Interoperability
MATTERS
an initiative of The Sequoia Project

Consumer Engagement Strategy Workgroup

Kick-Off Meeting

March 26, 2024

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project

Meeting Agenda

- Welcome and Introductions (10 min)

- Intro to The Sequoia Project and Interoperability Matters (10 min)

- Review the Workgroup Charter (2 min)

- Snapshot – consumer perspectives on data access (10 min)

- Policy overview – the evolution of the right of access (10 min)

- Open Discussion

- Roadmap, homework and wrap-up (3 min)

Consumer Engagement Strategy Workgroup Lead

Anna McCollister

Welcome Consumer Engagement Workgroup Members!

- Henry Archibong, HealthMark Group
- Allison Aubuchon, WellConnector
- Jennifer Blumenthal, OneRecord
- Whitney Bowman-Zatzkin, RareDots
- Stephanie Broderick, Clinical Architecture
- Hans Buitendijk, Oracle
- Hugo Campos, Consultant
- Bart Carlson, Azuba Corporation
- Barbara Carr, Verisma
- Dan Chavez, Santa Cruz HIO
- Grace Cordovano, Enlightening Results
- Jeff Coughlin, American Medical Association
- Tammy Coutts, EHRA
- Dave Debronkart, HL-7 Patient Engagement

- Yssa DeWoody, Ring14
- Cathriona Dolphin-Dempsey, Stanford Health Care
- John Gaines, MatchRite
- Eddie Gonzalez-Loumiet, Ruvos
- Mike Graglia, Cure SynGAP1
- Thomas Grannan, Azuba Corporation
- Joe Hernandez, BluIP
- Jen Horonjeff, Savvy Cooperative
- Nabbil Khan, Lifeline Biosciences
- Shannah Koss, Koss on Care LLC
- Allison Kozee, MRO Corporation
- Jason Kulatunga, FastenHealth
- Amy Laine, Sandwych
- Virginia Lorenzi, The New York Presbyterian
- Tushar Malhotra, eClinical Works
- Desla Mancilla, BCBSA
- Shamekka Marty, Patient/Caregiver Advocate

- Josh Mast, Oracle
- Elizabeth McElhiney, Verisma
- Chrissa McFarlane, Patientory
- Lana Moriarty, ONC Tiffany O'Donnell, MRO Corporation
- Adaeze Okonkwo, Government of DC
- Melis Ozturk, IBM
- Eric Pan, Stanford
- Josh Parker, AthenaHealth
- AJ Peterson, Netsmart
- Sam Segall, Datavant
- Paul Seville, Deloitte
- Alexis Shaner, Hawai'i Pacific Health
- Stacey Tinianov, Patient Advocate/Consultant
- Jaffer Traish, FindHelp
- Janice Tufte, Hassanah Consulting
- Brian Van Wyk, Epic
- Diana Warner, MRO Corporation
- Duncan Weatherston, Smile Digital Health
- Carol Zinder, inTandem Health

Introduction: The Sequoia Project and Interoperability Matters

Our Vision

To make the right health information
accessible at the right place and time
to improve the health and welfare of all

Connected We Stand

Sequoias are among the oldest, tallest trees
on earth. Individually, they cannot reach the
great heights of giant sequoias. Together, their
complex, interconnected root system helps
them withstand nature's forces and flourish.
Only connected can they reach great heights.
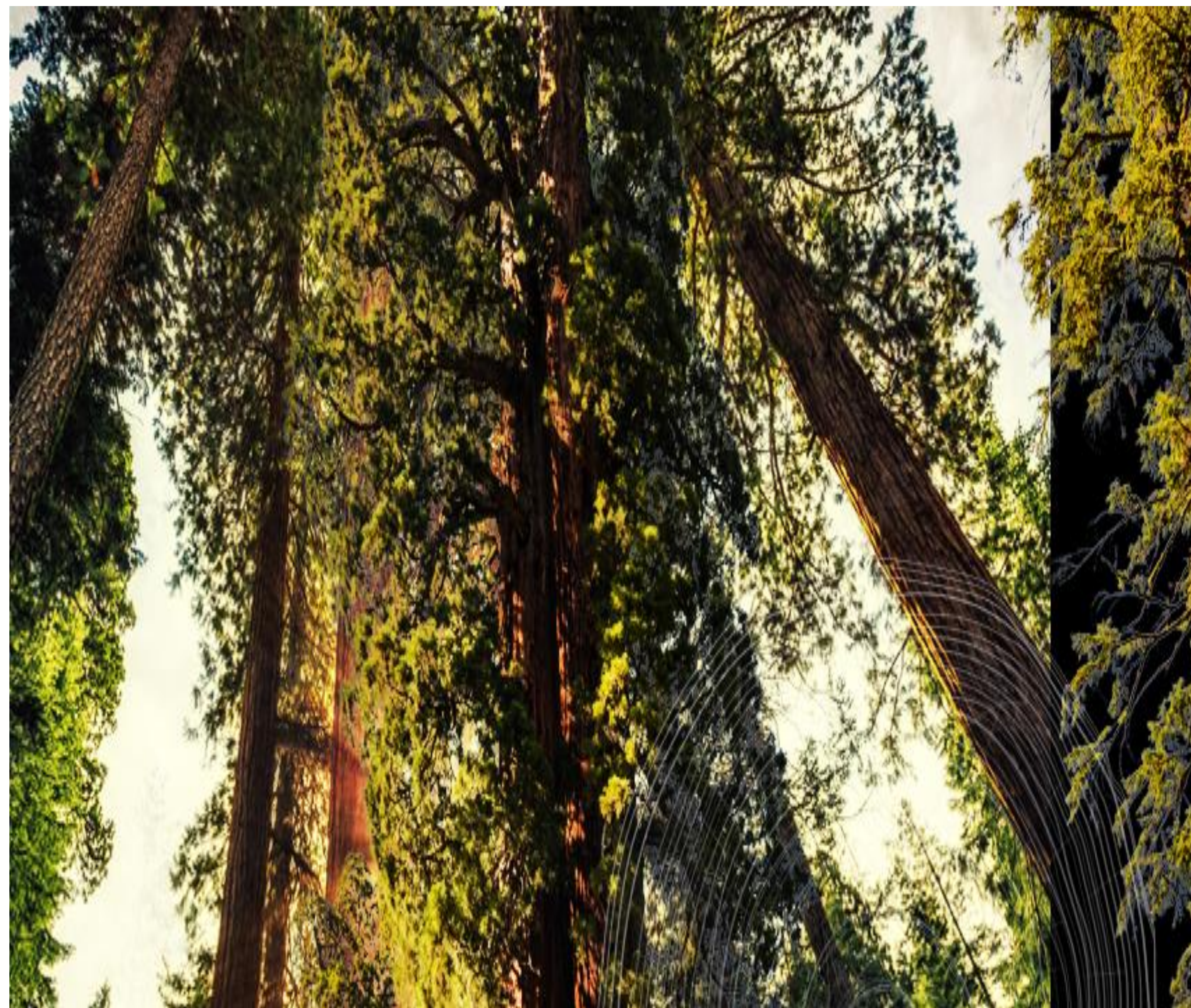
The Sequoia Project's Role

The Sequoia Project is a trusted, independent
advocate for nationwide health information exchange.

