# The Sequoia Project & Interoperability Matters

THSA Mini Interoperability Symposium February 13, 2025

Didi Davis VP, Informatics, Conformance and Interoperability

**Chantal Worzala VP, Strategy and Engagement** 





#### **Discussion Topics**

- The Sequoia Project Overview
- Interoperability Matters Initiative
  - Data Usability Workgroup
  - Data Usability Taking Root Movement
  - Information Sharing Workgroup
  - Privacy and Consent Workgroup



### The Sequoia Project

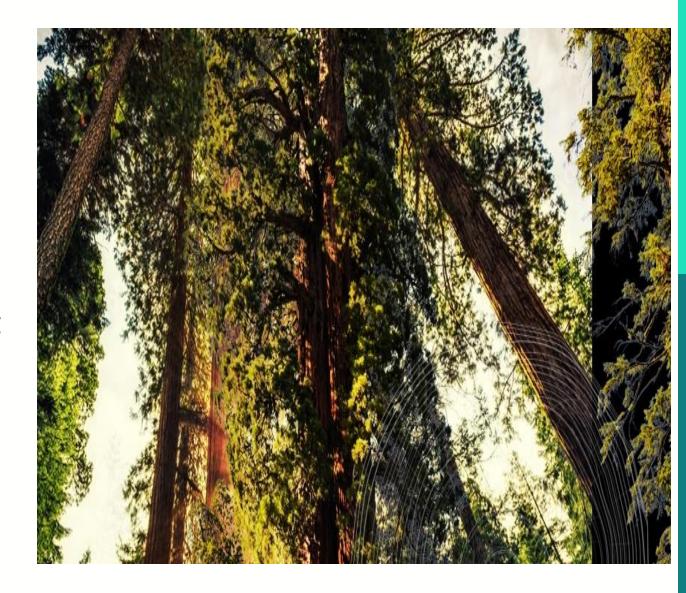
#### Our Vision



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.





#### **Our Role**

The Sequoia Project is an independent, trusted advocate for nationwide health information exchange. In the public interest we steward current programs, incubate new initiatives and educate the community.



Together, we're solving the challenges of secure, interoperable nationwide health information exchange (HIE).



#### Sequoia Members Shape Interoperability for the Public Good









































































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#### Sequoia Members Shape Interoperability for the Public Good









































































### Interoperability Matters

A public-private cooperative that solves high-impact challenges to enable nationwide health information exchange



## Your needs are our focus

We bring together diverse stakeholders in health IT and healthcare to create a community of practice.



National-level issues



Maximum stakeholder engagement



Real-world implementation

#### WORKGROUPS









TEFCA Community of Practice







**Pharmacy** 



Public Health Patient Voices

Contact Us To Learn More: InteropMatters@SequoiaProject.org

## Your priorities drive our process

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







**Prioritize** 



Solve



Interoperability Matters:

Data Usability Workgroup

#### **Data Usability Workgroup Leadership**



Adam Davis, MD, Co-chair Sutter Health



Bill Gregg, MD, Co-chair HCA Healthcare



Didi Davis, VP The Sequoia Project

#### **Data Usability Workgroup Charter**

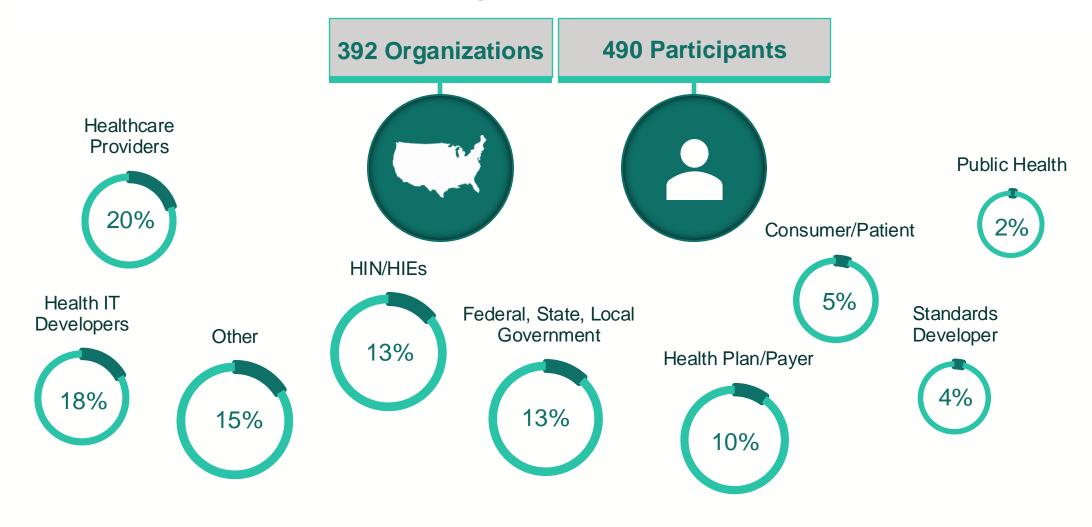
- Data Usability Workgroup Charter
- Key Deliverable:
  - Development of iterative implementation guidance focusing on Data Quality and Usability that addresses each of the following high-level use cases:
    - Provider-to-provider health information exchange
    - Provider-to-Public Health Agency information exchange
    - Healthcare entity-to-consumer information exchange
  - Must be implementable in 18 months



