Interoperability MATTERS
an initiative of The Sequoia Project

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

the sequoia project

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Background

- The Sequoia Project's vision is to make the right health information accessible at the right place and time to improve the health and welfare of all people.

- Consumers weren't at the interoperability table and Sequoia decided to change that.

- The **Consumer Voices** workgroup was formed in Fall 2022 with a charter to share experiences, priorities, and recommendations for accessing, using, and sharing health data.

- The workgroup convened virtually on a monthly basis between December 2022 and April 2023. Participants engaged in polls and facilitated discussions to share perspectives at workgroup meetings. Poll results were analyzed and reported, and experiences were captured and recorded.

- **This report is a summary of what we heard.**

The Sequoia Project identified two consumer engagement goals.

1

Listening to consumers

2

Acting on what we heard

About the Workgroup

Bringing the consumer's voice to Sequoia's work

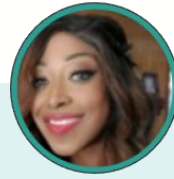

Mallory   Ron   Antoinette   Rose   Shamekka   John   Marshay   Mark

2022-2023 Consumer Voices Workgroup **Members**

Grace Cordovano   Shannah Koss

2022-2023 Consumer Voices Workgroup **Co-Chairs**

Bren Shipley   Shawna Hembree

2022-2023 Consumer Voices Workgroup **Sequoia Staff**

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Workgroup Composition (n=8)

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

Diverse people.

Similar experiences.

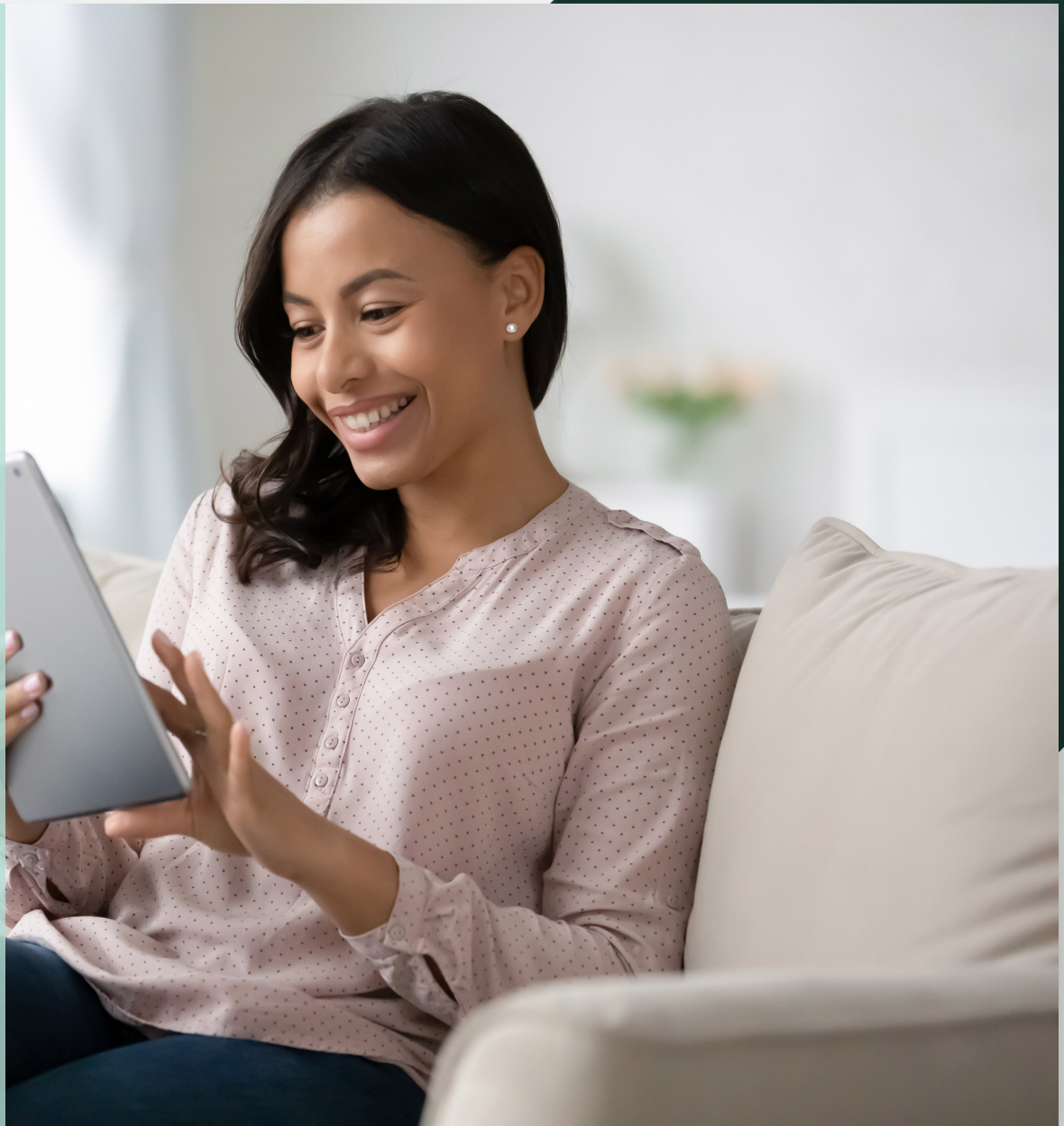Consumer Voices workgroup members are engaged patients and caregivers with **50% reporting 11+ healthcare visits a year.**

