



# Consumer Engagement Strategy Workgroup

## Meeting Seven

*September 24, 2024*

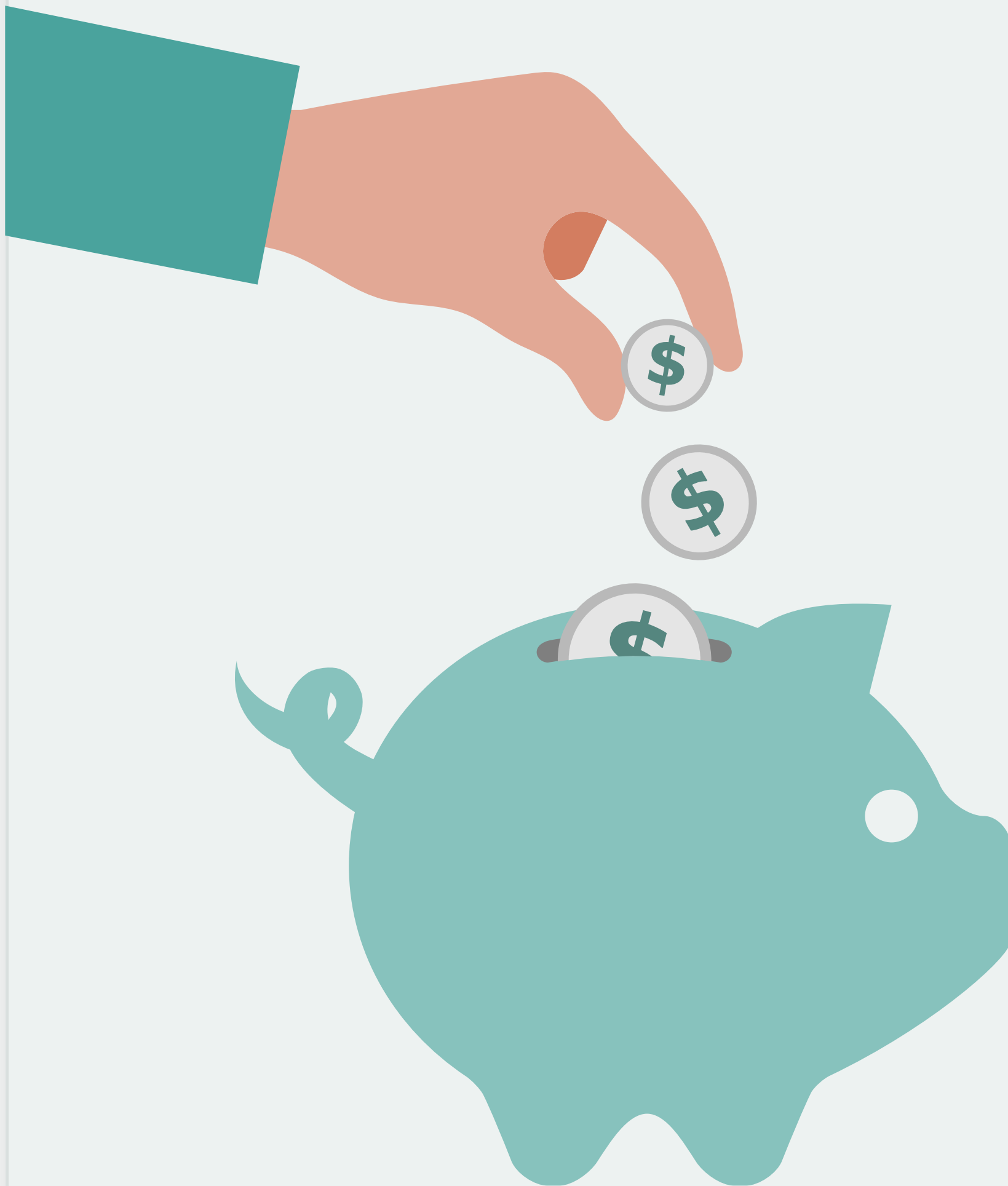
# CESWG Meeting Agenda – September 24, 2024

- Welcome – and workgroup charge
- Overview – Workgroup action plan
- Discussion and group input
- Group activity review – healthcare provider information audit
- 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
- John Gaines, MatchRite
- 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
- 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
- Sam Segall, Datavant
- Paul Seville, Deloitte
- Alexis Shaner, Hawai'i Pacific Health
- Sachin Sharma, JHCP
- Mark Smith, Altera Health
- 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

