



Interoperability  
**MATTERS**

an initiative of The Sequoia Project

# Consumer Engagement Strategy Workgroup

## Kick-Off Meeting

*May 28, 2024*

the  
**sequoia**<sup>®</sup>  
project

# Meeting Agenda

- Welcome – 2 minutes
- Workgroup charge – 5 minutes
- Presentation by ONC Director Micky Tripathi – 45 minutes
- Open Discussion and Q&A – 30 minutes
- Meeting wrap up and next steps – 5 minutes

# 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

# Workgroup Charge

# Consumer Engagement Strategy Workgroup



## Workgroup Vision

Make health data work better for consumers!

## Workgroup Goal

Work collaboratively to develop tools, propose solutions and recommend actions needed to ensure consumers can access, use and share their electronic health data in ways that will decrease patient workload and burden.

# 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

# Meaningful data access and use: Getting “there” from “here”

---

*Potential solutions for consumers’ biggest data pain points*

# Consumer Engagement Strategy Workgroup – How it will work

1

## Forming

- **Purpose** – what are we hoping to change?
- **Composition** – Who is participating?

2

## Norming

- **Process** – what should workgroup members expect?
- **Requirements** – what are workgroup members asked to do?

3

## Storming

- **Activity** – what are we doing to achieve our purpose?
- **Deliverables** – what are we going to produce?

We are here!

March

April

May

June

July

August

September

### Meeting One

*Workgroup Kickoff – Setting context*

- How does health data dysfunction impact patients' lives?
- What are the key needs that need to be addressed to make data work for patients?

### Meeting Two

*Deep Dive – Personal Access/Use*

- What does federal health IT policy dictate about personal access to health data?
- What are the barriers faced by a PHR company?

### Meeting Three

*\*\*Special Guest Facilitator – Barriers and Solutions to Personal Access*

- What are the specific policy and technical barriers preventing consistent personal access?
- What are the solutions?

### Meeting Four

*Deep Dive – Care Team Data Access*

- What is the current status for interoperability?
- What type of data is being exchanged and is it what we need?

### Meeting Five

*Deep Dive – Data Usefulness*

- Does the data that my HCP and I access serve my needs?
- What would application of best practices produce?

### Meeting Six

*Deep Dive – Awareness and Education*

- What are the specific rights to access and how do patients learn about their rights?
- What can patients do if their rights aren't being fulfilled?

### Meeting Seven

*Workgroup deliverables*

- Summarize needs, barriers and solutions from worksheet
- Review and decide upon recommended solutions

Worksheet Contributions





## Contact Us

[interopmatters@sequoiaproject.org](mailto:interopmatters@sequoiaproject.org)

[amccollister@sequoiaproject.org](mailto:amccollister@sequoiaproject.org)

For additional information visit our [website](#).

## Sustainability & You: A Call to Action for Workgroup Participants

The Sequoia Project is a 501c(3) non-profit working to improve interoperability for the public good. The Interoperability Matters Program -- including this workgroup -- is made possible in part by member dues.

Please help us sustain the impact of our collective work by **identifying potential funding sources** that believe, like you do, in the power of cross-industry convenings to solve shared problems.

Perhaps your organization has a corporate foundation, or you are aware of relevant grantors or associations that may want to get behind this work.

**Drop us an email at [InteropMatters@sequoiaproject.org](mailto:InteropMatters@sequoiaproject.org)**