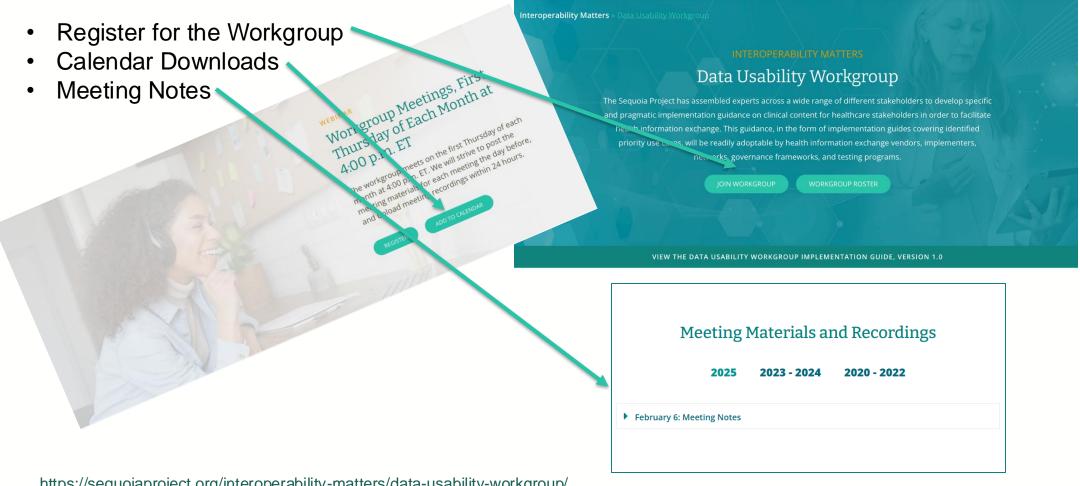
#### **Charter Purpose**

- Develop specific and pragmatic implementation guides on clinical content for healthcare stakeholders to facilitate health information exchange.
- Cover identified priority use cases, that are readily adoptable by health information exchange vendors, implementers, networks, governance frameworks, and testing programs.
- Target improvements necessary to enable semantic interoperability of health information to improve the quality & usability of data received by end users within their workflows.
- Build on existing work (e.g. AHIMA, HL7 C-CDA, LOINC, SNOMED, ONC, USCDI V1 and USCDI V3, joint Carequality-CommonWell Document Content Workgroup, etc.) and coordinate with related SDOs and industry initiatives

#### **Workgroup Members**



#### Website, Meeting and Workgroup Logistics



https://sequoiaproject.org/interoperability-matters/data-usability-workgroup/ Interopmatters@sequoiaproject.org

#### **Table of Contents**

- Executive Summary & Phases Timeline
  - Phase 1 Administration & Prioritization
  - Phase 2 IG Development
  - Phase 3 IG Public Comment
  - Phase 4 IG Publication
- Statement of Intent
- Sections/Chapters
  - Seven Topic Categories
  - Guidance with SHALL, SHOULD, MAY
- References
- Appendix A High Priority Lab Results
- Appendix B A Priority list of documents for information sharing















#### **Use Cases**

- Provider-to-provider health information exchange
- Provider-to-public health agency information exchange
- Healthcare entity-to-consumer information exchange

#### **Section / Chapter Structure**

- Problem statement
- Use Cases
- Existing Published Work
- Guidance
- Future Efforts



#### **DUWG Implementation Guide Version 2.0**

The implementation guide covers the identified priority use cases that can be readily adopted within health information exchange vendors, implementers, networks, governance frameworks, and testing programs with 18 months. Some key changes in this version include:

- Added guidance for receiving systems in addition to sending systems
- Advancing the baseline requirements from USCDI V1 (Problem, Allergy, Medications, Immunizations ONLY) to all data classes within USCDI V3
- Expanded guidance to be technology agnostic with added requirements for HL7® FHIR®, HL7 v2.x and HL7 C-CDA across the topic categories
- Added an additional topic category for laboratory