# Patient Stipends



## ***Patient participants have earned stipends!!***

- \$100/workgroup meeting
- Payable in December
- Who is eligible?
  - Primary driver of your participation is representing and communicating the voice of a “patient”
- Who is a patient?
  - Somebody whose original and/or primary interface with the healthcare system and health data policy was as a patient and/or caregiver struggling to access their data to inform personal health and care treatments and decisions
  - Participation is not directly subsidized by their job
- How to apply?
- Email Amber Nava: [anava@sequoiaproject.org](mailto:anava@sequoiaproject.org)



# 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)**





*Save  
the Date*

DECEMBER 11 2024  
**Annual  
Meeting**  
NASHVILLE, TENNESSEE

***Sponsorships Available!***



# 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

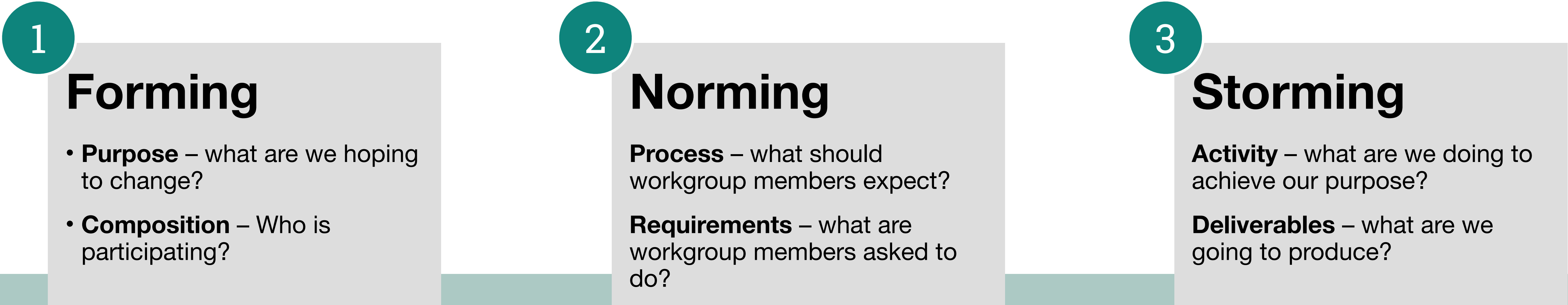
I understand my rights to data access, how and by whom my data is used and can advocate for myself and others

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.

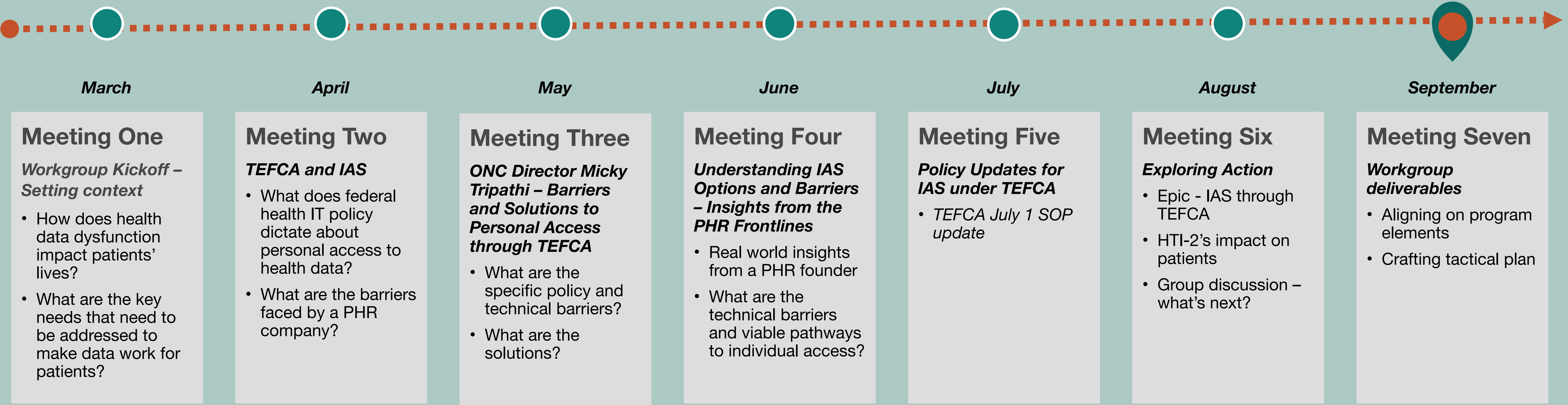
My data access rights are clearly articulated in my patient portal and provider's office, so that I can see and understand them within the context in which that knowledge is relevant

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

# Consumer Engagement Strategy Workgroup – Our Evolving Roadmap



We are here!