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

(n=8)

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

(n=8)

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.**
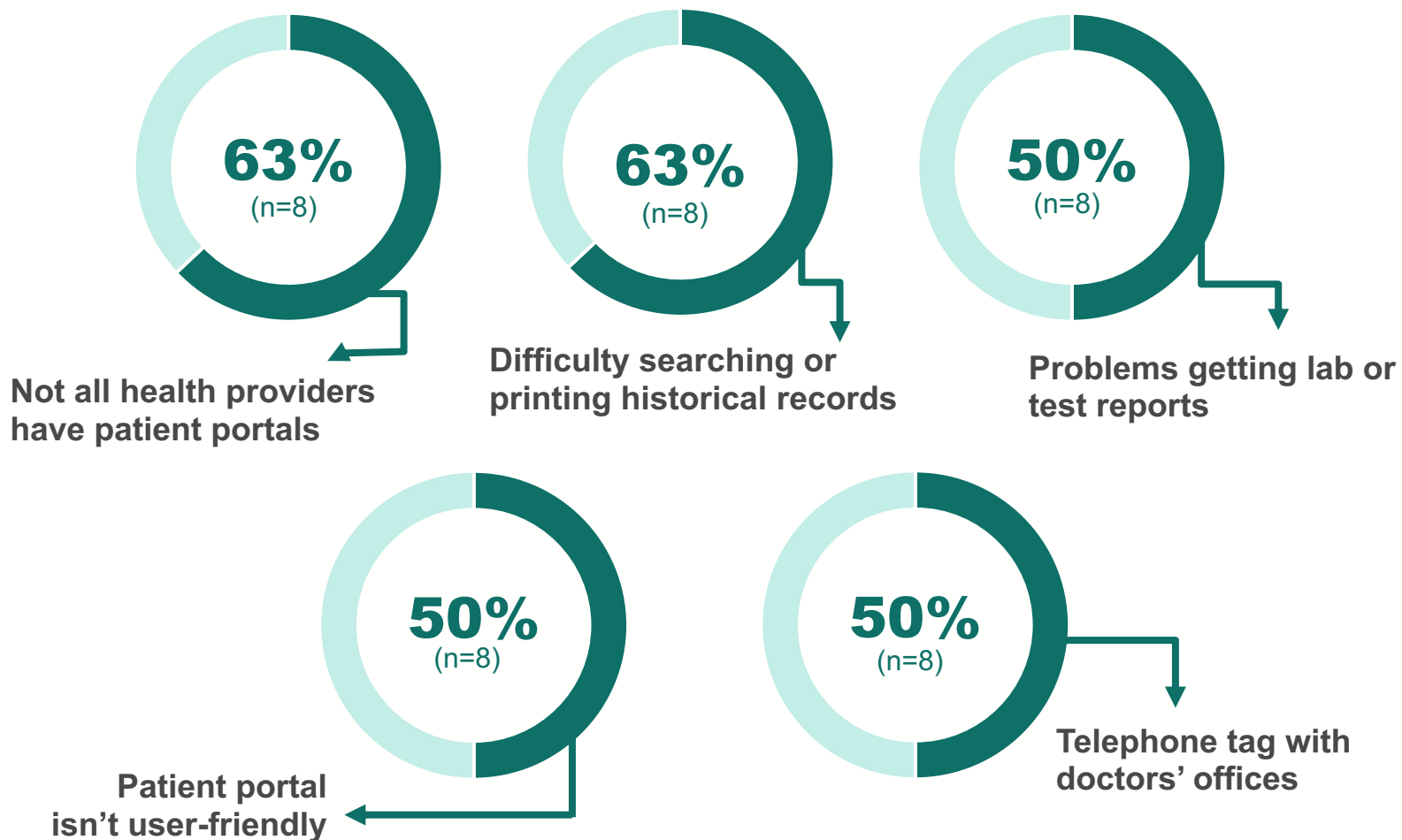
(n=8)

Findings

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

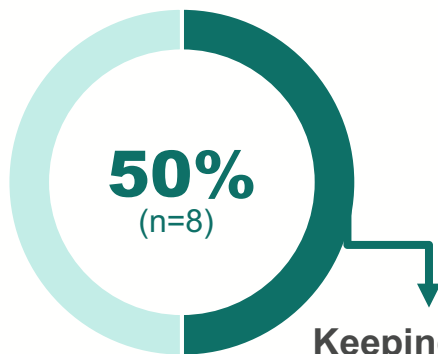…get results not in the patient portal

…search or print historical records

Most common shared experiences as *Patients:*

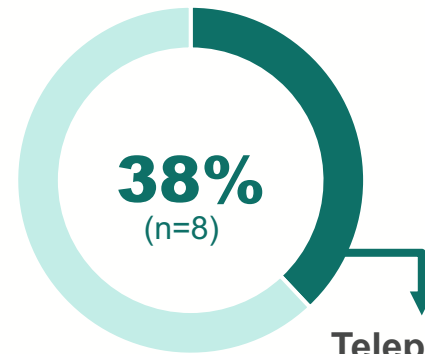**63%** (n=8)

Not all health providers have patient portals

63% (n=8)

Difficulty searching or printing historical records

50% (n=8)

Problems getting lab or test reports

50% (n=8)

Patient portal isn't user-friendly

50% (n=8)

Telephone tag with doctors' offices

Consequences of Gaps in Interoperability

57% said trying to get medical records was stressful, time-consuming, or confusing