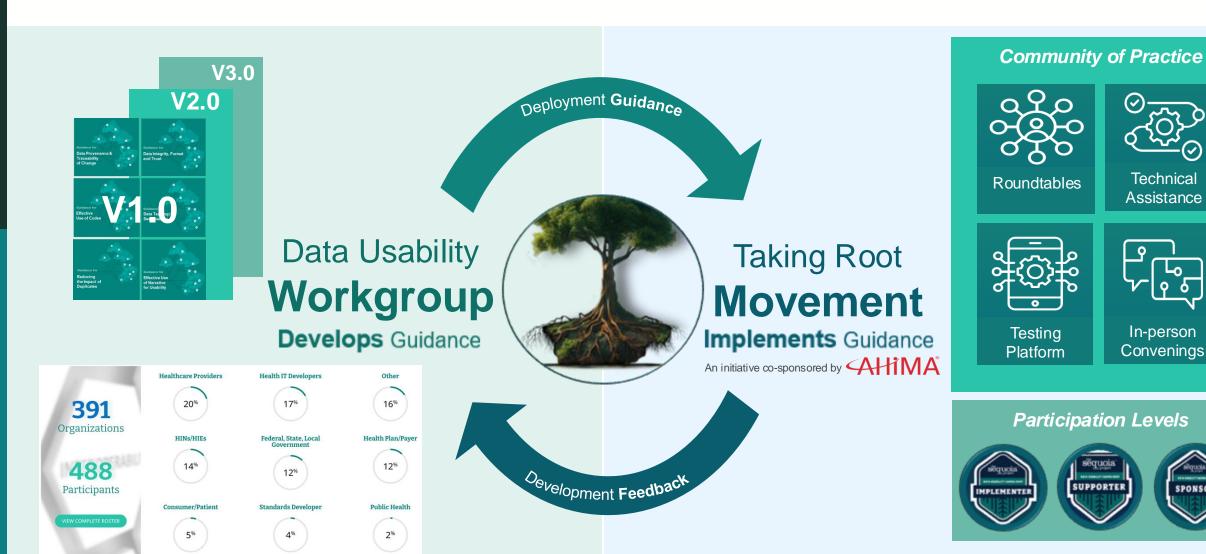


## Data Usability Taking Root Movement Thank you to our Co-Sponsor



## What is the difference between the **Data Usability Taking Root Movement** and the **Data Usability Workgroup**?

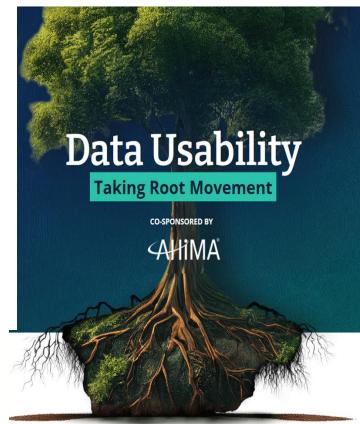




#### **Data Usability Taking Root Program**







#### Pledges Secured from Implementers & Supporters

Performance Scorecards, Technical Assistance Office Hours, Monthly Roundtables



#### Putting Guidance Into Practice

#### **Identify where to start**

- Which V1.0 sections are priorities?
- Which can be done quickly?
- What is the timeframe?

#### Track progress

- Potential self-reported score card promotes transparency and healthy competition
- # elements supported
- % of customers supporting

#### **Incremental approach**

- Enables rollout in conjunction with other IT projects
- Elevates data usability for all IT projects UAP

#### **Other Considerations**

- Leverage for governmental programs (e.g., EHR certification, USCDI, TEFCA, etc)
- Address as part of Data Usability Round Table