Supports multiple independent initiatives, each with their own
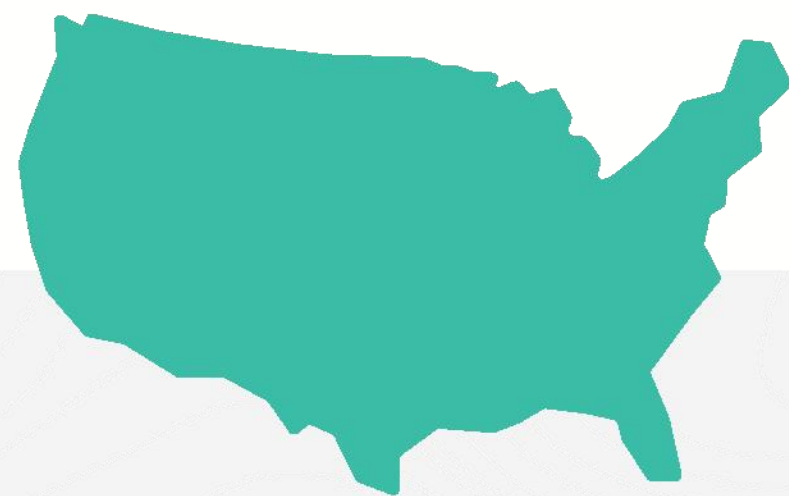mission, governance, membership and structure.

SECURE

INTEROPERABLE

NATIONWIDE

Your priorities drive our process

We set our course based on our members' challenges, barriers, gaps, and opportunities.

Identify
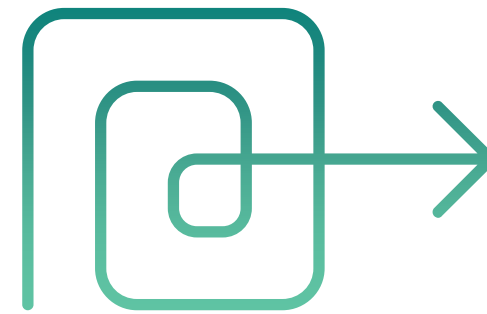
Prioritize
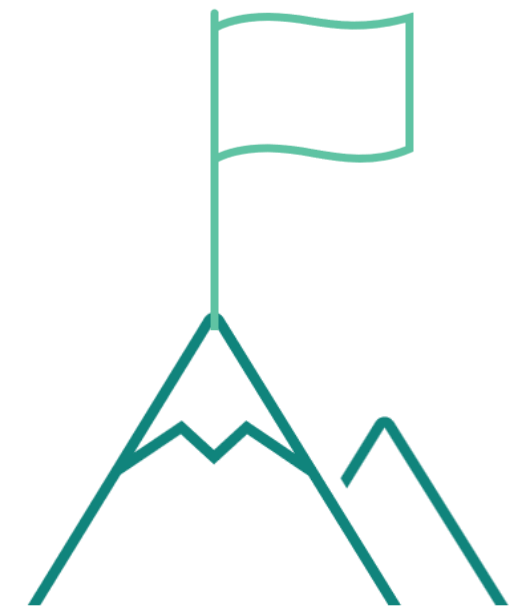
Solve

Your voice matters

You have an impact at all levels within the Interoperability Matters initiative.

Members & Stakeholders

Leadership Council

Workgroups

Public Advisory Forum

Implementation
Best Practices
Training

Actionable Guidance to Transform Interoperability for Public Good

Dialogue with Policymakers

Policy Resources

FAQs

Workgroups

- Made up mostly of **members**, but also some other **stakeholders**

- Produce **best practices, policy resources, implementation guides,** and **tools**

In Progress
- Information Sharing
- Public Health
- Data Usability
- Consumer Voices
- **Consumer Engagement Strategy** ★
- Privacy & Consent
- Payer-to-Payer API

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Implementation

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Actionable Guidance to Transform Interoperability for Public Good
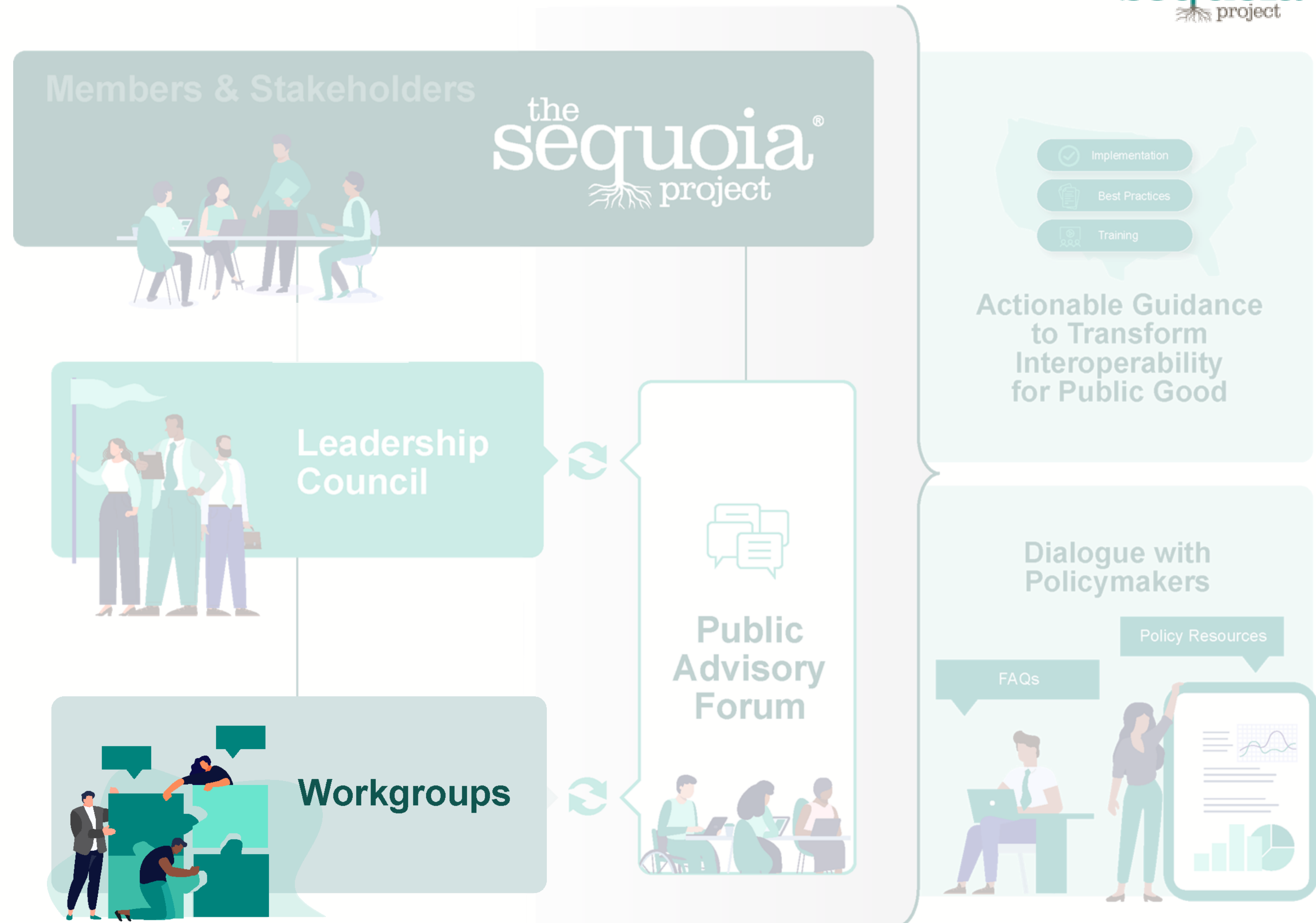
Dialogue with Policymakers

Policy Resources

FAQs

Workgroups

Workgroups	Deliverables	Impact
Information Sharing	• Interpreting and applying regulations • Best Practices	• Promote shared understanding and inform ONC frequently asked questions • Support compliance efforts
Public Health	• Catalog lessons learned from COVID response	• Findings and recommendations to improve information sharing with public health agencies
Data Usability	• Implementation guide to improve usability of data exchanged by addressing key pain points	• Consensus driven prioritized pain points • Progress towards implementing improvements to data
Consumer Voices	• Findings and recommendations on challenges individuals experiencing accessing information	• Informed future work for consumer engagement • Elevated issues to core interop community
Consumer Engagement	• Recommend what implementation steps can be taken to improve consumer access	• Engage implementation community in making incremental progress to improve access
Privacy & Consent	• Identifying gaps and challenges that could be bridged to address privacy and consent	• Inform policy makers and implementation community on key challenges and needs to support privacy and consent management
Payer-to-Payer API Implementation	• Best practices to enable payer-to-payer API implementation in support of CMS regulations	• Support payer implementation efforts for a coordinated national-level approach that reduces burden

the sequoia project ®

Interoperability matters.
Become a member and help promote information sharing for the public good.