43% had hesitancy to switch doctors for fear of losing medical history

43% experienced a hospital emergency and with no record of meds, allergies

43% experienced duplicating tests / images because they weren't shared between providers

43% said they had to go in-person to pick up medical records

43% said spending time getting medical records took time away from self-care / caregiving

29% had to cancel appointments because medical records weren't available

(n=8)

Most common shared experiences as *Caregivers:*

50%
(n=8)

→ **Keeping track of multiple patient portals**

38%
(n=8)

→ **Telephone tag with doctors' offices**

50%
(n=8)
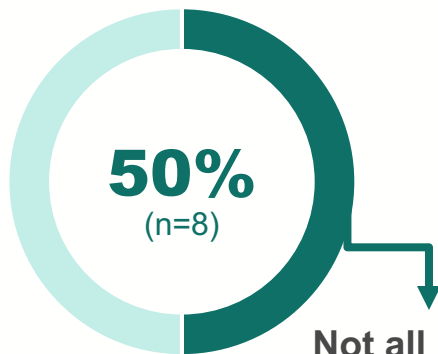
→ **Not all health providers use a patient portal**

38%
(n=8)
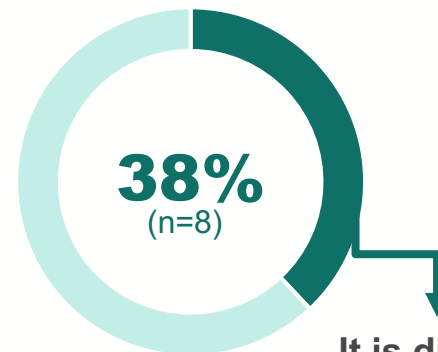
→ **It is difficult to stay on top of medications**

Priorities for Using Health Records

Priorities

1 — *"Having all my Electronic Health Information (EHI) in one place"*

2 — *"Sharing my EHI with other healthcare providers"* including *"Sharing images with providers who didn't take or order the images"*

3 — *"Using my EHI to manage my own health"*
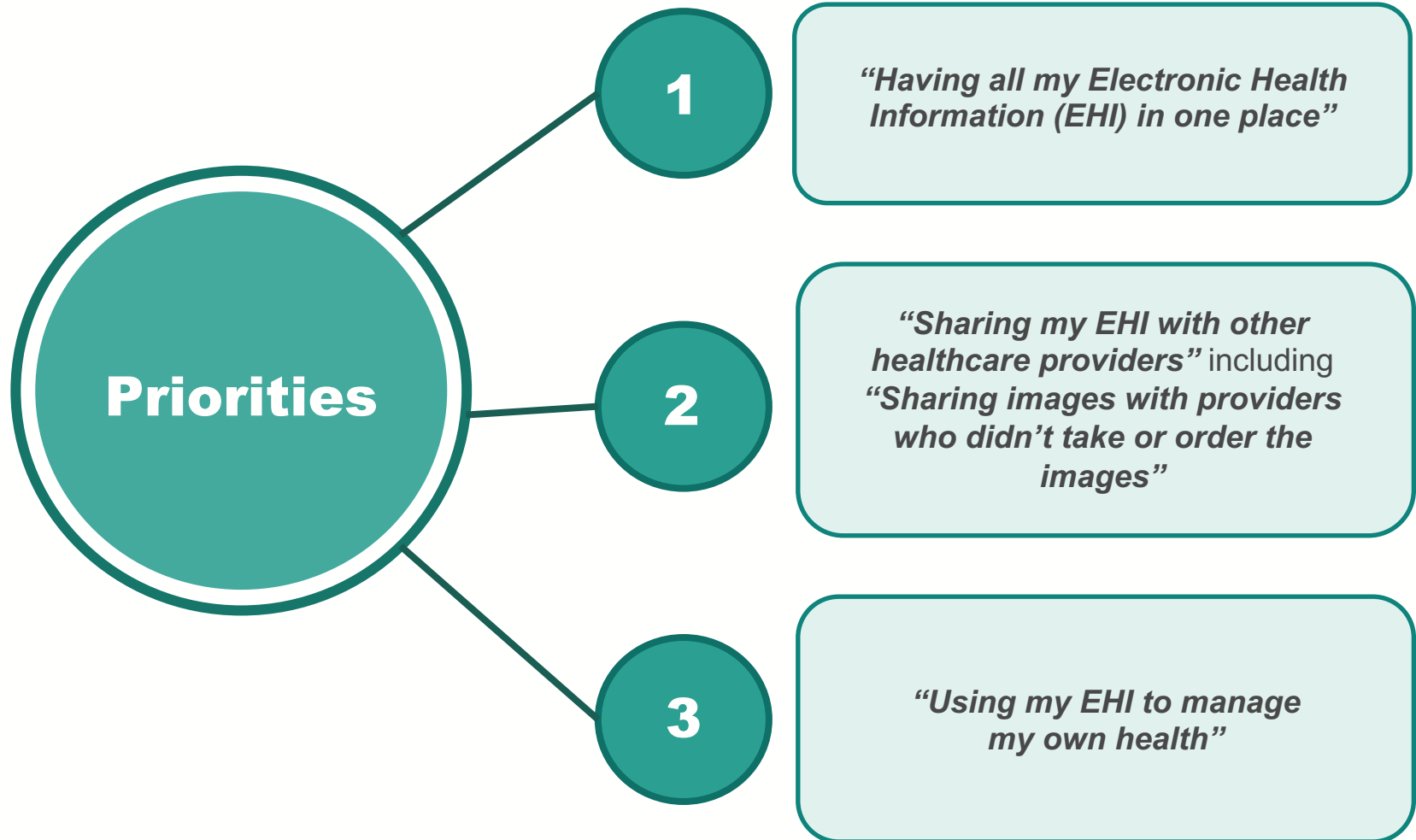
Using Health Records

- Workgroup participants agree that "**one size doesn't fit all**" and that patients should be able to choose when they receive test results.