**Participants** choose their own implementation pathway and pace...





#### Implementation Enablers

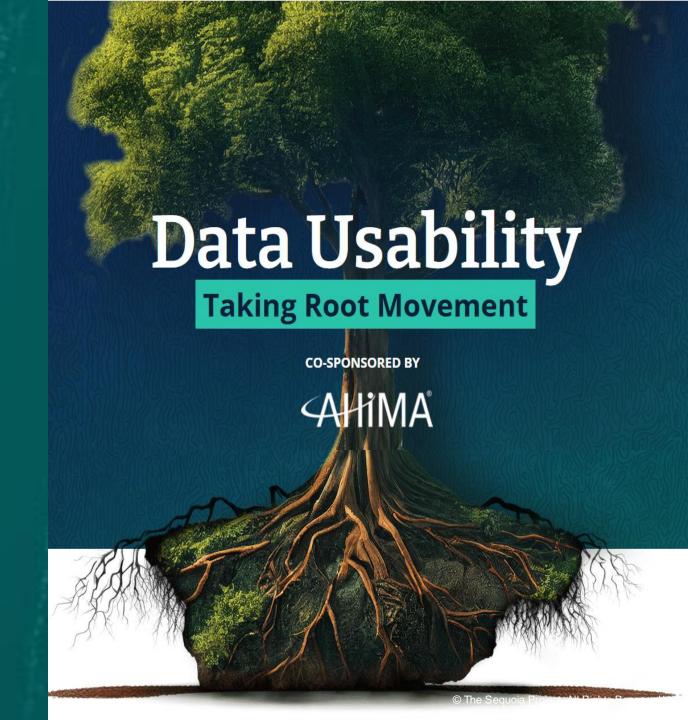




#### **Technical Assistance Needs – 2024 Focus**



It's time for data usability guidance to take root.





Information Sharing Workgroup

Information Sharing Workgroup Toolkit



- Although the Information Blocking rule was introduced in 2020, the enforcement rules were not
  effective until September 2023 and July 2024, respectively, and in 2025 we expect to see enforcement
  and action through the Office of the Inspector General (OIG) and other federal agencies
- The Information Sharing Workgroup identified a need for educational resources to support smaller organizations, as well as the broader healthcare community, that may not yet be ready for the compliance with the Information Blocking Rule
- To address this, the Workgroup developed an educational and informational toolkit
- This toolkit is free for the community and can be accessed on The Sequoia Project's webpage by any
  organization that wishes to utilize it

https://sequoiaproject.org/information-sharing-toolkit/

#### Implementation Guidance Task Group: Purpose, Structure, Process

In 2024, the Information Sharing Workgroup maintained its role in convening and educating stakeholders. The group refined its strategic direction and formed a Task Group to focus on identifying and producing concrete, actionable deliverables that add meaningful value to the stakeholder community and reflect diverse perspectives and needs.

#### Purpose:

• The Task Group focused on the completion of defined, time-bound deliverables to form a toolkit that provided specific, targeted guidance (e.g., templates, tip sheets, standardized language, etc.) for compliance with the Information Blocking Rules.

#### Structure:

• The Task Group had two Co-Chairs, Melissa (Mel) Soliz (Velatura HIE Corporation) and Matt Becker (Kno2). Subgroups were formed and met on an as-needed basis.

#### **Process:**

 The Task Group provided progress reports to the full Information Sharing Workgroup and final approval of deliverables was sought through Interoperability Matters

#### **Information Sharing Work Group Members**

#### Associations and Organizations - Health IT Community

- Jeff Coughlin, AMA
- Lauren Riplinger, AHIMA
- Matt Reid, AMA
- Andrew Tomlinson, AHIMA

#### Consumers/Data Requesters

- Jennifer Blumenthal, OneRecord
- Deven McGraw, Ciitizen

#### **Developers**

- Matt Becker, Kno2
- Leigh Burchell, Altera Health
- Alex Desilets, eClinicalWorks
- Josh Mast, Oracle Health (Co-chair)
- Elizabeth McElhiney, Verisma
- Anthony Murray, MRO Corporation
- Rosh Singh, Cozeva
- Ladd Wiley, Epic
- -Moliehi Weitnauer, MRO Corp

#### Health Information Networks & Service Providers

- Elizabeth Delahoussaye, Datavant
- Darlene Carr, New Jersey Innovation Institute
- Daniel Kim, SureScripts
- Lacey Millsap, OCHIN
- Dan Paoletti, The Ohio Health Information Partnership
- Sam Roods, New York eHealth Collaborative
- Pat Russell, eHealth Exchange
- Melissa Soliz, Velatura HIE Corporation
- Alan Swenson, Carequality

#### Healthcare Providers / Physicians

- Roberta Baranda, Valley Children's Healthcare
- Matthew Eisenberg, Stanford Health Care
- Ammon Fillmore, AdventHealth (Co-chair)
- Hilary Greer, HCA
- Steven Lane, Health Gorilla
- Lori Richter, Common Spirit
- Matthew Shafiroff, White Plains Hospital
- Sid Thornton, Intermountain Healthcare
- Virginia Lorenzi, New York Presbyterian Hospital
- Vicki Giatzikis, New York Presbyterian Hospital

#### **Payers**

- Nancy Beavin, Medica
- Kellie Greer, Evernorth
- Brian Malachowski, CVS Health

#### Legal Disclaimer

This Toolkit is not legal advice.

