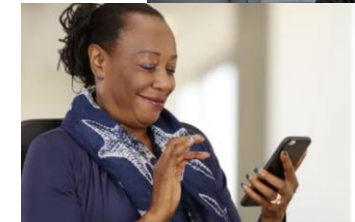


Consumer Voices
will help
The Sequoia Project
achieve its vision.

**Our vision is to make the
right health information
accessible at the right place
and time to improve the
health and welfare of
all Americans.**

The **Consumer Voices Workgroup** is a newly-launched Interoperability Matters workgroup that was established by the Sequoia Project to:

- ✓ bring the consumer's voice to Sequoia's work
- ✓ better understand the barriers consumers face
- ✓ inform strategies to address those barriers



Over the next 5 months consumers will share their experiences, priorities, and recommendations for obtaining, using, and sharing their medical records.

- The workgroup represents people from all walks of life. We sought participants who are **not steeped in the complexity of healthcare, regulation, and health IT.**
- Their voices will help us develop strategies to make it easier for all consumers to access, use, and share health data while keeping it private and secure.





COVID taught us about existing inequities in healthcare access that are made worse by challenges with technology.

- Health inequities – black and brown people and people from different cultures experienced worse health, healthcare access and health outcomes
- Digital divide
- Health inequities are caused and made worse by limited access to technology and high-speed Internet (broadband)
- Everyone should benefit from improved access to electronic health information

Recruiting Consumer Voices Workgroup Members

It's your data.
Tell us how you want it.
Health data used to be paper.
Now it's all electronic.

By law, patients and caregivers have a right to get patient data...

Health data includes:

Medical records	Allergies
Conditions and illnesses	X-rays
Vital signs	Lab test results
Vaccines	Medical bills and payment
Medications	

...when they want it

...how they want it

Your experience and opinions can help find new ways to make sure patients and caregivers get health data when and how they need it.

Your thoughts about...

▶ Patient rights and needs	▶ Technology
▶ Privacy & security	▶ Special needs of minors & healthcare representatives
▶ Caregiver needs	

...can help patients and their families...

▶ Better manage their health	▶ Share their data with multiple doctors
▶ Make sure their information is right	▶ Save time and money

What you want and need matters!

Join our patient and caregiver work group
We are seeking a diverse group of 18 adult patients and caregivers who can...

Participate 2-4 hours a month

Join meetings online

Share needs and opinions about health data

Commit for 6 months

Make your voice heard

Learn more or sign up
consumervoces@sequoiaproject.org

Receive \$500 every three months for your participation

the sequoia project
sequoiaproject.org

Who is the Sequoia Project?
Independent | Nonprofit | Founded in 2012
We work with government and industry to help all Americans get health data in a way that meets their needs.

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- Diversity
- Engaged Patients
- Engaged Caregivers
- Nationwide

Consumer Voices Workgroup

- Regions: Northeast, Southeast, Mid-Atlantic, Mid-West, Mountain, West Coast
- Healthcare setting: Urban, Suburban, Rural
- Gender: 37% Male, 63% Female
- Race/Ethnicity: 37% self-identified as non-white
- Orientation: 25% self-identified as LGBTQ
- Insurance: Employer, Medicaid, Medicaid/Medicare



Mallory



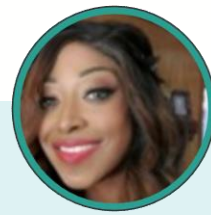
Ron



Antoinette



Rose



Shamekka



John



Marshay



Mark



Grace



Shannah

2022-2023 Consumer Voices Workgroup Members and Co-Chairs

Consumer Voices Survey Results



Consumer Voices workgroup members are engaged patients and caregivers with **50% reporting 11+ healthcare visits a year.**

87% of members are caregivers for patients aged 1-81+.