- There were **lots of uses** for health records outside of healthcare.

- Most workgroup participants had difficulty **understanding some of the reports** and results that show up in their patient portals, and many reported **finding errors in their health records**.
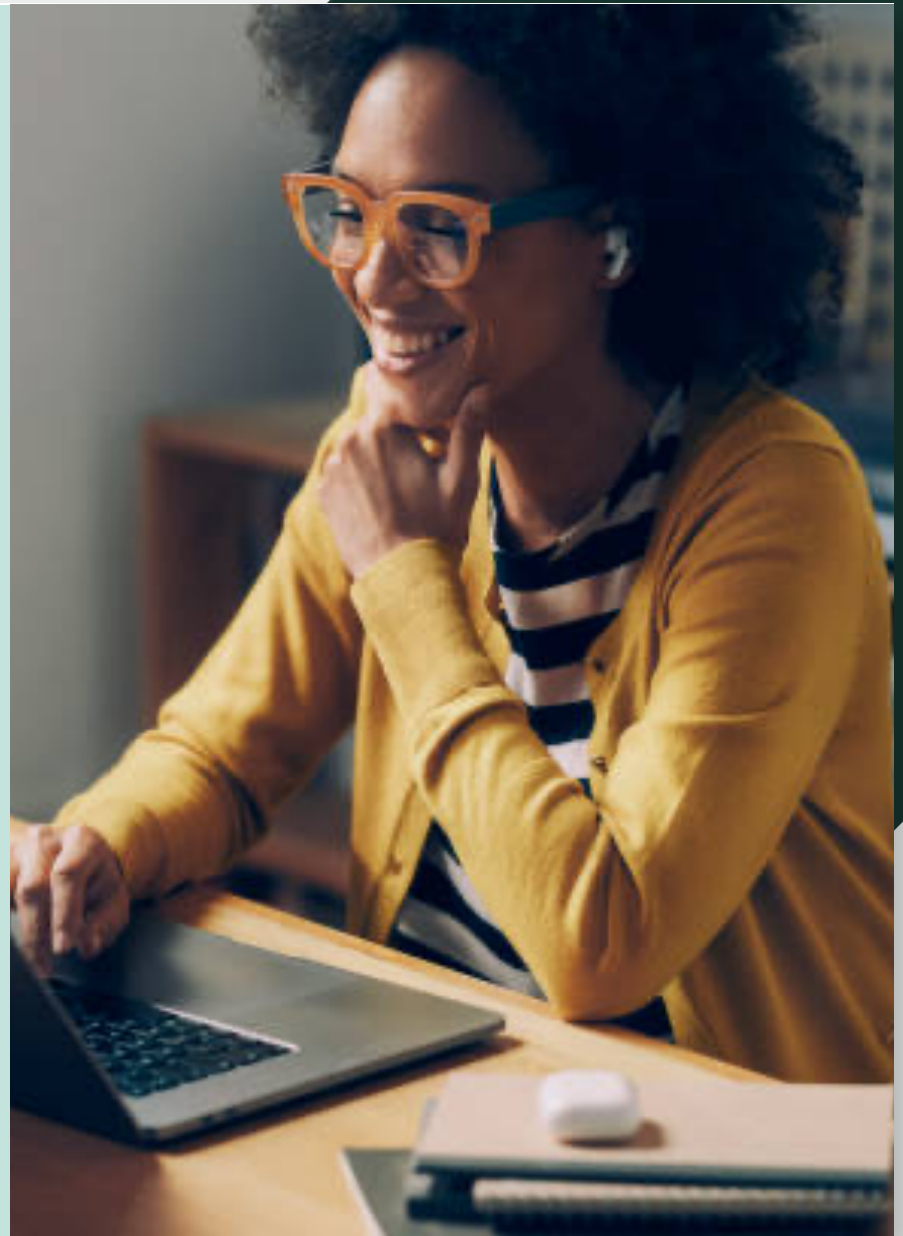
Knowing Your Rights

- **None** of the workgroup participants were aware of the federal government protecting their rights to health information via "info blocking rules".

- **None** of the workgroup participants were aware of HealthIT.gov or how to file a HIPAA or info blocking complaint.

- **Only one** of the workgroup participants was aware of health information exchanges (HIEs) or their state's Opt-in or Opt-out requirements to participate in their state's HIE.

- **None** of the workgroup members knew if their healthcare providers participated in HIEs.

- **Many** workgroup members reported they don't see or read the HIPAA form they are asked to digitally sign.

Hear Directly from Patients and Caregivers

Using My Health Records: https://youtu.be/PJF1vOr7BMs

Accessing My Health Records: https://youtu.be/5GCG16zFPvs

Sharing My Health Records: https://youtu.be/zSbvZle7MuI

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Workgroup Recommendations

Consumer Voices – Fear & Burden of Access

" 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….. **"**

" I 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 …. **"**

" If my new providers had access to my health information, I wouldn't have to worry about remembering to tell them everything…. **"**

Accessing Health Records

"

- There should be one place that I can access that connects all my doctors, so I have all my health information in one place, instead of scattered across multiple systems that I need to keep updating and correcting.