Please consult with your legal counsel on whether IBR applies to you or your organization and what compliance might mean for you or your organization.

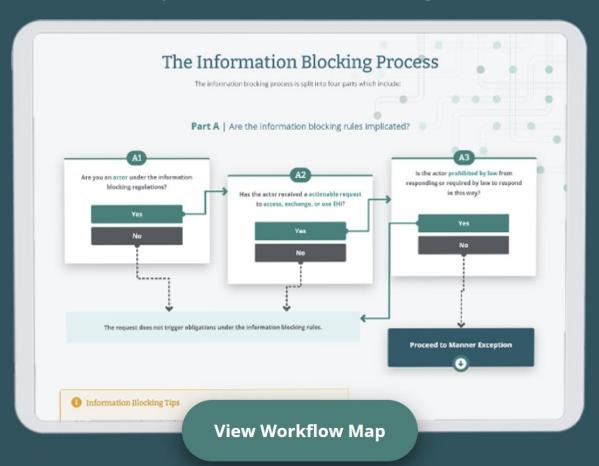
Please also note that this Information Sharing
Toolkit has not been updated with the changes to
IBR found in Health Data, Technology, and
Interoperability: Trusted Exchange Framework and
Common Agreement (HTI-2) Final Rule, and the
Health Data, Technology, and Interoperability:
Protecting Care Access (HTI-3) Final Rule

#### Information Sharing Toolkit

This Information Sharing Toolkit consists of the following informational material about compliance with the Information Blocking Rule (IBR)

#### **IBR Exception Workflow Map**

for Manner, Fees, and Licensing



#### Downloadable Resources

- Information Sharing Toolkit Summary
- Sample Information Sharing Compliance Project Tool
- Sample Information Sharing Compliance Project Tool
- Sample Information Sharing Policy (for HIPAA-regulated entities)
- Information Blocking Rule (IBR) Workflow for IBR Exceptions

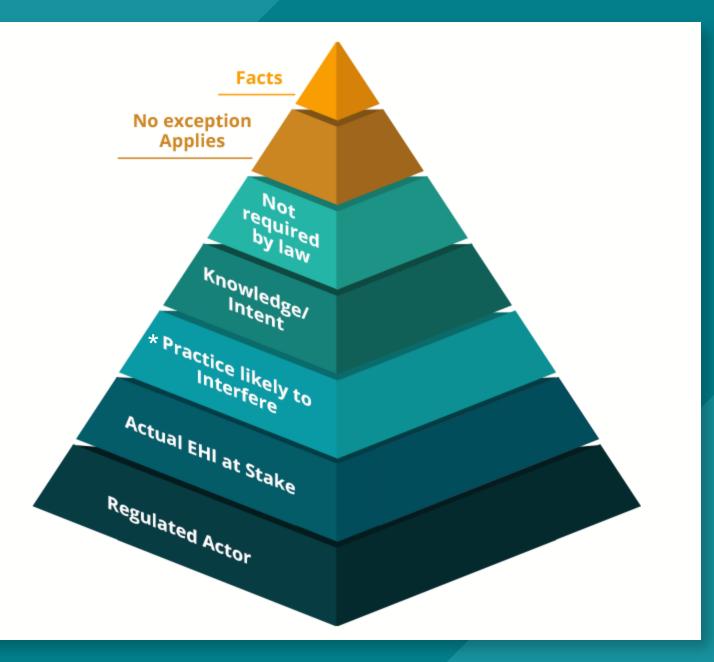


#### What Is Information Blocking?

- <u>Information blocking</u> is a (1) practice conducted by an (2) actor that is (3) not required by law or (4) covered by an applicable exception that is (5) likely to interfere with (6) access, exchange, or use of (7) EHI and that
- (i) for health IT developer of certified health IT ("developer"), health information network, or health information exchange, the actor (8) knows, or should know, is likely to interfere with access, exchange, or use of EHI; or
- (ii) for actors acting as a health care provider, the actor (9) knows is unreasonable and is likely to interfere with access, exchange, or use.
- Assessing whether a practice is information blocking turns on the <u>individual facts and</u> <u>circumstances</u>, including <u>intent</u> and whether the practice satisfies an exception. Not meeting an exception does not mean the actor is information blocking.

## Factors in Assessing Whether a Practice is Information Blocking

\*ASTP/ONC has emphasized that Information Blocking can occur even without a request, such as through a practice related to contract terms or a failure to meet reporting requirements. See this FAQ





## The Building Blocks of Information Blocking

#### (1) Practice

A practice is an <u>act or omission</u> by an actor, including responding or failing to respond to a request.