Join at sequoiaproject.org/join

The Sequoia Project is the independent, trusted advocate for nationwide health information exchange.

Review of Charter

Broad Workgroup Charter
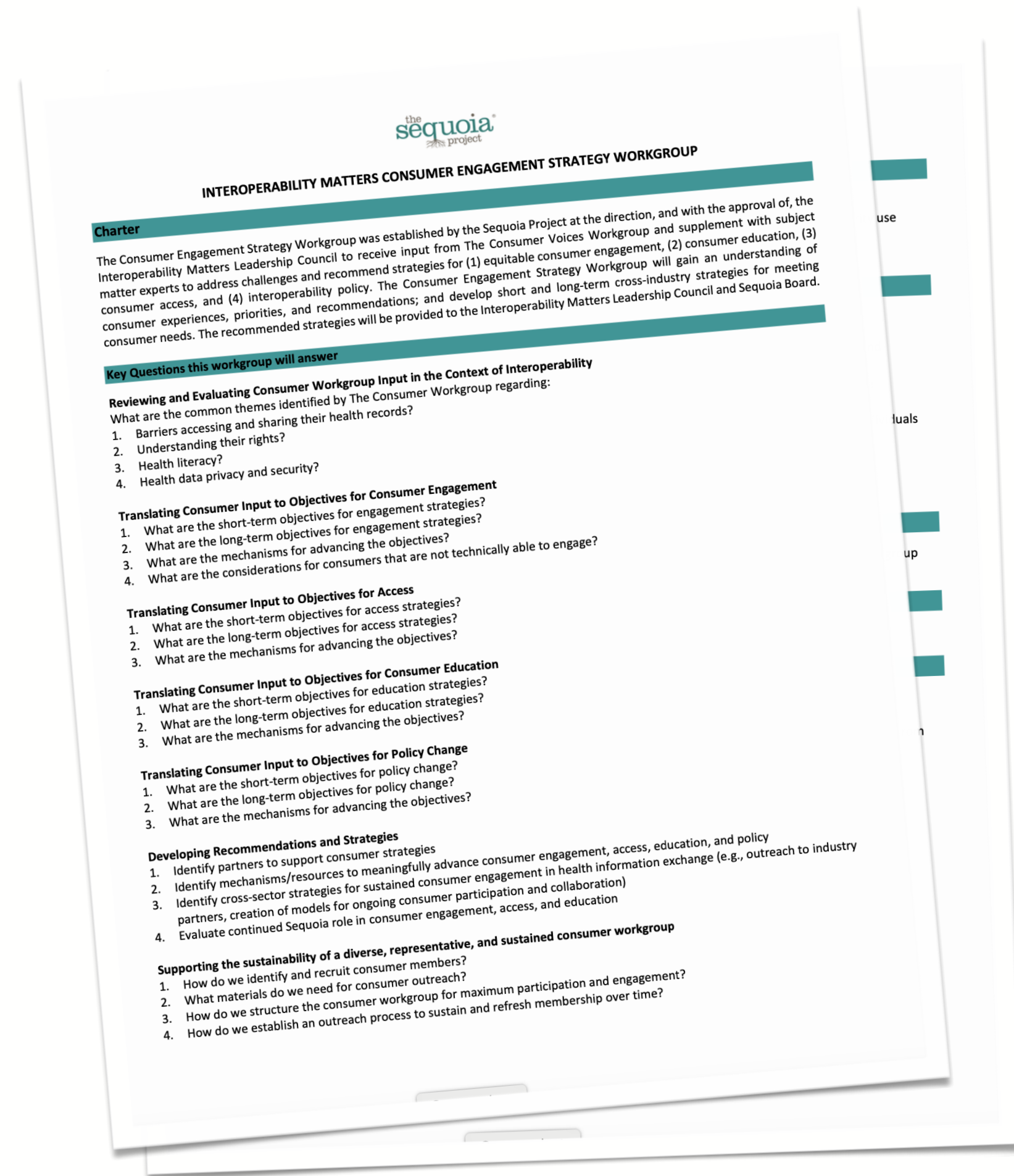
"The Consumer Engagement Strategy Workgroup will gain an understanding of consumer experiences, priorities, and recommendations; and develop short and long-term cross-industry strategies for meeting consumer needs."

Charter identifies key questions for the workgroup to explore
- Reviewing consumer workgroup input in the context of interoperability
- Translating consumer input into objectives for:
  - Consumer engagement
  - Data access
  - Consumer education
  - Policy change
- Developing recommendations and strategies
- Supporting the sustainability of consumer engagement in Sequoia work

Workgroup Deliverables
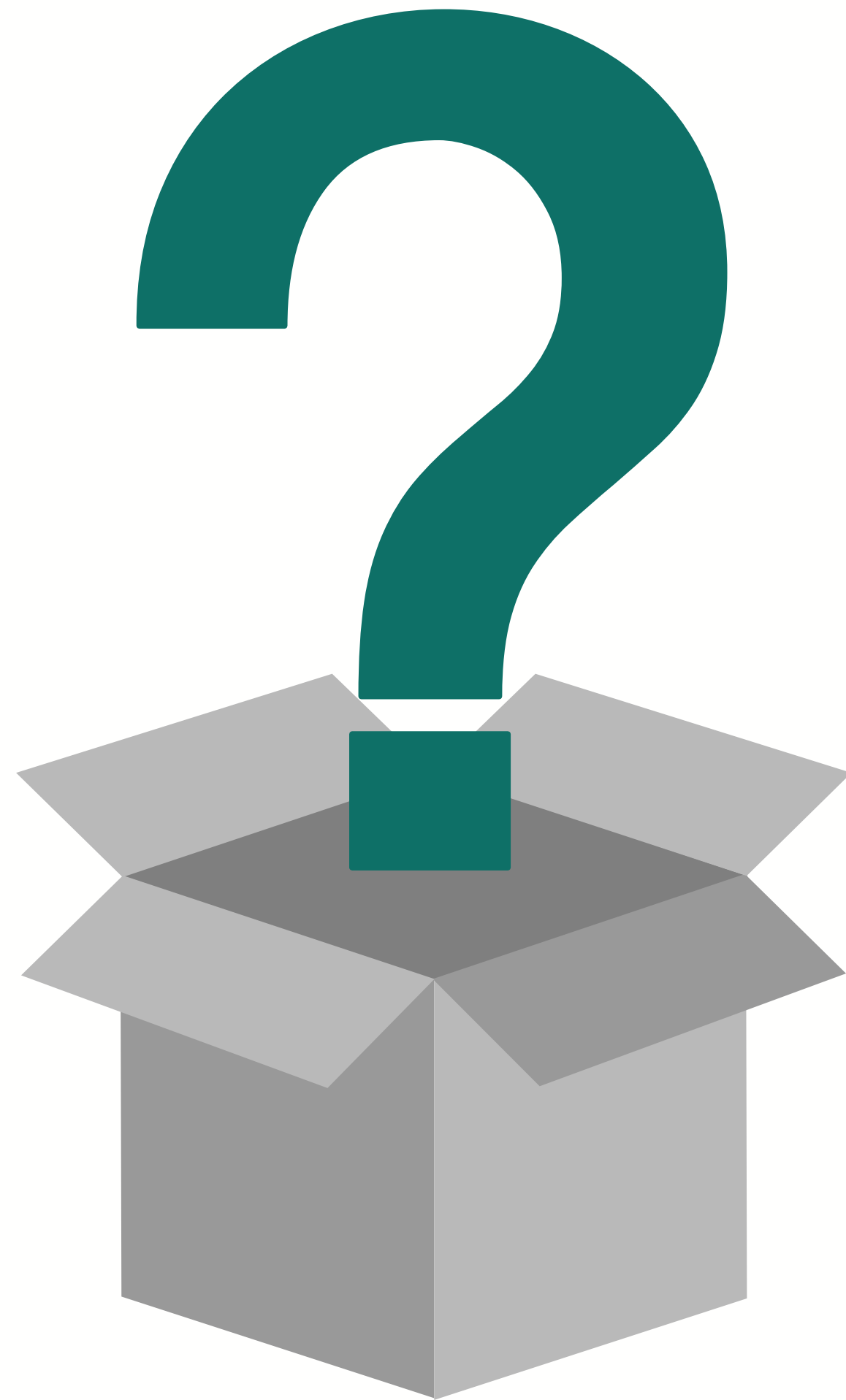
- Charter doesn't specify workgroup deliverables
- Our mandate is to make an impact that matters
  - ✓ Specific
  - ✓ Achievable
  - ✓ Measurable
  - ✓ Time-limited