- Patient portals need to "talk to each other", for example keeping medication lists and test results up-to-date, so I don't have to remember to tell each of my doctors using their own system about medication changes and labs.

- There should be a way that I can use one user ID and password for all my patient portals.

- Why can't I use my voice as my password to access multiple patient portals?

Managing health records across multiple providers and patient portals is a heavy administrative burden especially if I am dealing with chronic conditions and am a caregiver.

"

Consumer Voices – Accessing Medical History

" **I wanted to access medical records from twelve years ago. I was told, Oh, we don't need to keep your records that long. I didn't know that. So now there's no way for me to access the historical records I need...** "

Accessing Health Records

- Patient portals should allow patients to search historical records by clicking on date range or type of test, etc.

- When giving patients links to start using a patient portal, the doctor's office should also provide a link to a tutorial on how to use the patient portal. Not one workgroup participant had been sent a link to a video/tutorial on how to use their patient portal, how to share their records with other providers via the portal, how to message their doctor, how to navigate the site, or generally how to maximize use of existing functionality.

"

It would be helpful if we could easily find what we were looking for.

"

Accessing Health Records

"

- Patient portals should be designed from a patient's point of view for accessing, using, and sharing their health information, not a clinician's or doctor's office point of view. User interface design needs to start with the patient.

- Allow for personalized preferences

- Differences between mobile app and desktop app should be clearly communicated to patients as some functionality is not available on mobile apps.

If patient portals are the means for electronically accessing health information, it would be helpful if they were designed with us in mind.

"

Consumer Voices – Lack of Digital Access

> " My HMO has a patient portal where I can access information from my visit by using a drop-down menu by the physician's name. But not all the HMO's physicians that I see post information. My PCP does, but specialists don't, and urgent care doesn't. So, I have incomplete records… "

> " I called Mom's PCP several times requesting a prescription refill. No one called back. When we finally went to the office in person, I realized why. Behind the reception desk were rows upon rows, floor to ceiling, of filing cabinets of paper medical records. Staff was carrying armfuls of patient folders around. They were swamped and buried in mountains of paper. Which led to Mom not getting her medication, becoming ill, and being hospitalized. "

> " My primary care doctor has most of my medical records. They have a patient portal but ask patients not to use it because it's confusing, not easy to use, and they are waiting to upgrade to a new one… "

Accessing Health Records

- Small practices and specialists should have access to affordable electronic health systems.

- Use of electronic health records with patient portals could be tied to provider licensure or reimbursement.

- Even with portals, providers still need to be able to communicate with patients that don't use computers.

"

It would be helpful if all doctors used electronic health records and patient portals.

Until they do, my health information will always be scattered and digitally incomplete.

"

Consumer Voices – Images

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

> **"** Not having images available in the patient portal is really frustrating for me. I get frequent MRIs and X-rays to stay on top of my medical condition. But I can only access the radiologist readings that are filled with medical jargon and difficult to navigate. I must request the image separately for each location I want it sent for second opinions. **"**

Consumer Voices – Medications

" 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… "

" I would want pharmacies to participate in the HIE so they would know about my allergies…. "

" I am a caregiver for my uncle, who is insulin dependent. I **can't get his prescription refilled through a patient portal**. I must call the doctor's office and leave a message, then wait to see if I hear back, then call back. His prescription wasn't refilled in time and now he's in the hospital…. "

" They [doctors' offices] make you go around in circles. If you call to refill a prescription and leave a message, they never get back to you and if you use the patient portal, staff monitoring the portal messages say they have 24-48 hours to read the message and then must wait to talk to the doctor before refilling the prescription. **It's no faster using the portal when it comes to refilling prescriptions**… "

Accessing Health Records

- Electronic communication doesn't mean instant communication. Office staff can take 2+ days before reading a message a patient submits through the patient portal, forcing the patient to also phone the office. It feels to the patient that the portal is designed for one-way communication, with the doctor saying, "I didn't know you called."

- It would be helpful if the patient portal concept was leveraged for electronic bi-lateral communication:
    - Call logs
    - Alerts after multiple calls
    - A "trouble ticket" system similar to a Help Desk that is only closed once the patient agrees their issue has been resolved
    - Auto call back for patients in queue, like other industries use.

> **"Even with access to patient portals, there is still way too much telephone tag with doctors' offices."**

Consumer Voices – Errors in Health Records

> " I found out my health record had listed a whole bunch of drugs I wasn't taking and never took. It made me look like I was one of those people shopping for pills. "

> " I discovered that my health records listed ALS as a condition. I've never been diagnosed or treated for ALS. "

> " I found errors in my health records, but I don't know how to get them removed. "

Accessing Health Records

"

- Make it easier for a patient to flag an inaccuracy they find when accessing their records. Errors will happen, but a patient should be able to <u>easily</u> correct them.

It is frustrating to find errors in my health records and not know how to easily get them corrected.

"

Consumer Voices – Awareness of Resources

Only HHS knows about Healthit.gov. Why can't they tell patients about it?

Accessing Health Records

"

- Patients are not aware of HealthIT.gov; HHS can promote this resource via public service announcements.