#### (4) Covered by an Applicable Exception

If a practice satisfies an <u>exception</u>, it is not information blocking. Note, however, that the fact that a practice that <u>does not satisfy</u> an exception does not mean that the practice constitutes information blocking.

#### (7) EHI

The information blocking rules only apply when the information to be accessed, exchanged, or used constitutes EHI.

#### (2) Actor

An <u>actor</u> is a health care provider, health IT developer of certified health IT, health information network or health information exchange.

#### (5) Likely to Interfere

A practice is "<u>likely to interfere</u>" if it is likely to prevent, materially discourage, or otherwise inhibit access, exchange, or use of EHI. Determining whether a practice is likely to interfere requires a case-by-case assessment of the specific facts and circumstances.

#### (8) Knows, or Should Know

A developer, HIN or HIE is engaging in information blocking only if the actor knows, or should know, that a practice is likely to interfere with access, exchange, or use of EHI. The actor must be acting with actual knowledge, reckless disregard or deliberate ignorance.

#### (3) Not Required by Law

Federal and state law may, in certain instances, require an actor to interfere with access, exchange, or use. Practices required by law do not constitute information blocking, nor does refusing to engage in practices prohibited by law.

#### (6) Access, Exchange, or Use

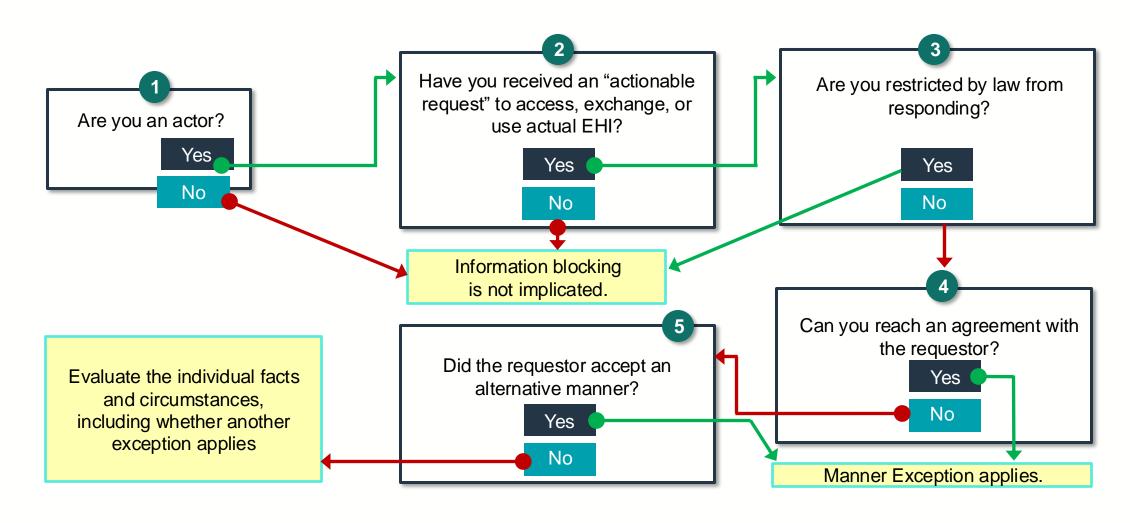
For the information blocking rules to be implicated, there must be a relationship between the practice and the need to access, exchange, or use EHI.

#### (9) Knows

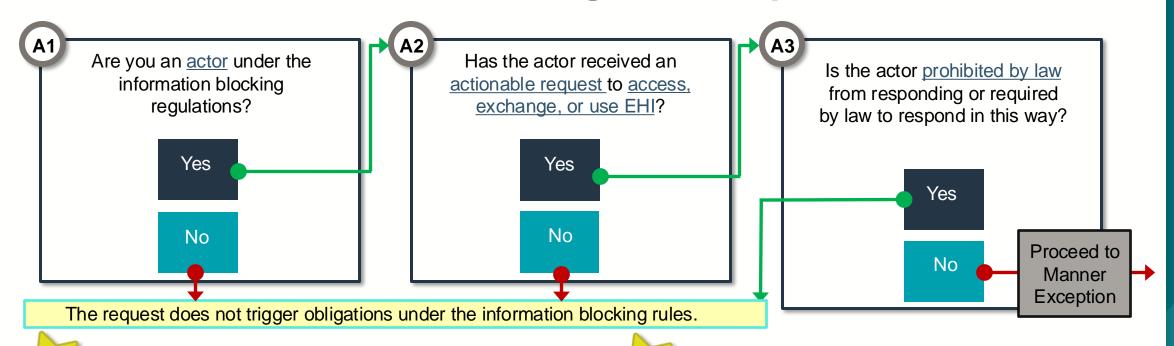
A provider is engaging in information blocking only if the actor knows that a practice is unreasonable and likely to interfere with access, exchange, or use of EHI. The actor must be acting with actual knowledge.