Why do consumers care about data access?

Insights into patient data dysfunction

Anna's Diabetes Treatment Regimen

Devices
TDCS, TENS, EMS, Nutrition Tracker, Apple Watch, Sleep Tracker, Digital Scale, EEG, BP Monitor, Heart Rate Monitor, Insulin Pump, BGM, CGM

Labs
Neutrophils, BUN, Serum Creatinine, HDL/LDL, Calcium, Micro Albumin, HbA1C, Sodium, Potassium, Iron, Hemoglobin, Albumin, GFR

Drugs
ASPR, DXMP, TEL, KMN, SRLN, ESD, TOR, SYN, BPRN, TRVTB, EYELEA, VNFR, MHCL, NVLG, AZLST, SYMLIN, ESA, ETAB, VCTZ, DPLN

Lifestyle
Co Q10, NAC, Stress Mgmt, D3, B12, Nutrition, Folic Acid, Omega3/DHA, Strength Training, Yoga, Vit E, EGCG, Fis/Quer, Meditation, Cardio, I-Theanine, Nitric Oxide, Sleep, Probiotic, Puppies!!

Doctors
Cardio, PCP, Breast, Urologist, Opthal/Glauc, Endo, Derm, Therapist, ENT, Chiro, Nephrol, Psych, Podiatrist, Rheum, Ob/Gyn, Opthal/Retina

@theannamc

Consumer Voices Workgroup

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

the sequoia project

Documentation

Extensive interviews, recordings and quotes from patients detailing frustrations related to accessing, using, sharing and managing their health data

Recommendations

19 recommendations for accessing health records

7 recommendations for using health records

22 recommendations for sharing health records

What workgroup participants most wanted from health data?

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"*
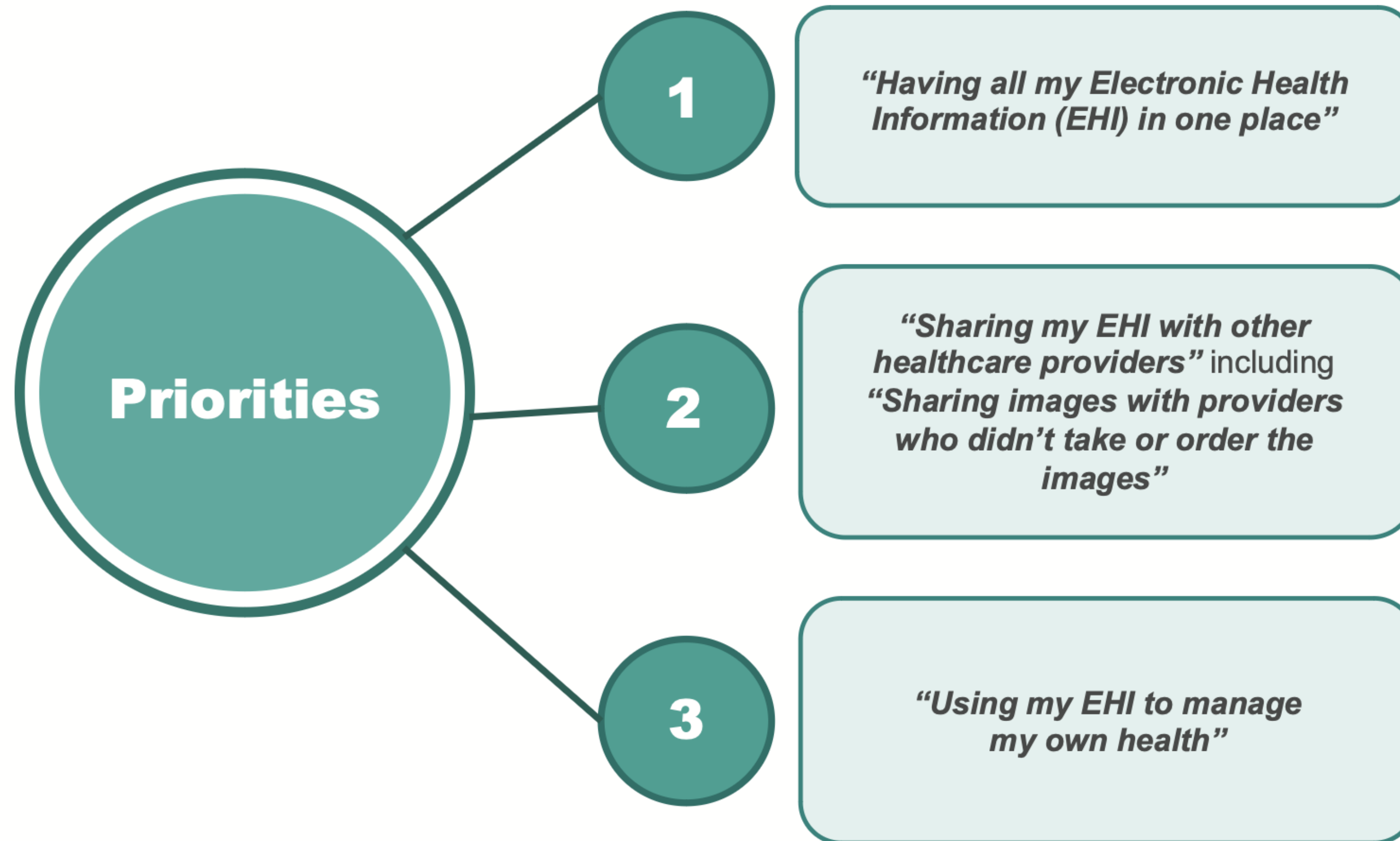
What they experienced – *Frustration*

