Interoperability MATTERS

an initiative of The Sequoia Project

Consumer Engagement Strategy Workgroup

March 25, 2025

the sequoia project

CESWG Meeting Agenda – March 25, 2025

- Welcome – and workgroup charge
- Overview – Workgroup action plan
- Tool Kit Element Discussion
  - Patient Data Rights – Deven McGraw
  - Electronic Health Information Compendium – Tammy Coutts
  - Fees Guidance – Brandi Ryan-Cabot
  - Proxy Access – Deven McGraw
  - Adolescent Data Policies – Virginia Lorenzi, Vicki Giatzikis
  - Portal Data Access – Joe Hernandez
  - Historical Data – Duncan Weatherspoon
  - Data Access Options – Duncan Weatherspoon
  - Data Format Options – Duncan Weatherspoon
  - Design Guidance – Cathriona Dolphin-Dempsey
  - Implementation Tools – Cathriona Dolphin Dempsey
  - Search Term Mapping – Eric Pan
- Meeting wrap up and next steps

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
- David Corso, Azuba Corporation
- Jeff Coughlin, American Medical Association
- Tammy Coutts, EHRA
- Dave Debronkart, HL-7 Patient Engagement
- Cathriona Dolphin-Dempsey, Stanford Health Care
- Tina Feldmann, eHealth Exchange
- Eddie Gonzalez-Loumiet, Ruvos
- Katie Goulette, MiHIN
- Mike Graglia, Cure SynGAP1
- Thomas Grannan, Azuba Corporation
- Joseph Hernandez, BluIP
- Jen Horonjeff, Savvy Cooperative
- Gena Jarosch, MiHIN
- Chris Jones, MatchRite Care
- 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
- Shamekka Marty, Patient/Caregiver Advocate
- Josh Mast, Oracle
- Elizabeth McElhiney, Verisma
- Chrissa McFarlane, Patientory
- Deven McGraw, Ciitizen
- 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
- Aileen Rowan, Oliver Wyman
- Brandi Ryan-Cabot, Contexture
- Paul Seville, Deloitte
- Alexis Shaner, Hawai'i Pacific Health
- Sachin Sharma, JHCP
- Stacey Tinianov, Patient Advocate/ Consultant
- Jaffer Traish, FindHelp
- Janice Tufte, Hassanah Consulting
- Brian Van Wyk, Epic
- Vanessa Vogel-Farley, Global Genes
- Diana Warner, MRO Corporation
- Duncan Weatherston, Smile Digital Health
- Carol Zinder, inTandem Health

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

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 in a timely manner.

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

Happy Birthday!!

Consumer Engagement Strategy Workgroup – Our Evolving Roadmap

2025

2024

Group Activities

- Documented state of patient data dysfunction
- Explored barriers to functional PHRs
- Dove deep into current state of policy - rights and limitations
- Developed plans to create tools to enable industry to comply with existing policy

January

2025 Kickoff!

- Define best practices
- Outline tool kit elements
- Recruit volunteers for toolkit development
- Community input plans

February

Tool Kit Development

- Review and refine best practices
- Finalize leads and support for tool kit element development
- Clarify expectations for tool development
- Create process for development

March

Review drafts and prepare for community buy-in

- Review first draft of tool kit elements

April

Review materials/ prepare for community input

- Review revised draft of toolkit elements
- Discuss plans for community input

May

Review and Refine

- Report progress on community input
- Explore paths to adoption
- Solicit and identify policy recommendations

June

Release!

- Review revisions from community
- Develop industry pledge
- Refine policy recommendations

July

Review and Explore

- Explore paths to adoption
- Review/refine industry pledge content
- Prepare for toolkit/ best practices release