## **Overall Process Workflow for Evaluating Requests**



## A. Are the Information Blocking Rules Implicated?



Not every request implicates the information blocking rules; only requests that could be necessary to access, exchange, or use existing EHI ("actionable requests"). For example, a request to develop new software features or interpretive tools, or a request for non-EHI data like audit logs don't implicate information blocking.

Consider using and publicizing a standard pathway to receive requests (e.g., an intake form, web portals, dedicated email account). Train your organization to route all requests to that process. A request shouldn't be deemed actionable unless the requestor has given you enough information to evaluate the request and take action on it.

# ORGANIZATION'S INFORMATION SHARING COMPLIANCE PROJECT TOOL

This is a tool intended to assist Organization with its compliance with the Information Blocking Rule (42 U.S.C. § 300jj-52 and 45 C.F.R. Part 171) (collectively, "IBR"). It provides a step-by-step approach for identifying, assessing and addressing practices that may implicate the IBR. IBR compliance is ongoing. <u>Organization must continue to monitor, investigate and remediate IBR compliance concerns after completion of the items listed on this action plan.</u>

#### **RESPONSIBILITIES AND EDUCATION**

- •Step 1: Create an IRB Compliance Action Plan
- •Step 2: Establish an Information Blocking Workgroup
- •Step 3: Education for the IBW and its Subgroups

#### **IDENTIFY AND ASSESS SOURCES OF EHI**

- •Step 4: EHI Sources
- •Step 5: EHI Systems
- •Step 6: EHI Vendors and Partners

#### IDENTIFY AND ASSESS EHI PRACTICES-CLOSE COMPLIANCE GAPS/ALIGN WITH EXCEPTIONS

- •Step 7: EHI Practices
- •Step 8: EHI Policies
- •Step 9: EHI Contracts

#### TRAINING, MONITORING, AND ENFORCEMENT

- •Step 10: Marketing/External Communications
- •Step 11: Workforce Member Training
- •Step 12: Compliance Program and Reporting

## ORGANIZATION'S INFORMATION SHARING COMPLIANCE PROJECT TOOL

	Action Item	Primary Owner(s)	Supporting Personnel	Notes	Review ETA	Final ETA	Completed
	RESPONSIBILITY AND EDUCATION						
Step #1	<ul> <li>Create an IBR Compliance Action Plan</li> <li>Responsibility for IBR compliance and delegation of responsibilities (with deadlines)</li> <li>Education</li> <li>Identify/assess Organizations IBR actor status (more than one might apply)</li> <li>Identify/assess sources of EHI</li> <li>Identify/assess EHI practices; review for compliance gaps and alignment with IBR exceptions</li> <li>Implement compliance action items, including training for workforce members and a complaint process</li> </ul>						
Step #2	<ul> <li>Establish an Information Blocking Workgroup (IBW)</li> <li>Establish or designate Organization's IBW and define scope of IBW's purpose and subgroups:</li> <li>Take a multi-disciplinary approach on staffing the IBW (e.g., compliance, legal, clinical, business, health IT, etc.)</li> <li>Identify an executive to take ownership of compliance and coordinate activities among IBW subgroups</li> <li>Create subgroups or delegate to individuals the task of investigating and addressing specific IBR action items</li> <li>Delineate a project management process for IBW compliance (e.g., policy revision, contract revision, training, and implementation)</li> </ul>						
Step #3	<ul> <li>Education for the IBW and its Subgroups</li> <li>Provide and document training on IBR compliance for IBW and any subgroups (multiple training session may be needed)</li> <li>Schedule routine standing meetings and/or forums for IBR discussions</li> </ul>						



**Privacy and Consent Workgroup** 

Moving Toward Computable
Consent: A Landscape Review

#### INTEROPERABILITY MATTERS

## Privacy & Consent Workgroup

Established by the Interoperability Matters Leadership Council, the Privacy & Consent Workgroup will identify initial steps to further propel the healthcare community towards supporting proper information exchange that appropriately protects privacy.

# **Moving Toward Computable Consent: A Landscape Review**

In January 2025, the Workgroup published a white paper public feedback

This landscape review explains the importance of managing privacy and consent when sharing personal health information, scans the current landscape of challenges facing those entrusted with personal health information, enumerates existing solutions, and 5 explores the strengths and deficiencies of these approaches.