# Preparing For Action

## Consumer Engagement Strategy Workgroup



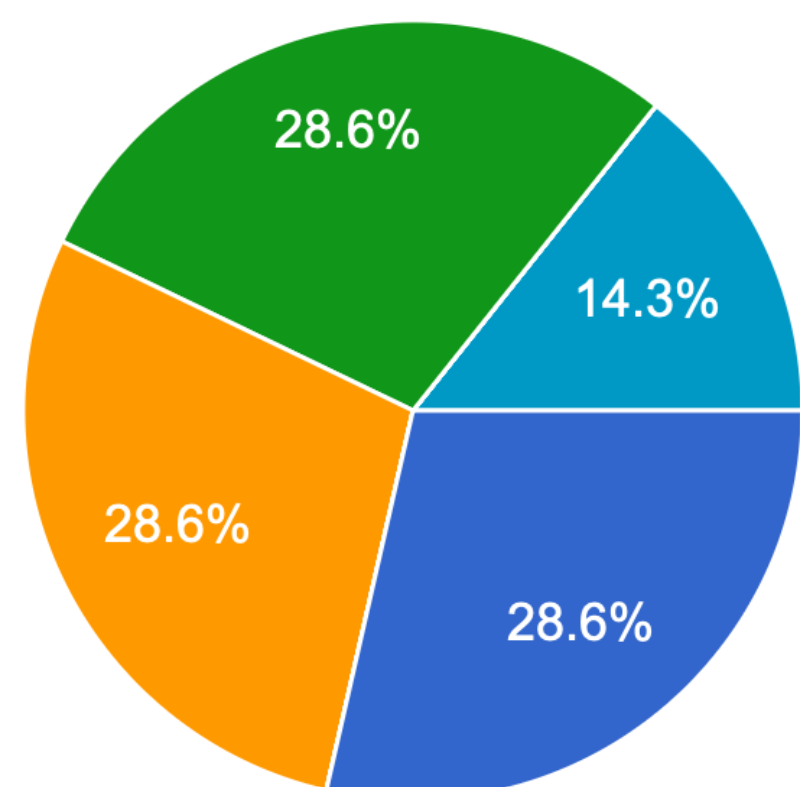
### Workgroup Vision

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.

*The survey says...*



- Develop and submit comments to the proposed HTI-2 rule, focused on elem...
- Develop and submit comments as a workgroup to the proposed USCDI V6...
- Develop a set of workgroup recommendations aimed at alleviating...
- Create informational toolkit for provider institutions, EHR companies and patie...
- Conduct survey of patients about the...
- I think multiple of these would be helpf...

