Consumer Voices
The Sequoia Project Elevating Consumer Engagement
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”
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.

Consumer Voices will help The Sequoia Project achieve its vision.
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

- 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

2022-2023 Consumer Voices Workgroup Members and Co-Chairs

Mallory  Ron  Antoinette  Rose  Shamekka  John  Marshay  Mark  Grace  Shannah
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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
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“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 ...."
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…
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…
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"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....."
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"Requesting medical records brings everyone dealing with a catastrophic diagnosis to their knees. It shouldn't be this complicated…"
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The Path Forward
Historically patients have faced many challenges to accessing their medical records

<table>
<thead>
<tr>
<th>HEALTH INSTITUTION</th>
<th>SCORE</th>
<th>REPORTED AS OF</th>
<th>NOT COMPLIANT — RECORDS NOT SENT</th>
<th>NOT COMPLIANT — RECORDS RECEIVED</th>
<th>HIPAA COMPLIANT WITH INTERVENTION</th>
<th>STAR RATING</th>
<th>HIPAA COMPLIANT SEAMLESS PROCESS</th>
<th>HIPAA COMPLIANT PATIENT FOCUSED</th>
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<td>★★★★★</td>
<td>4/22/21</td>
<td>★</td>
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<td>★</td>
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<td>Access Health LA</td>
<td>St. Bernard Community Health Center 8050 West Judge Perez Drive Ste 1300, Chalmette, LA</td>
<td>★★★★★</td>
<td>8/19/22</td>
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<td>★★★★★</td>
<td>8/25/22</td>
<td></td>
<td></td>
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<td>★</td>
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<td>Ascension St. Vincent Fishers 13861 Old Road, Fishers, IN</td>
<td>★★★★★</td>
<td>8/25/22</td>
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<td>ACES — San Diego 5333 Mission Center Rd Suite 110, San Diego, CA</td>
<td>★★★★★</td>
<td>10/5/21</td>
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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

* term borrowed from board-certified patient advocate and Consumer Voices Co-chair, Grace Cordovano, PhD, BCPA
TEFCA is a potential path 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
Thank you for your participation

sequoiaproject.org