- Health IT.gov could provide patient rights information to providers and hospitals via educational pamphlets, posters, videos, or other resources directing patients to resources for understanding their rights. All should be written in plain language.

- HHS could create a directory of patient rights across a broad spectrum (e.g., HIPAA, workplace accommodations, no surprise billing, etc.)

- This educational information could be required standard posting on provider websites and patient portals.

I was not aware of my rights for accessing my health records and how to file a complaint if I thought my rights had been violated.

"

Consumer Voices – Access Without Usability

" I am a grad student and still have trouble understanding the reports posted on my health records. I end up spending time googling medical terms and asking people I know in the medical field to help decipher the report… "

" I learned that I had a torn MCL by reading a report on my portal. My doctor said, No, I disagree. This report isn't right… "

" Whenever I have a blood test, I access the results in my patient portal. It would be helpful to see the changes over time to see how I am progressing. "

" I read the MRI report that was posted to my health records and was terrified by the language. My doctor said, Oh, your spine is in great shape… "

Accessing Health Records - Ideal

"

- A robust sort function -- by type of provider (rheumatology, dermatology, etc.), condition, medication, date range, etc.
- A history of medications, surgeries, procedures, tests, diagnostics, images, diagnoses, allergies, and lab results overtime; should not be purged and should travel with you to new providers
- Ability to view a list of everyone that my records have been shared with
- Ability to set and change preferences on privacy and what specific information I want to have shared with specific providers or organizations for specific time periods
- One central place to digitally store Advance Directives so all providers know my wishes (or those of the person I'm caregiving for)
- One central place to digitally store my emergency contacts
- More bi-directional messaging features to post to provider/staff who can then respond and provide guidance to eliminate telephone tag especially around medication refills and authorizations

If there was a utopia for accessing my health information, it would be easy, all in one place, understandable, and allow me to share it when and how I want.

"

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Accessing Health Records – Ideal (continued)

"

- An easy way to access my information, with a balance between identity verification/ authentication and access
- An easy way to correct errors
- An easy way I can go in myself to share records for non-treatment purposes (e.g., school, disability, life insurance)
- HIPAA and other forms I've been asked to sign, with ability to change my mind and update forms
- Ability to choose at a specific test level whether I want to see results as soon as they are ready or once my provider has reviewed them
- Ability to make my own appointments
- Reminders for medication refills and authorizations
- Information hub with links specific to my condition, medications, procedures, side effects, clinical trials I might be interested in, support groups, etc.

If there was a utopia for accessing my health information, it would be easy, all in one place, understandable, and allow me to share it when and how I want.

"

Using Health Records

"

- Results and reports posted to patient portals should be written in plain language so that patients can understand them. Without a lay person interpretation, the documents are not useful for patients and are often written in a way that is unnecessarily stressful and scary to read.

- Use lay person terms rather than medical terminology/jargon, provide contextual information, and translation or summary of results.

- Provide a 'typical range' for test results.

It would be helpful if I could understand the reports and test results posted to my patient portal.

"

Consumer Voices – Test Results

" I prefer to have test results and reports available to me as soon as they are available because I found out my doctor didn't discuss some of the results with me, which was worrying because the test showed I was pre-diabetic, and I didn't have another appointment scheduled with the doctor. "

" There are some results – like a cancer diagnosis - that probably should not be accessible to patients before they get a call from their doctor, as it could lead to self-harming. "

" I'd like to see my test results as soon as they are available because I start to get anxious and worried waiting for results and I don't want to wait until the doctor has time to review them and call me. "

" I prefer to have test results and reports available to me as soon as they are available because there was a delay in posting clinical notes and a year after the fact, I discovered notes that showed evidence of mini strokes that my doctor never talked to me about. Maybe the process is manual, and understaffing delayed getting the information on the portal…. "

Using Health Records

- Patient portals should allow for individual choice on when test results are posted: as soon as they are available or after my doctor has reviewed them. The preference should be available at the test level.

- Patient portals could alert the patient "You have new results" and "Your doctor has now reviewed your results".

- Patients have unique preferences and anxiety triggers. Some become anxious waiting for results and not knowing, while others become anxious knowing and not being able to talk about them with their doctor right away.

- In certain caregiver situations, the patient may want their proxy to be notified of results first.

"

It would be helpful if I could decide if I want to see results before or after my doctor has had a chance to review them.

"

Using & Sharing Health Records

"

- Since all providers don't use the same electronic health records (EHR), they should at least all share the medications that they prescribe me with my PCP so there is one comprehensive list of current medications, medication allergies, and adverse medication interactions in one place.

- Why is it that every time I see my provider, I am asked to review the medication list, we correct errors, and the next time I'm there the same errors are still in the EHR? The corrected medication list should be saved in the EHR and across all EHRs for all my providers. I should also be able to make notes next to the medications in the patient portal, e.g., never took this, stopped taking this, can't afford this, made me dizzy, my insurance won't cover this, etc.

- Medication refill requests results in telephone tag, unanswered portal messages, missed dosages, pain, and sometimes hospitalization. Can the EHR send both me and my provider an alert / reminder as to when medication is approaching empty, how many refills are left, when a pre-auth will expire, etc. to prevent emergencies?

It would be helpful if my medications were accurate, and all my providers were working off the same list.

"

Sharing Health Records

"

- Lab and test results should automatically be sent to my PCP, so everything is in one place, and I don't have to chase down results.

- A central exchange for information where specialists have access to lab/test results ordered by PCPs.

