Interoperability MATTERS
an initiative of The Sequoia Project

Consumer Engagement Strategy Workgroup

Meeting Ten

January 28, 2025

the sequoia project

CESWG Meeting Agenda – December 17, 2024

- Welcome – and workgroup charge
- Overview – Workgroup action plan
- Focusing on our tasks
  - Best practices – review and refine
    - Discussion and group input
  - Tool kit elements – review and input
    - Discussion and group input
- 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

Consumer Engagement Strategy Workgroup – Our Evolving Roadmap

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?

March

Meeting One

Workgroup Kickoff – Setting context

- How does health data dysfunction impact patients' lives?
- What are key needs to to make data work for patients?

April

Meeting Two

TEFCA and IAS

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

May

Meeting Three

Meeting Three

ONC Director Micky Tripathi – Barriers and Solutions to Personal Access through TEFCA

- What are the specific policy and technical barriers?
- What are the solutions?

June

Meeting Four

Understanding IAS Options and Barriers – Insights from PHR Frontlines

- Real world insights from a PHR founder
- What are barriers and pathways to individual access?

July

Meeting Five

Policy Updates for IAS under TEFCA

- *TEFCA July 1 SOP update*

August

Meeting Six

Exploring Action

- Epic - IAS through TEFCA
- HTI-2's impact on patients
- Group discussion – what's next?

September

Meeting Seven

Workgroup deliverables

- Aligning on program elements
- Crafting tactical plan

November

Meeting Eight

Workgroup deliverables

- Audit results
- Best practices discussion
- Tool kit development

December

Meeting Nine

Workgroup deliverables

- Best practices
- Tool kit development

Consumer Engagement Strategy Workgroup – Our Evolving Roadmap

2025

We are here!

January

2025 Kickoff!

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

February

Review and Refine

- Review and refine best practices
- Review and refine toolkit elements
- Discuss policy recommendations

March

Prepare for Release

- Prepare to release draft best practices and tool kit for community input
- Review/refine industry pledge content
- Review policy recommendations

April

Review and Refine

- Review revisions from community
- Finalize industry pledge
- Prepare for toolkit final release
- Finalize policy recommendations

May

Release!

- Release best practices and toolkit
- Explore future activities

June

Review and Explore

- Review success metrics
- Explore next-phase

Planning for action

Our path to action…

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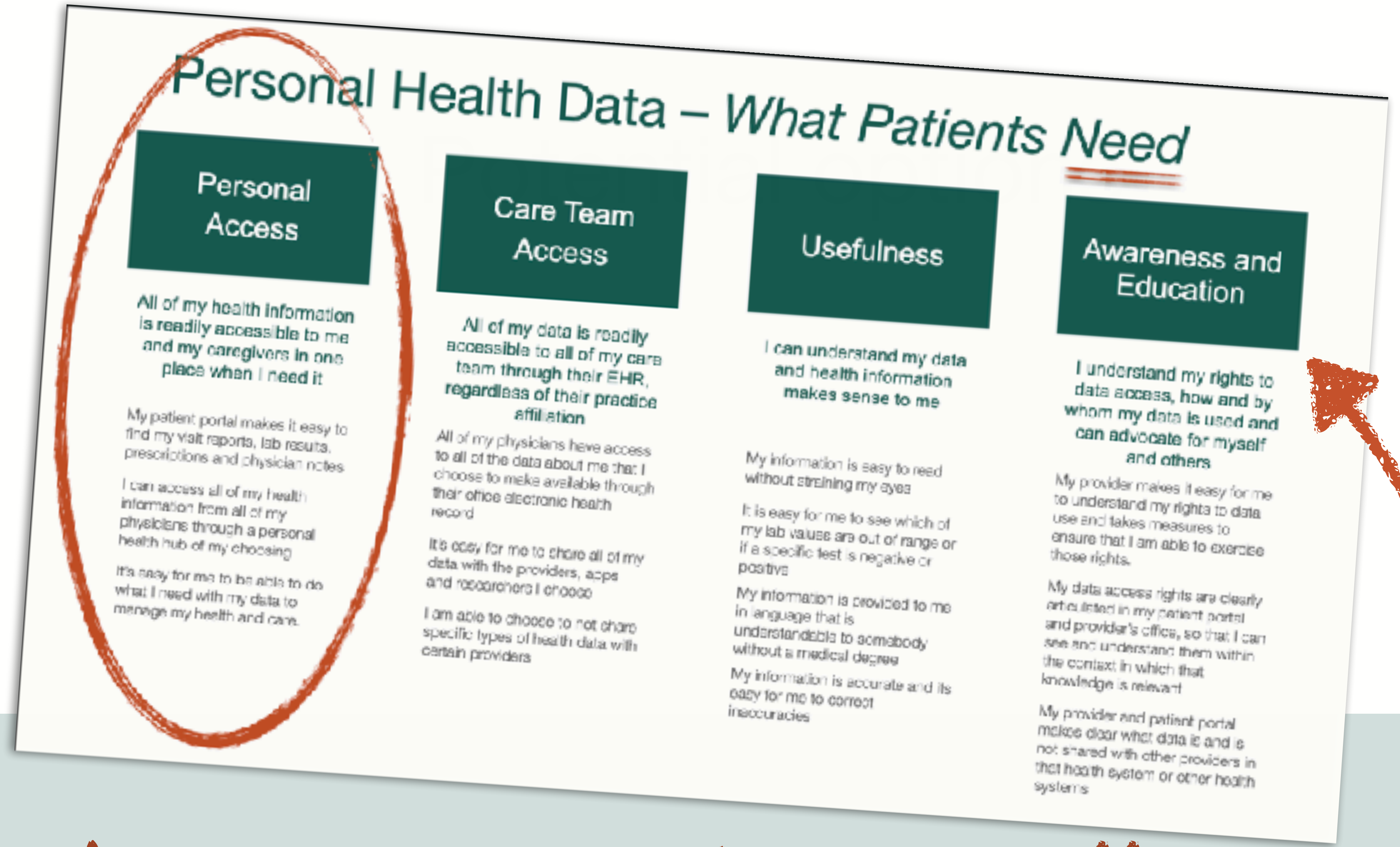