Consumer Voices workgroup members had mixed results easily getting what they wanted online, especially when they needed to...
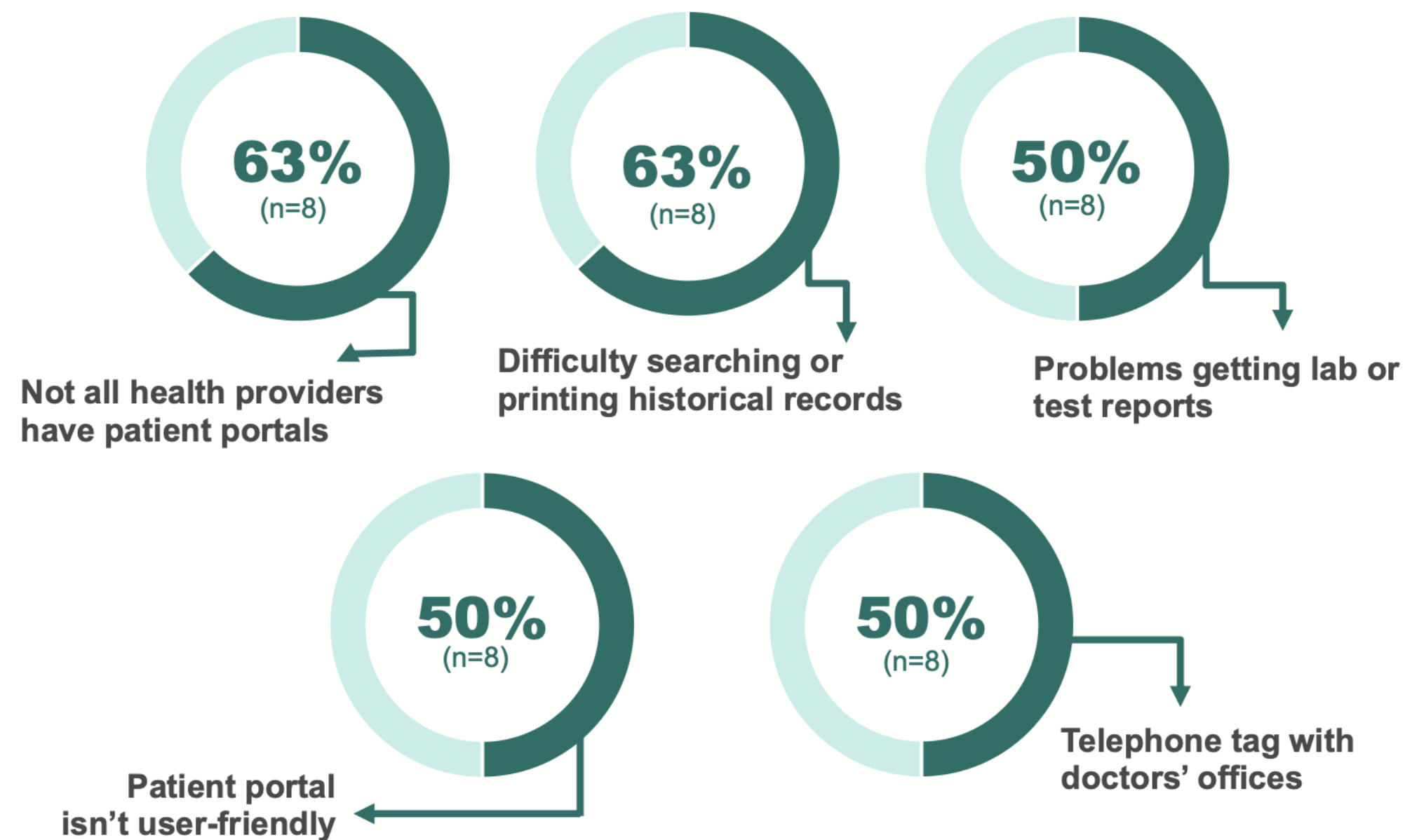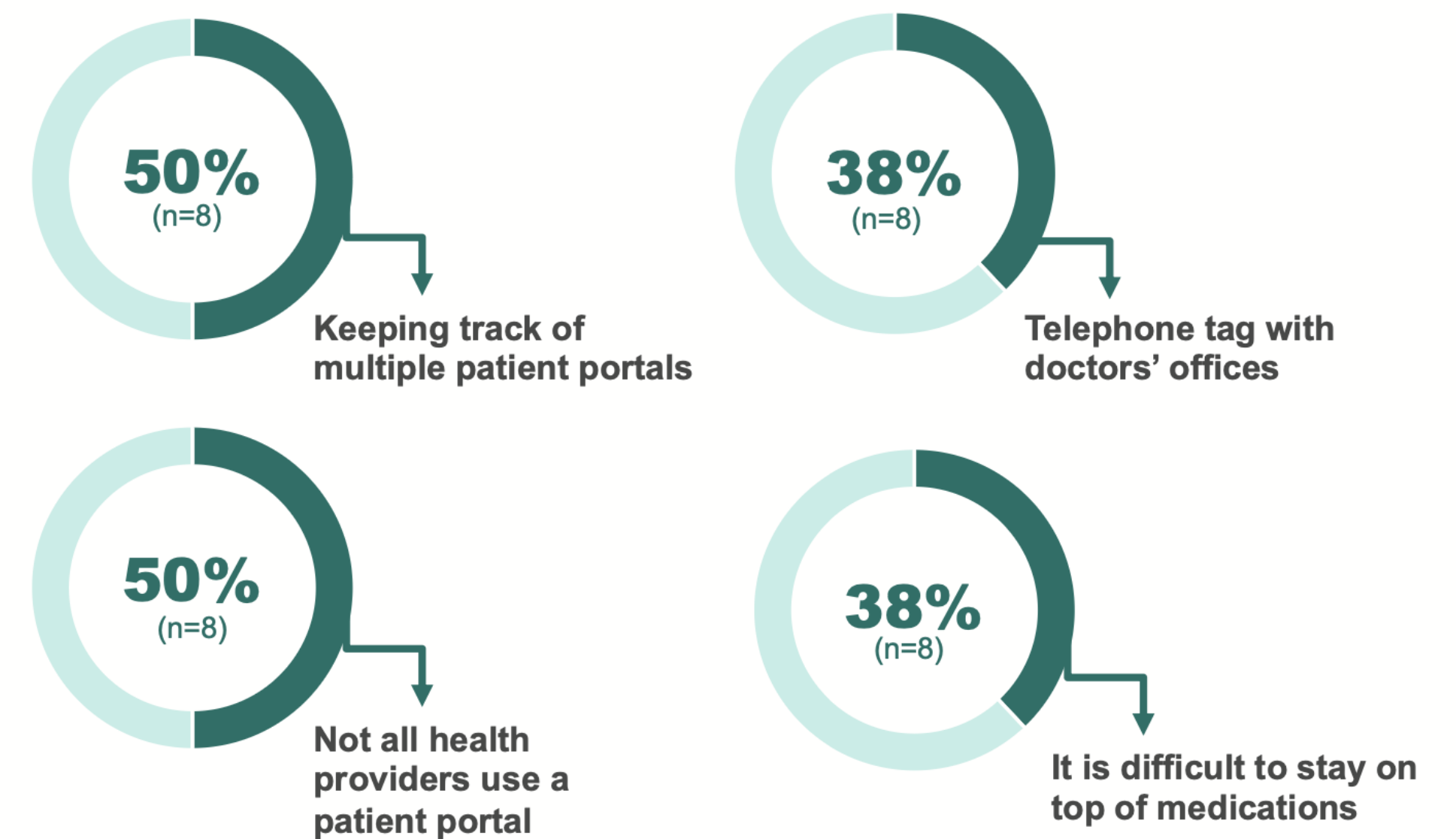- Use multiple patient portals
- Access images
- Access records as a caregiver
- Get results not available in the patient portal
- Access, search or print historical records

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

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

The Plight of the Patient

"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**."