- Patients should be able to access and share not only the radiologist's report, but also the results and images.

It would be helpful if my health records were shared without my having to chase them down.

"

Sharing Health Records

"

- Make reports, test results and medical records easy to download so they can be printed, scanned, emailed, etc.

- Provide a "referral" button, that aggregates all the health information the patient would typically need for going to a referral or second opinion.

- Provide a feature where the patient can enter a recipient name, contact information, and click on the health information the patient wants to send to the recipient. Eliminates the paper "release of information" form and process whereby the patient needs to go in-person to the office, fill out the form, play telephone tag; also provider staff time and delays.

It would be helpful if I could self-determine and self-direct sharing of my health information.

"

Sharing Health Records

"

- Post information exchange participation in providers' offices or hospitals

- Add extra page (or QR code) explaining what an HIE is and why their participation is beneficial to the patient and a list of area health providers that will also share information as a result; also direct to healthit.gov for more information

We didn't know about HIEs or if our providers participated in them.

"

Consumer Voices – Awareness of Patient Rights

" I'm not given a HIPAA form and I don't know if they [the provider's office] changed anything, but I'd want to know if they did. "

" I don't even get to see what I'm being asked to sign at the provider's office. It just sounds outrageous to me…. "

" If you do ask for it, the HIPAA form is a bunch of legal mumbo jumbo. Patients and caregivers don't have the time or knowledge to plow through the red tape, and what happens if you don't sign it? "

" I thought I trusted my providers as a source of information about my rights until I saw this presentation…. "

" I see a lot of doctors. It's bad enough going to see them but now on top of that I'm expected to read through four pages of documents for each doctor and try to make sense of them?… "

HIPAA & Consent to Share Health Records

"

- Signatures on legal documents should be optional (not required) for checking in; patients don't bring their lawyers to their appointments.

- Instead, you should be able to just sign that you were given the opportunity to see the HIPAA form.

- Patients shouldn't have to sign a form they can't see or don't understand in order to complete their check-in for an appointment; "if you don't sign this, I can't get you checked in and the doctor can't see you today".

- Check-in kiosks and tablets shouldn't require patients to sign documents they don't understand or agree with to continue to the appointment.

- A consultation upon intake for new patients to discuss paperwork with the provider's office.

- Providers should be required to tell patients if they've changed the HIPAA form since their last visit.

I'm not provided a HIPAA form when asked to digitally sign in at my provider's office.

"

HIPAA & Consent to Share Health Records

"

- Simplify HIPAA forms so people can understand them.

- Standardize HIPAA forms so they are the same for all providers.

- Remove other purposes from the form. Billing and financial terms, for instance, should be their own forms. Consent to treat me isn't the same as consent to share my information, consent to bill me, consent to enroll me in a scientific study, or consent to sue me if my insurance company doesn't pay you what you think they should.

- Consent to share my information should be on my patient portal so I can change it when I want to depending on the other health providers that I want to share my information with and for certain health conditions or time periods.

- Have the HIPAA form on the patient portal so you don't have to try to read through a 4-page document when checking in at the provider office

I don't really understand all that is on a HIPAA form, but don't want to be turned away from my appointment.

"

Next Steps

Consumer Engagement

1 The Consumer Voices Workgroup Report of Findings concludes the work envisioned under the 2022-2023 Consumer Voices inaugural charter. The report will be presented to The Sequoia Project Board, Interoperability Matters Leadership Council, and Consumer Engagement Strategy Workgroup. It will be published on The Sequoia Project website.

2 The Consumer Engagement Strategy Workgroup will be formed Summer 2023 to undertake work to gain an understanding of consumer experiences, priorities and recommendations and develop short and long-term cross-industry strategies for meeting consumer needs.

3 A new 2023-2024 charter will be created and approved by the Interoperability Matters Leadership Council to retain (and augment as needed) the Consumer Voices Workgroup to serve as an ongoing sounding board for the Consumer Engagement Strategy Workgroup and other Interoperability Matters workgroups (e.g., Public Health, Information Sharing, Data Usability) when they need consumer perspective across a variety of interoperability topics.

Consumer Engagement

4 The perspectives shared by patients and caregivers during the Consumer Voices Workgroup proved how important it is for industry and policymakers building a national interoperability roadmap to listen to everyday people. In support of patient-centric interoperability, we will continue to explore how to sustain the Consumer Voices Workgroup through funding from collaborative partners and the Federal government.

Contact

The Sequoia Project is a 501(c)(3) non-profit and trusted advocate for nationwide health information exchange in the public interest. Our work is made possible through annual dues from our member organizations, sponsorships from collaborative partners, and grant funding.

To join us in this vital work, contact us at **memberservices@sequoiaproject.org**
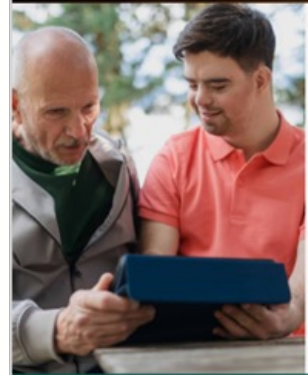
Appendix

Workgroup Recruiting

Consumer Voices Workgroup Charter

Charter

The Consumer Workgroup was established by the Sequoia Project with the approval of the Interoperability Matters Leadership Council to (1) bring the consumer's voice to Sequoia's work, (2) better understand the barriers consumers face in health information exchange, and (3) inform strategies for Sequoia to address the barriers. The Consumer Workgroup will share experiences, priorities and recommendations which will be used by The Consumer Engagement Strategy Workgroup to develop short and long-term cross-sector strategies for consumer engagement, access, education, and policy.