Personal Health Data – *What Patients Need*

Personal Access	Care Team Access	Usefulness	Awareness and Education
All of my health information is readily accessible to me and my caregivers in one place when I need it	**All of my data is readily accessible to all of my care team through their EHR, regardless of their practice affiliation**	**I can understand my data and health information makes sense to me**	**I understand my rights to data access, how and by whom my data is used and can advocate for myself and others**
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.	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	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	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

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?

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

For our FIRST set of workgroup deliverables…

Our starting point

- Established, legal patient rights to data as defined by the 21st Century Cures Act, HIPAA and federal rules and interpretations related to these laws

What we’re doing

- Developing recommendations and informational tools that will enable patients and the providers and vendors who serve them to make it easy to access data in a time of urgent need

What we’re NOT doing (YET!!)

- Defining new data elements that should be required by federal law
- Imagining new functionality for the patient portal

Why is this important?

CESWG Activities

Make it easy for provider practices/institutions to meet patient data needs NOW

Personal Health Data – *What Patients Need*

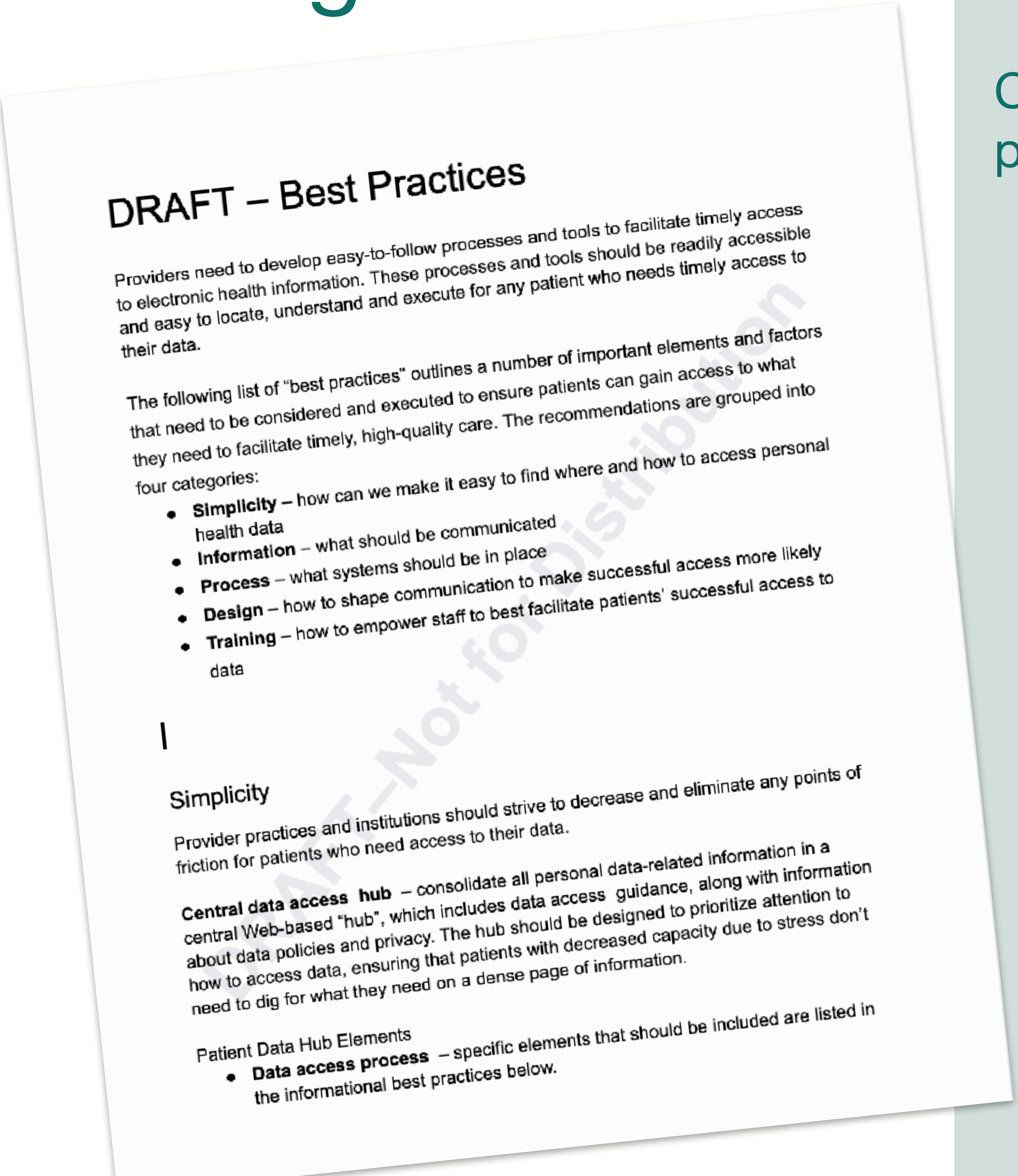
Personal Access

Care Team Access

Usefulness

Awareness and Education

Defining Best Practices



DRAFT – Best Practices