"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…..** "

"**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. "

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

"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… "**

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

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

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

…ave 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…"**

…questing a prescription …ally went to the office in …ption desk were rows …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 … upgrade to a …

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

"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."**

"I'm **not given a HIPAA form and I don't know** if th… changed anything, but I'd want to know if they did. …

"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 …

"I keep a list of **several patient portals, user IDs, and passwords on a Google doc** that I share with family member… to keep track of all my doctors and medical records …. "

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

"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…**"

…medical **records from twelve years ago.** I …keep your records that long. I …me to access

"I wanted to … was told, O… didn't know … **the histori…**

"I found out my health record had list… **drugs I wasn't taki…** was …

- Data scattered across health systems and records
- Portals that don't meet basic requirements
- EHR errors that are impossible to correct
- ER visits due to lack of access to information
- User interfaces designed based on hospital needs
- Lack of physician access to data from other systems
- Inconsistent use of portals – no access to data
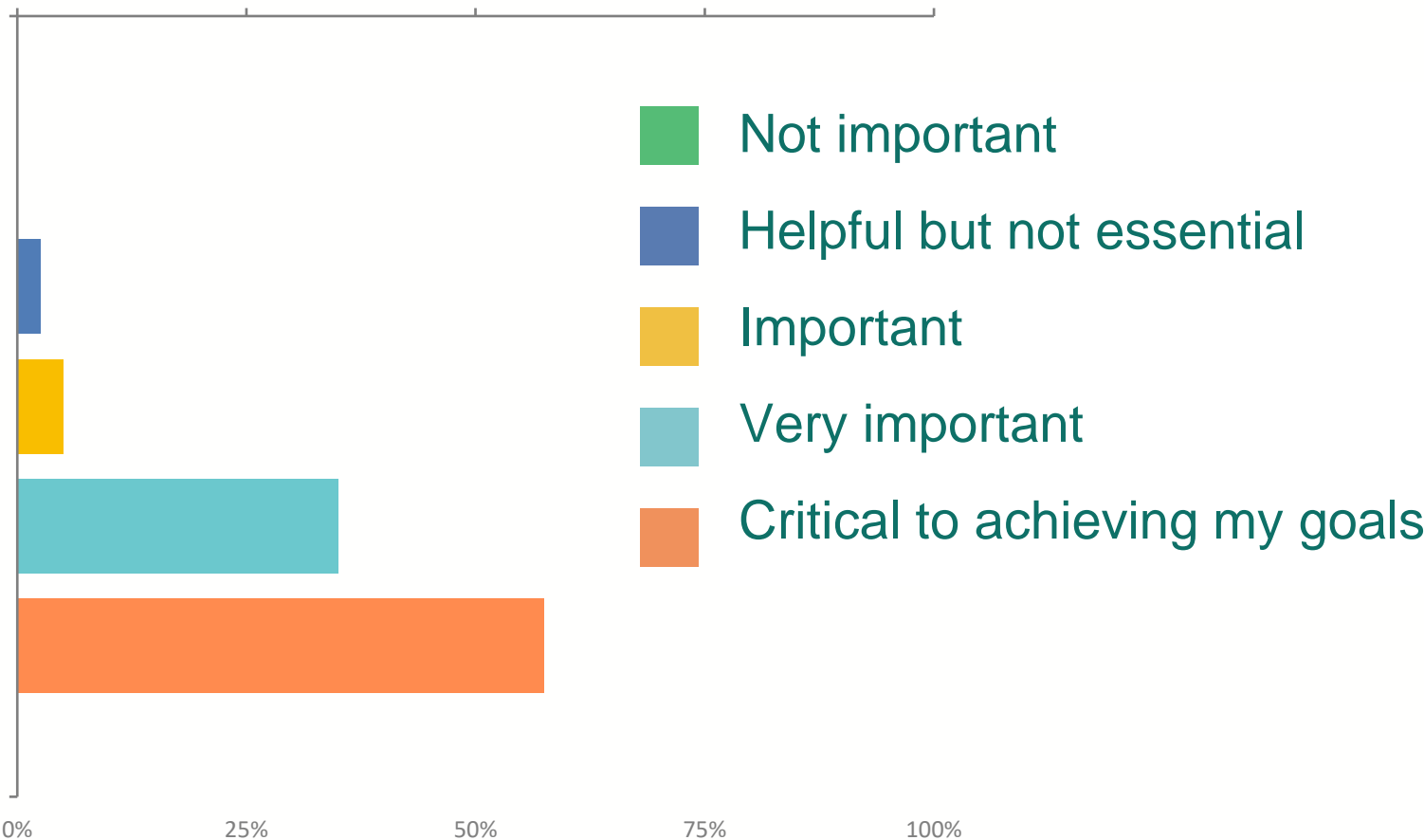- No awareness of rights or how to report violations

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
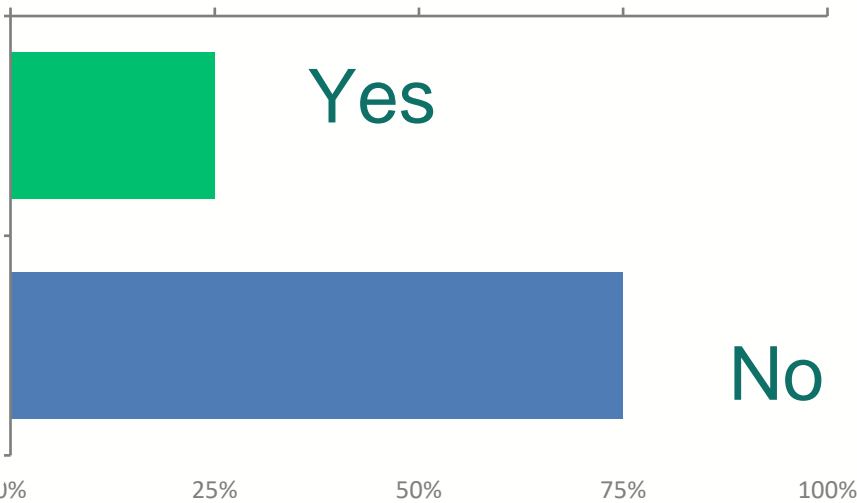
(n=8)

- Increased burden of disease
- Duplicate tests
- Canceled appointments
- Fear and frustration
- Medical errors
- Unnecessary hospitalizations
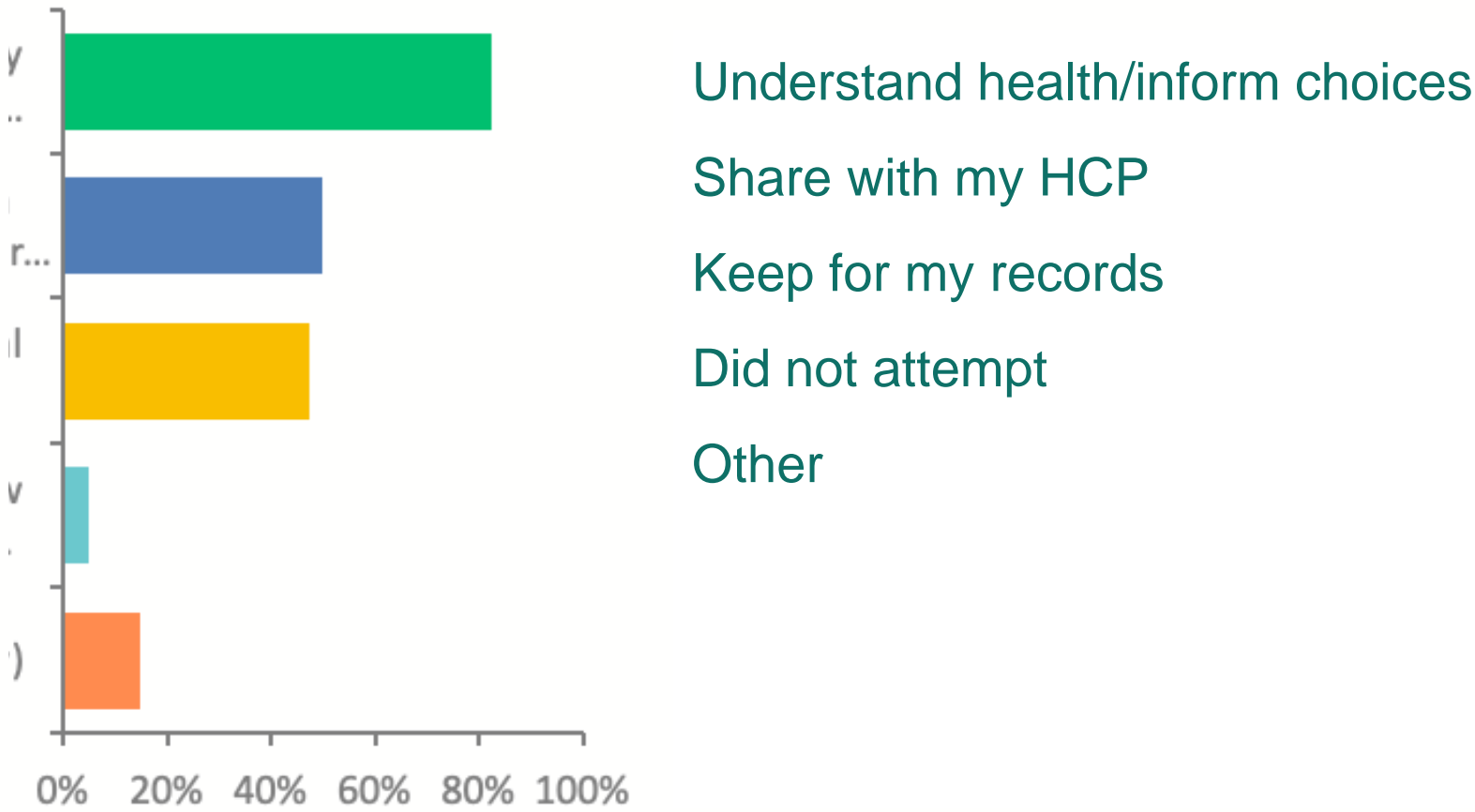
LinkedIn Survey on EHR data access