## Potential options

Provide input into policy – immediate opportunities

- HTI-2 comments
- USCDI comments
- Sequoia Project data usability standards

Develop recommendations

- ASTP/ONC
- Health IT industry
- Sequoia Board

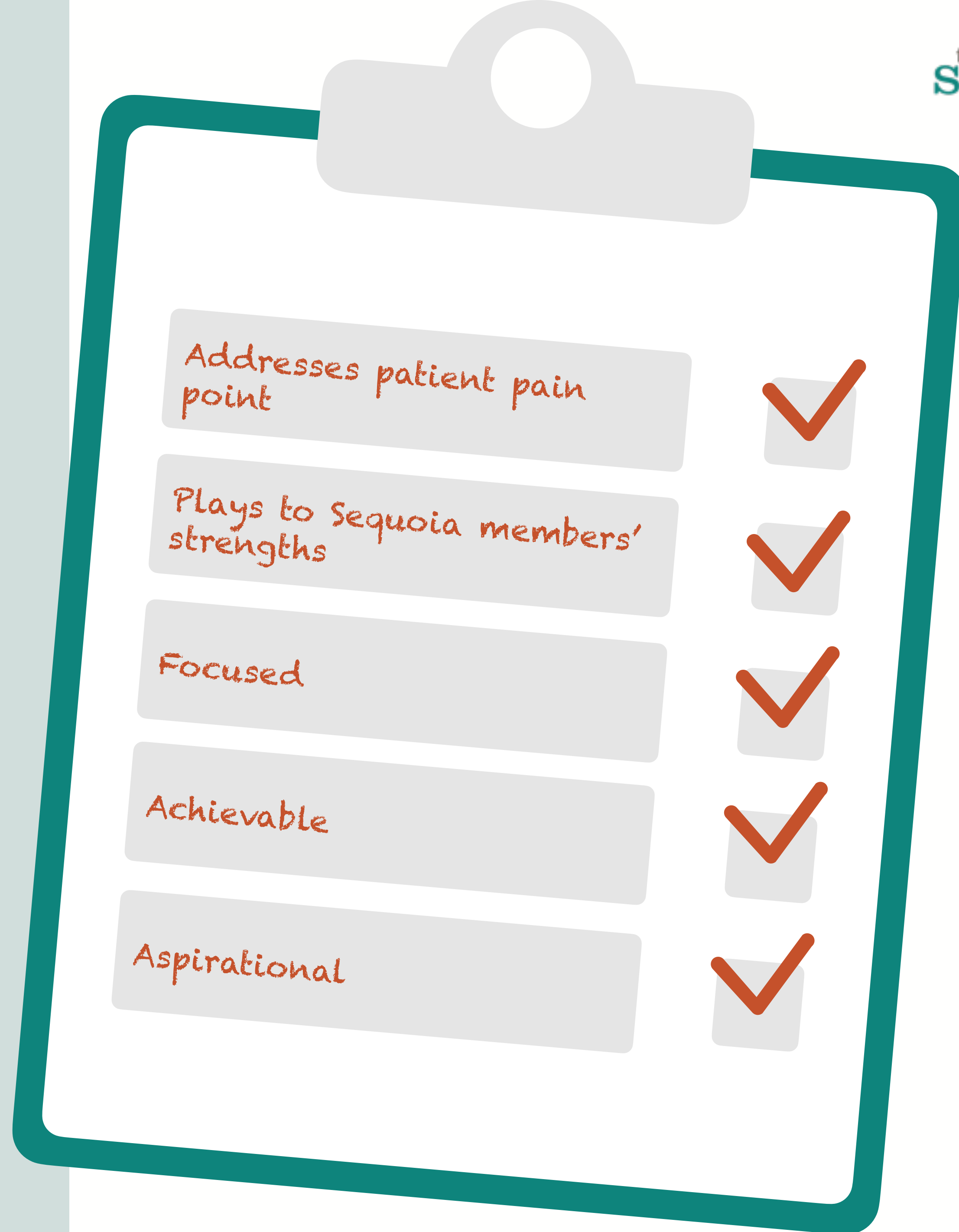
Develop informational resources

- For Sequoia Website
- Toolkits:
  - For Sequoia members
  - For patient advocacy groups

# Evaluating Options



*What might we do as a workgroup to help decrease patient workload and burden by making it easier to access, use and share data?*





# Workgroup Activity Plan

---

# Moving To Action

## Goal

*Patients facing a health crisis know how to access their data, who to contact if they can't and where to report violations of their data access rights*

## Objectives

1

Drive industry-wide excellence in notifying patients of their data access rights

2

Create materials that can be adopted by industry and advocacy groups about data access rights

3

Actively promote and incentivize adoption of data rights awareness



# 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

# Industry Best Practices – Informing patients of their data access rights

*Guidelines for providers and EHR companies for how, when and where to inform patients about their data access rights and steps they can take when they experience barriers to data access*

- Conduct an audit of how/where hospitals/providers and EHR companies inform patients of their rights to data access and steps they can take if they experience barriers to data access
- Develop recommended language/resources that should be provided to patients
- Conduct user experience testing for where to locate the information



# Patient Data Rights Tool Kit

*Tool kit of informational and digital assets that can be adopted by industry and advocacy groups about patient data rights, who to contact when issues arise and how to report violations*

- Develop succinct language that summarizes patients' legal rights to data
- Develop links for reporting data access violations to government authorities
- Create data access rights informational section for Sequoia Project's Website
- Develop digital/social graphics tool kit
- Make request to search engines to elevate information in search

## Patient Data Rights Tool Kit

*Develop industry  
“pledge” for  
Sequoia members  
and industry to sign  
agreeing to adopt  
recommended best  
practices*

- Craft pledge language
- Secure commitments from workgroup member companies to “sign on”
- Announce pledge at Sequoia project annual meeting



## ASTP/ONC Recommendation

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

*Once the other steps have been completed, implemented and adopted...*

- Send formal recommendations to ASTP/ONC requesting that future certification standards include requirement for informing patients of their data access rights in obvious location on patient data access points
- Recommendations should include requirement to list who to contact if data isn't readily accessible
- Gain support from provider institution
- Report violations to government

# Group Assignment

*Capture the current state of data access rights information*

- 1 Go to the website of your primary healthcare provider or institution
- 2 Search for where it informs you of your rights to data access
- 3 Describe the experience and respond to questions in google form
- 4 Take screenshots of location of information

## Industry Best Practices – Informing patients of their data access rights

*Guidelines for providers and EHR companies for how, when and where to inform patients about their data access rights and steps they can take when they experience barriers to data access*

- Conduct an audit of how/where hospitals/providers and EHR companies inform patients of their rights to data access and steps they can take if they experience barriers to data access
- Develop recommended language/resources that should be provided to patients
- Conduct user experience testing for where to locate the information



Thank You!!



**Contact Us**

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

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

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