Providers need to develop easy-to-follow processes and tools to facilitate timely access to electronic health information. These processes and tools should be readily accessible and easy to locate, understand and execute for any patient who needs timely access to their data.

The following list of "best practices" outlines a number of important elements and factors that need to be considered and executed to ensure patients can gain access to what they need to facilitate timely, high-quality care. The recommendations are grouped into four categories:

- **Simplicity –** how can we make it easy to find where and how to access personal health data
- **Information** – what should be communicated
- **Process** – what systems should be in place
- **Design** – how to shape communication to make successful access more likely
- **Training** – how to empower staff to best facilitate patients' successful access to data

Simplicity

Provider practices and institutions should strive to decrease and eliminate any points of friction for patients who need access to their data.

Central data access hub – consolidate all personal data-related information in a central Web-based "hub", which includes data access guidance, along with information about data policies and privacy. The hub should be designed to prioritize attention to how to access data, ensuring that patients with decreased capacity due to stress don't need to dig for what they need on a dense page of information.

Patient Data Hub Elements

- **Data access process** – specific elements that should be included are listed in the informational best practices below.

Creating a benchmark of excellence for provider practices, institutions and vendors

1 Do the categories make sense?

2 Have we covered all of the important areas?

3 Can any of these recommendations be eliminated while still accomplishing our task?

[DRAFT Best Practices Google Doc]