Key Questions this workgroup will answer

2022-2023 | Establishing a Baseline of Understanding for the Consumer Experience
1. Have you tried to access your health records? How easy was it?
2. Have you experienced problems *easily obtaining* your health records?
3. Have you experienced problems *using* your health records?
4. Have you experienced problems when trying to *share* your health records?

2022-2023 | Understanding Consumer Priorities
1. What is most important to you about accessing and using your health records? As a patient? As a caregiver?
2. What are the ways you most easily access personal information using technology today?
3. How do you access your health information using technology today?

2022-2023 | Identifying Gaps Between Experience and Ideal
1. What were the most positive experiences you've had obtaining your health records?
2. If you've had problems *obtaining* your health records, what would have made your experience better for you?
3. If you've had problems *using* your health records, what would have made your experience better for you?
4. If you've had problems *sharing* your health records, what would have made your experience better for you?

Consumer Workgroup Charter – Page 2

2022-2023 | Establishing a Baseline of Understanding for Consumer Education Needs

1. How familiar are you with your rights to obtain, share, and protect your health records?
2. What information would be most helpful to you to understand and exercise your rights?
3. What are the best ways for people to receive and understand this information?
4. What do you think would help people learn about their rights? How do we get the word out?

Guiding Principles

The consumer's voice matters.

Membership

The Consumer Workgroup is comprised of a diverse group of ~15 consumers, consumer-patients, and caregivers. Members will be able to serve on the workgroup as long as they have not missed three or more meetings.

Meeting Frequency

The Consumer Workgroup will meet virtually once a month. The Consumer Workgroup will meet as needed to collaborate with The Consumer Engagement Strategy Workgroup.

Meeting Preparation and Staffing

The Consumer Workgroup will initially be co-chaired by one Sequoia staff member and one Sequoia Board Member with the potential for a Consumer Member co-chair. Meeting materials will be posted to the Consumer Engagement webpage on Sequoia's website.

Consumer Workgroup Charter – Page 3

Member Stipends

Each Consumer Workgroup member will receive a stipend in the amount of $500 every three months for participating in monthly meetings.

Meeting Ground Rules

1. **Attend** virtual meetings consistently to ensure active participation.
2. **Prepare** for meetings by: a. planning a quiet location to join forum meetings virtually without distraction; b. making sure you can open the virtual meeting link on your computer, phone, or other device; c. reviewing materials distributed prior to the meeting, and d. preparing to raise questions and comments about issues being discussed.
3. **Listen** respectfully and learn from other points of view
4. **Speak** respectfully and share your point of view
5. **Respect** diversity, there are many different perspectives
6. Respect any **confidential discussions** held within the Workgroup

Evaluation

Consumer Workgroup members will be asked to participate in online surveys to provide insights to the Consumer Engagement Strategy Workgroup.
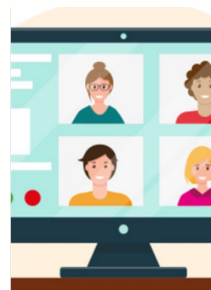
Workgroup Polls
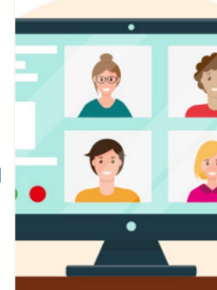
Interactive Poll #1

Considerations for Caregivers
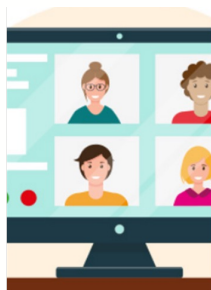
Interactive Poll #2

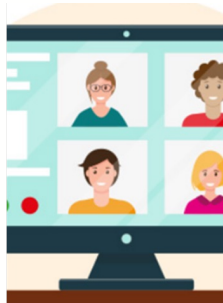**It's good that I can access my medical records online, but….**

Interactive Poll #3

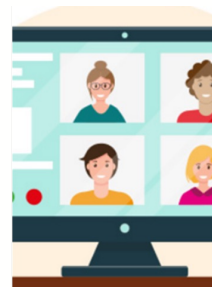**There are consequences of not having medical information on hand when I need it….**

Interactive Poll #4

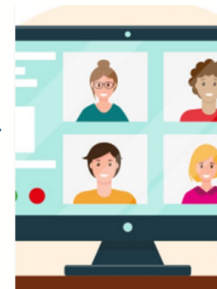**Are there other ways that you personally have used health records?**

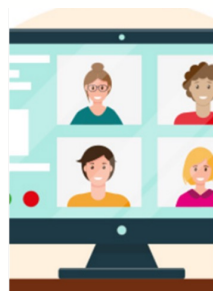**Interactive Poll #5**

Accuracy and usefulness of health records

Interactive Poll #6
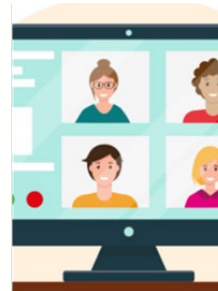
My preferences for receiving test results…

Interactive Poll #7

What matters most to me about *accessing* my health records

Interactive Poll #8

Your Rights

✋

Interactive Poll #9

What matters most to me about *using and sharing* my health records