Q1: How important is it to you that you can access the electronic health records for you or your loved ones?
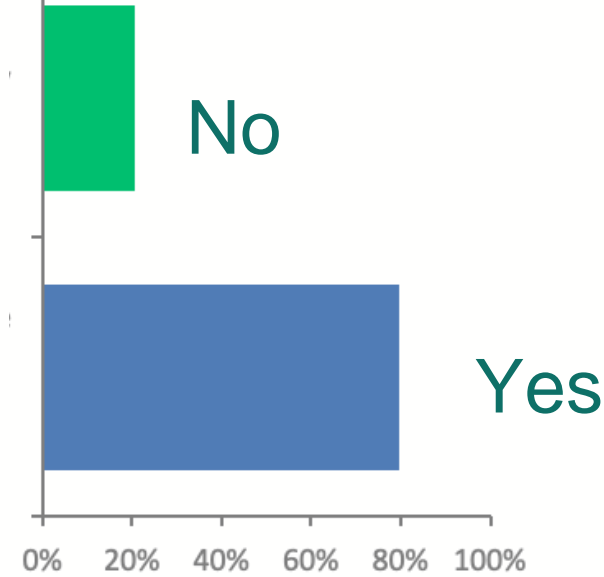

- Not important
- Helpful but not essential
- Important
- Very important
- Critical to achieving my goals

Q4: If you viewed or attempted to view your data, what was your purpose?

- Understand health/inform choices
- Share with my HCP
- Keep for my records
- Did not attempt
- Other

Q2: Are you now able to access, use and share your health data in the ways that you want?

Yes

No

Q12: Have you experienced any negative consequences caused by the inability for you or your health care provider to access your health data when you needed it?

No

Yes

25

Personal Health Data – *What Patients Need*

Personal Access

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

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

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

It's easy for me to be able to do what I need with my data to manage my health and care.

Care Team Access

All of my data is readily accessible to all of my care team 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

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

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

Usefulness

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

My information is easy to read without straining my eyes

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.

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

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

Policy landscape
The evolution of consumer access rights

HIPAA Individual Right of Access Summary(§164.524)

- Individuals (and personal representatives), have the right to access their protected health information (PHI) in one or more "**designated record sets**" maintained by or for a covered entity (CE).

- This includes the *right to inspect or obtain a copy*, or both, of the PHI, as well as to direct the covered entity to transmit a copy to a designated person or entity of the individual's choice **(3rd party directive).**

- Two categories of information are excluded from the right of access:
  - Psychotherapy notes
  - Information compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding

HIPAA Right of Access Summary(§164.524) Continued

- A CE may require a **written request** (including electronic)

- A CE must take reasonable steps to **verify identity** (164.514)

- A CE may **not impose unreasonable measures** on the individual in order to meet the above

- A CE must provide access in the **form and format** requested, if readily producible

- A CE must provide access (in whole or in part) no later than **30 days from request (**with possible 30-day extension**)**

- A CE may charge a **reasonable, cost based fee** for copies

- A CE may deny an individual's request for access under certain **limited** circumstances

HIPAA Individual Right of Access History
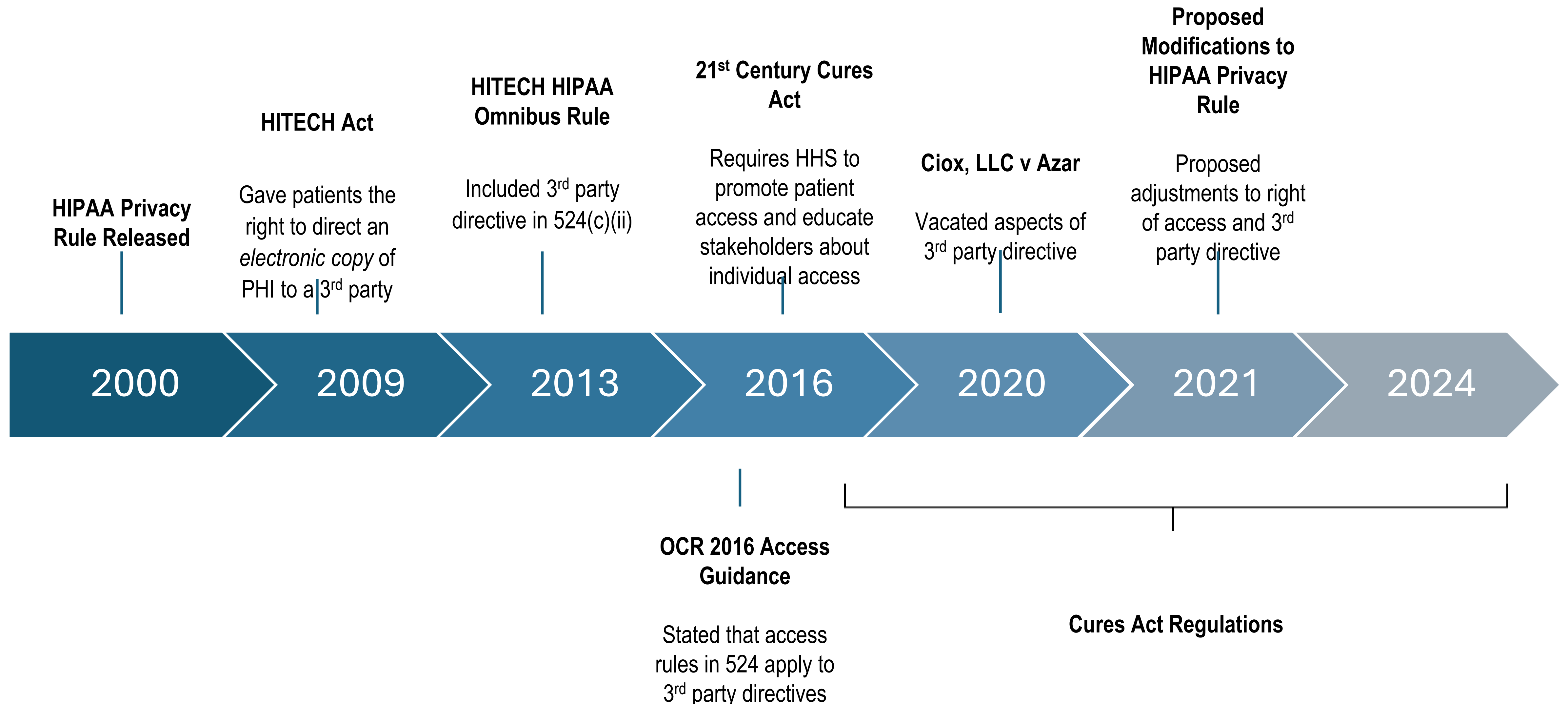
Ciox Health LLC v Azar, et al.