### **Table of Contents**

- 1. Introduction
- 2. Individual Perspectives on Privacy and Consent
- 3. Policy Challenges
- 4. Operational Challenges to Consent Management
- 5. Technology Challenges to Consent Management
- 6. Exploring Existing Consent Models and Frameworks
- 7. Conclusion
  - Call to Action

## **Timeline**

January 2024: Workgroup Kickoff

**Landscape Review / Key Pain Points Discussions** 



# Moving Toward Computable Consent: A Landscape Review

**Privacy & Consent Workgroup Whitepaper** 

The Privacy & Consent Workgroup is seeking public feedback on version 1 of the workgroup's whitepaper through **Friday**, **February 21**. The workgroup will review all feedback to be incorporated into an updated whitepaper for the community to implement.

DOWNLOAD WHITEPAPER

SUBMIT FEEDBACK

The Privacy and Consent Workgroup recently released a white paper for public feedback.

This landscape review is a first step and reflects lessons learned from a series of presentations from those working to implement privacy and consent approaches at state, regional, and local levels.

We invite your feedback to help shape the next steps!

https://sequoiaproject.org/interoperability-matters/privacy-consent-workgroup-whitepaper-feedback/

# **Call For Action**

The Privacy and Consent Workgroup calls on interested organizations in a call for action to tackle specific implementation issues that will advance the use of standards-based consent management and data segmentation for privacy so that information exchange can occur in ways that are both compliant with privacy rules and respect individuals' privacy preferences.



### **Topics to be addressed could include:**

- Guidance on organizational-level policies and workflows to improve consent management, including consideration of break the glass functionality.
- Community engagement for standardizing consent approaches (opt-in/out, granular consent, etc.).
- Community engagement on technical standards for data segmentation and consent.
- Accessing and exchanging and using standardized consent across organizations
- Consideration of how best to deploy and utilize data segmentation capability in health IT.
- Other outstanding issues to be noted.

## **Workgroup Members**

Lauren Riplinger, American Health Information Association
Andrew Tomlinson, American Health Information Association

Jeff Coughlin, American Medical Association

Britt Bohannon, Atlas Health Hub

Bart Carlson, Azuba

Devi Mehta, Blue Cross Blue Shield Association

Hannah Galvin, Cambridge Health Alliance

Deven McGraw, Citizen Health (Co-Chair)

Tatum Sihina, Contra Costa Health

Mohammad Jafari, Senior Privacy and Integration Specialist

Rosh Singh, Cozeva

Caitlin Riccobono, CRISP Shared Services

Elizabeth Delahoussaye, **Datavant** 

Susan Clark, DirectTrust

Aaron Tait, Epic

Matt Molisani, Epic

Jaffer Traish, findhelp

Hilary Greer, HCA Healthcare

Steven Lane, Health Gorilla (Co-Chair)

Julie Lowry, Henry Ford Health

Alisa Kuehn, Indiana Health Information Exchange

Matt Becker, Kno2

Dennis Giokas, Marble

Mo Weitnauer, MRO Corp

Tucker Bair, MRO Corp

AJ Peterson, Netsmart

Helen Oscislawski, New Jersey Innovation Institute

Jennifer D'Angelo, New Jersey Innovation Institute

Samuel Roods, New York eHealth Collaborative

Daniel Werlin, NextGen

Lacey Millsap, OCHIN

Tim Noonan, Office for Civil Rights (liaison)

Kathryn Marchesini, Assistant Secretary for Technology Policy (liaison)

Hans Buitendijk, Oracle Health

Laurie Peters, Orion Health

Daniel Chavez, Serving Communities Health Information Organization

Lynne Nowak, Surescripts

Melany Ginnick-Frio, Social Security Administration

Martin Prahl, Social Security Administration

Peggy Pugh, US Department of Veterans Affairs

Lynne Harbin, US Department of Veterans Affairs

Elizabeth McElhiney, Verisma

Barbara Carr, Verisma

George Bessenyei, YoCierge, Inc.

Melissa (Mel) Soliz, Velatura HIE Corporation

#### **Sequoia Staff and SMEs**

Chantal Worzala

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Didi Davis, Liaison to the Data Usability Workgroup

Anna McColister, Liaison to the Consumer Engagement Strategy Workgroup





THSA Mini Interoperability Symposium

## **Questions & Discussion**

- https://sequoiaproject.org/
- https://sequoiaproject.org/interoperability-matters/