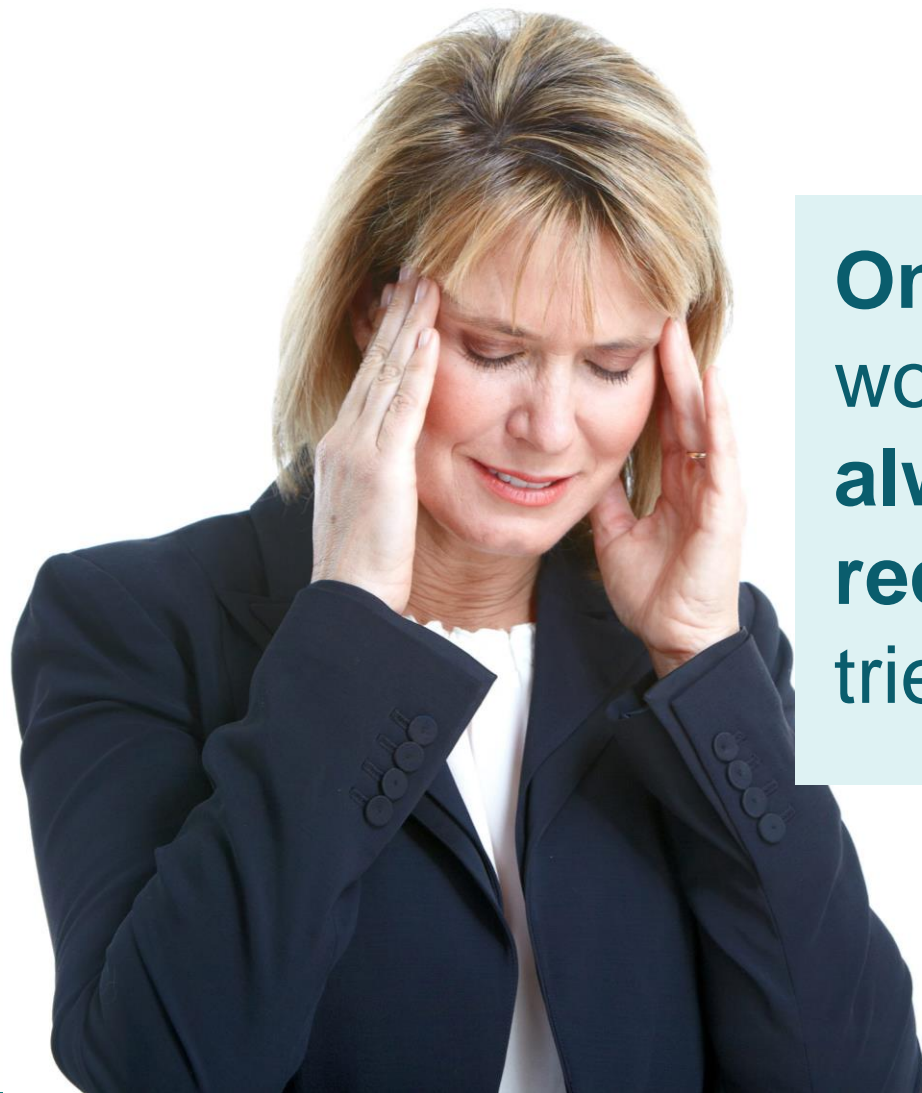




100% of Consumer Voices workgroup members **use a smart device or computer** to connect with healthcare teams; however, **80% of the people they care for do not.**

**87% of Consumer Voices
workgroup members have
tried to access medical
records online.**





One third of Consumer Voices workgroup members were **not always able to get the medical records** they wanted when they tried to access them online.

Consumer Voices workgroup members had **mixed results easily getting what they wanted online**, especially when they needed to...

...use multiple patient portals

...access images

...access as a caregiver

...get results not in the patient portal

...search or print historical records



Consumer Voices

“

I have to keep a list of several patient portals, user IDs, and passwords on a Google doc that I share with family members to keep track of all my doctors and medical records

”

Consumer Voices

“ I have a chronic condition and want to be able to easily get second opinions but it's not always easy. I have to play telephone tag with the doctor's office because I can't access images from the patient portal... ”

Consumer Voices

“

I was at the hospital emergency room and asked a family member to go to the house and take pictures of pill bottles and text them to me so that the doctors would know what medications the patient was taking...

”

Consumer Voices

“

Mom had a complicated medical history and multiple chronic health conditions. We wanted to switch doctors but were afraid of losing all her medical records.....

”

Consumer Voices

“


Requesting medical records brings everyone dealing with a catastrophic diagnosis to their knees. It shouldn't be this complicated...

”

Consumer Voices The Path Forward



Historically patients have faced many challenges to accessing their medical records

HEALTH INSTITUTION	SCORE	REPORTED AS OF	NOT COMPLIANT – RECORDS NOT SENT	NOT COMPLIANT – RECORDS RECEIVED	HIPAA COMPLIANT WITH INTERVENTION	STAR RATING + Expand Requirements	HIPAA COMPLIANT SEAMLESS PROCESS	HIPAA COMPLIANT PATIENT FOCUSED
						HIPAA COMPLIANT WITH EFFORT		
				★	★★	★★★	★★★★	★★★★★
Abundant Life Birth Center <i>611 Southwest Federal Highway, Stuart, FL</i>	★★★★★	4/22/21						●
Access Health LA St. Bernard Community Health Center <i>8050 West Judge Perez Drive Ste 1300, Chalmette, LA</i>	★★★★☆	8/19/22					●	
Acension St. Vincent Carmel <i>13500 N Meridian St, Carmel, IN</i>	★★★★★	8/25/22						●
Acension St. Vincent Fishers <i>13861 Olio Road, Fishers, IN</i>	★★★★★	8/25/22						●
ACES – San Diego <i>5333 Mission Center Rd Suite 110, San Diego, CA</i>	★★★★☆	10/5/21				●		
Ackerman Cancer Center <i>10881 San Jose Boulevard, Jacksonville, FL</i>	★★★★☆	10/5/21					●	
Ad-Park Pediatric Associates, S.C. <i>1640 West Lake Street, Addison, IL</i>	★★☆☆☆	7/28/22		●				

Source: www.patientrecordscorecard.com

Historical:

- Finding time to contact medical records office (often multiple times) during their regular business hours
- Getting office to send records in a way convenient for the patient (Fax? Mail? CD?)
- Paying for records
- Waiting for up to 30 days or longer

Today:

- Connecting and maintaining connections to multiple portals
- All records not present in the portal

“Patient
Administrative
Burden” *

** term borrowed from board-certified
patient advocate and Consumer Voices
Co-chair, Grace Cordovano, PhD, BCPA*

TEFCA is a potential path out of the out of the wilderness...



Coming Spring 2023

A **Consumer Engagement Strategy Workgroup** will be forming soon and will be open to Sequoia members to gain an understanding of consumer experiences, priorities and recommendations; and to develop short and long-term cross-sector strategies for meeting consumer needs.

Consumer Voices

Q+A





the
sequoia[®]
project

Thank you for your participation

sequoiaproject.org