Enabling Change through Action

Our path to action…

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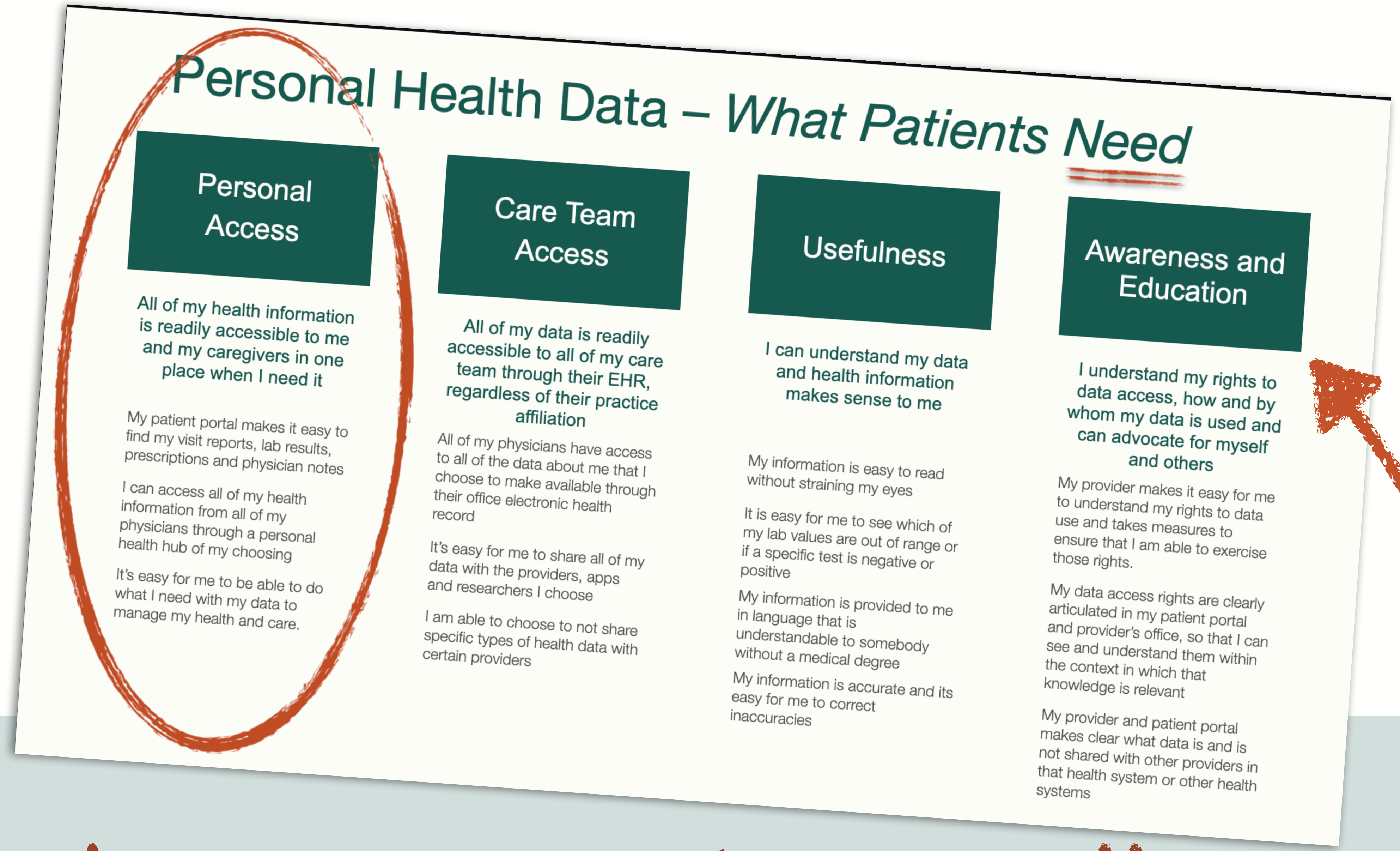

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Six Meetings focused on personal access!!

Patient access to all of their electronic health information (EHI) is a right, but …

Portals insufficient

- Provider/Industry focus
- Insufficient – subset of EHI
- Missing critical data
- Patients must interact with medical records

PHRs face barriers

- Technical barriers
- Policy/identity proofing
- Requires manual effort – difficult to scale/ automate

TEFCA still evolving

- Provider use is growing
- QHIN exchange evolving
- Patient matching barrier
- IAS through TEFCA emerging but not "real"

What can we do NOW to make patient access to their EHI easier?

We’re **Solving the “Last Mile Problem”** *for Patient Data Access*

Data Access Barriers Remain

- Barriers to patient data access are real and consequential
  - Can get some data but not all
  - Process is laborious and complex
- Patients STILL are most reliable method for sharing data among providers
  - Necessitates additional testing
  - Prevents longitudinal understanding
- Lack of access limits patient autonomy, self care and research

Policy is Mostly in Place

- 21st Century Cures and info blocking rule **requires** providers to give patients access to EHI in a **timely manner without undue delay**
  - Not well enforced
- Industry does not consistently comply with requirements for timely access
  - Not all EHI - only data in portal

Remaining Problems Operational and Logistical

- Industry focused on “certified EHR requirements” and HIPAA
- EHI access laws not prioritized
- Basic structures are in place
- Biggest issues are now logistical and procedural
  - Information
  - Process
  - Design
  - Training

We’re creating the tools to make it easier for provider practices and institutions to comply with the law!

- Best Practices guidance document
- Tool kit - make adoption easier
- Pledge - gain industry commitment
-

Moving to action

Goal – Our Desired End State

Patients facing a health crisis can readily access their personal health data in a timely manner, easily find the information they need to gain timely access and understand actions they can take if they are not given timely access

Objectives

1. Drive industry-wide excellence in facilitating timely access to all personal electronic health information
2. Give guidance to and provide materials for industry and providers on how to inform and empower patients to access their data in a timely manner
3. Actively promote and incentivize industry-wide adoption of practices aimed at enabling timely access to all personal data

Tactical plan

Best Practices

Develop industry-wide "best practices" and recommendations for providing readily accessible and obvious information to consumers about their rights to access their data

Tool Kit

Create tool kit with informational and digital assets that can be adopted by industry and placed where patients can find them in their time of need

Industry Pledge

Develop industry "pledge" to adopt recommended best practices

Policy Proposal

Create recommendation to ASTP/ONC to require placement of information in obvious, accessible location in EHR for all certified HIT

Toolkit Element – Review First Draft

Tool Kit Element – First Draft Review and Discussion

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Thank You!!

Contact Us

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amccollister@sequoiaproject.org

For additional information visit our website.