- *Vacated aspects of 3rd party directive*

- *Limited directive right to only electronic copies of EHI in EHR*

- *Removed Patient Rate limitations*

- *2021 HIPAA NPRM proposes to re-instate Patient Rate with modifications*

Federal Court Strikes Down HIPAA Fee Limitations for Third-Party Medical Records Requests

by: Jennifer Orr Mitchell , Jared M. Bruce of Dinsmore & Shohl LLP - Publications

Posted On Friday, January 31, 2020

RELATED PRACTICES & JURISDICTIONS

Health Law & Managed Care

Insurance Reinsurance & Surety

Litigation / Trial Practice

All Federal

D.C. Circuit (incl. bankruptcy)

https://www.hhs.gov/hipaa/court-order-right-of-access/index.html

21st Century Cures Act Regulations

2019: ONC 2015 Edition Cures Update

- New certification criteria that allow patients to access their Electronic Health Information (EHI) through an API
- Information blocking reinforced patient ability to access EHI through app of their choice

2019 & 2023: CMS Patient Access, Interoperability, and Prior Authorization Rules

- Requires regulated health plans to publish a Patient Access API to make information available to patients via the app of their choice

Trusted Exchange Framework and Common Agreement (TEFCA)

- Establishes Individual Access Services (IAS) as an exchange purpose and requires response

OCR Right of Access Enforcement Initiative

- Launched in 2019
- *44 settlements & 2 Civil Monetary Penalties to date*

Most Common HIPAA Violations In OCR-s Enforcement Actions (2020-2023)

Violation	Count
HIPAA Right Of Access	45
Risk Analysis	13
Reviews Of System Activity	5
Notice Of Privacy Practices	4
Risk Management	4
Audit Controls	3
Business Associate Agreements	3
Appointment Of A HIPAA Privacy Officer	2
Impermissible Disclosure On Social Media/Internet	3
Lack Of Technical Safeguards	3
Technical And Nontechnical Evaluation	3
HIPAA Privacy Rule Policies	2

THE HIPAA JOURNAL

OCR fines 11 healthcare orgs for HIPAA right-of-access cases

"It should not take a federal investigation before a HIPAA-covered entity provides patients, or their personal representatives, with access to their medical records," said OCR Director Lisa J. Pino.

By **Healthcare IT News** | July 18, 2022 | 04:11 PM

https://www.hipaajournal.com/state-of-hipaa/

What are the challenges ahead?

- Waiting for final rule on HIPAA Privacy proposed modifications

- Patients have more access to 3rd party apps but still need to connect organization by organization

- Patient needs to have and remember their provider credentials

- Challenges with demographics

  - Health systems/vendors use different algorithms with different demographics

  - Algorithms are biased

  - IAL2 verification requires permanent address or government issued ID

- Covered Entities risk HIPAA Breach for disclosing incorrect patient information to a non-HIPAA entity

- Varying interpretation about when a BAA is necessary (e.g., when the requestor is performing identity verification for the individual)

How do we make it happen?

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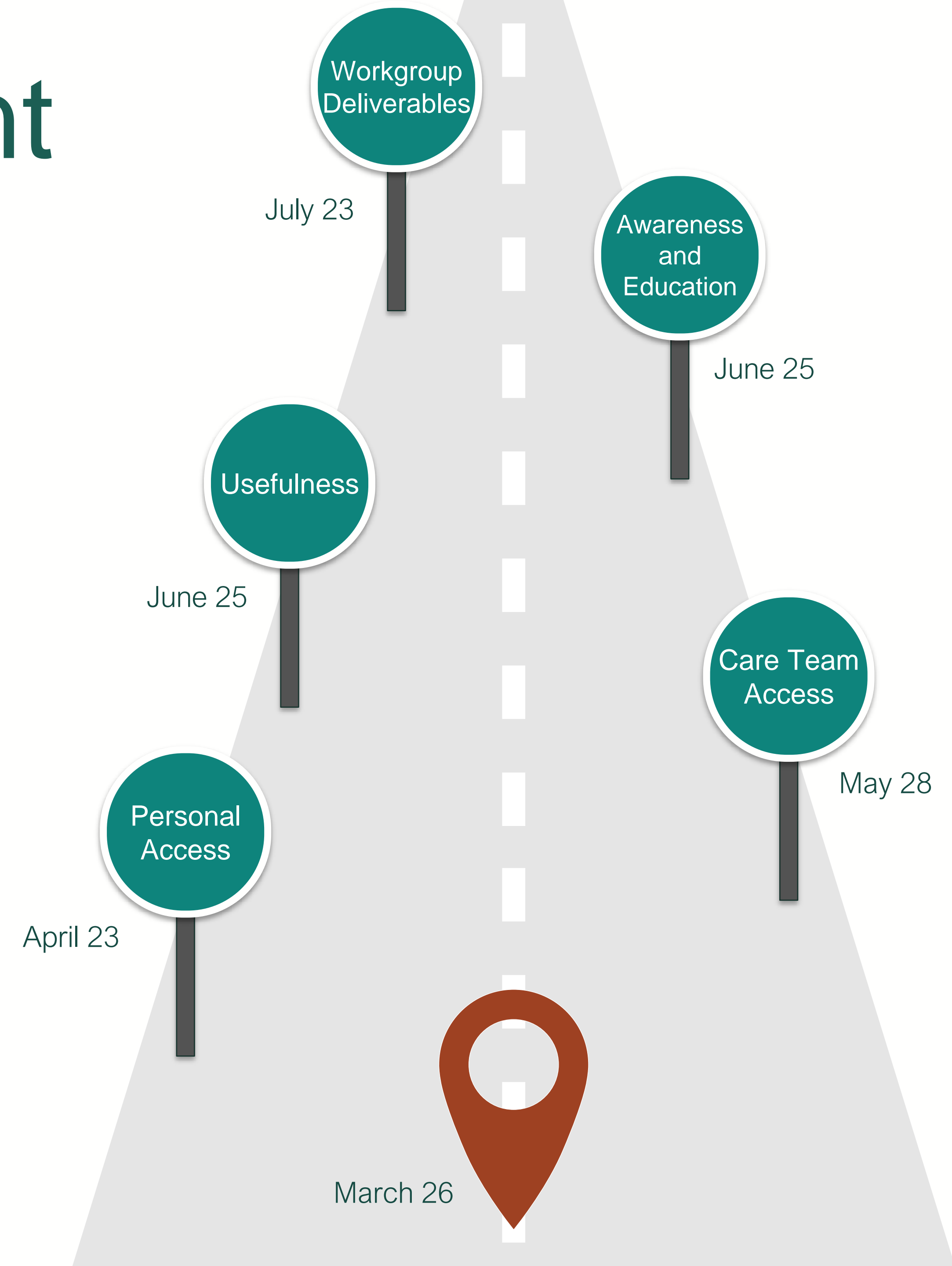
Open Discussion

Consumer Engagement Strategy Workgroup

Our roadmap

Your homework!
✓ Google form survey
✓ Send bio to Amber Nava

Workgroup Deliverables
July 23

Awareness and Education
June 25

Usefulness
June 25

Care Team Access
May 28

Personal Access
April 23

March 26

Contact Us

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amccollister@sequoiaproject.org

For additional information visit our website.