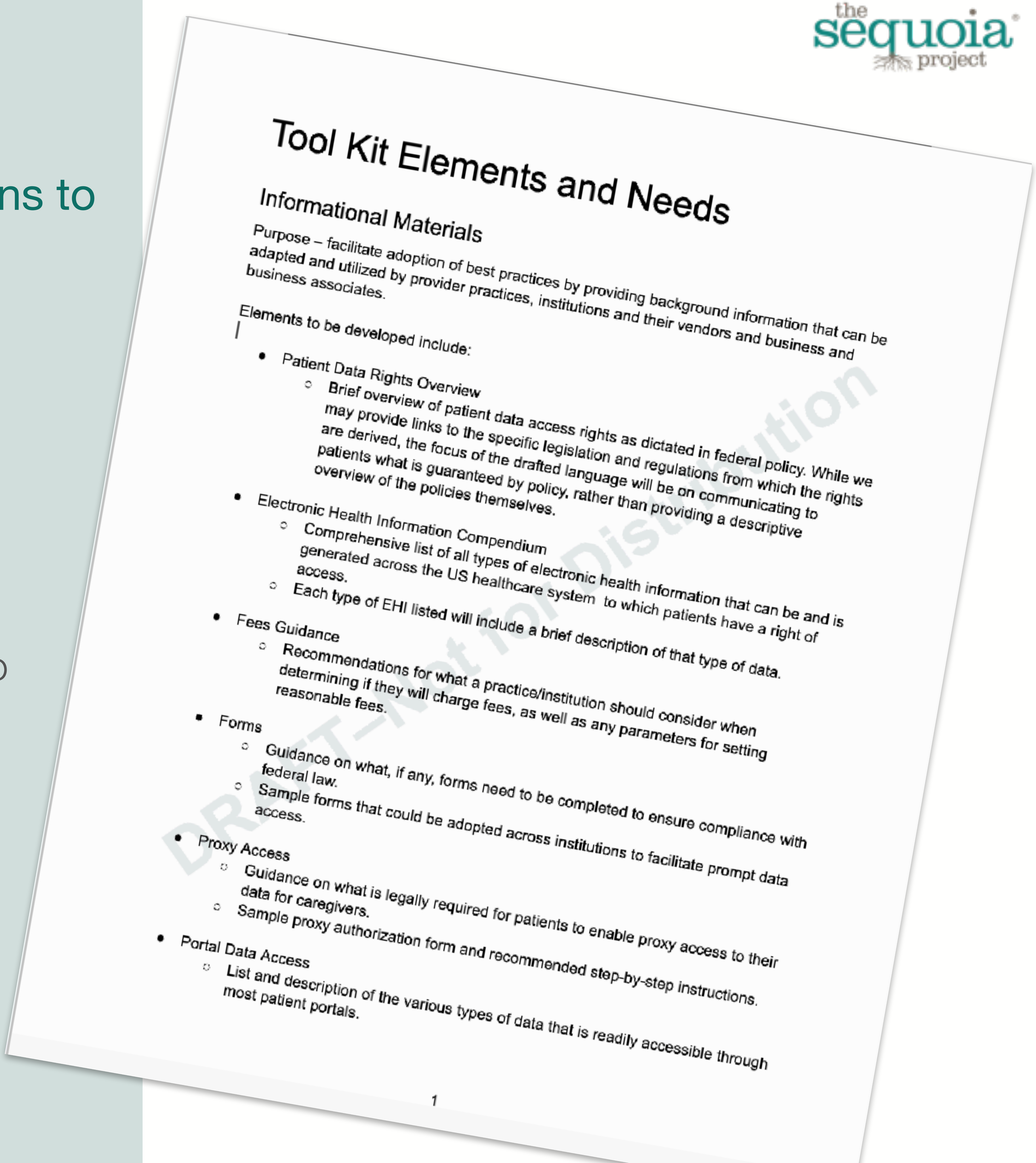
Outlining our Tool Kit

Making it easy for provider practices and institutions to adopt industry best practices

1. Will these tools be helpful?
2. Are these the right elements?
3. For provider practices/institutions who commit to adopting these best practices, what can we do to make implementation easy?

Volunteers needed!

DRAFT Tool Kit Elements



Tool Kit Elements and Needs

Informational Materials

Purpose – facilitate adoption of best practices by providing background information that can be adapted and utilized by provider practices, institutions and their vendors and business and business associates.

Elements to be developed include:

- Patient Data Rights Overview
  - Brief overview of patient data access rights as dictated in federal policy. While we may provide links to the specific legislation and regulations from which the rights are derived, the focus of the drafted language will be on communicating to patients what is guaranteed by policy, rather than providing a descriptive overview of the policies themselves.
- Electronic Health Information Compendium
  - Comprehensive list of all types of electronic health information that can be and is generated across the US healthcare system to which patients have a right of access.
  - Each type of EHI listed will include a brief description of that type of data.
- Fees Guidance
  - Recommendations for what a practice/institution should consider when determining if they will charge fees, as well as any parameters for setting reasonable fees.
- Forms
  - Guidance on what, if any, forms need to be completed to ensure compliance with federal law.
  - Sample forms that could be adopted across institutions to facilitate prompt data access.
- Proxy Access
  - Guidance on what is legally required for patients to enable proxy access to their data for caregivers.
  - Sample proxy authorization form and recommended step-by-step instructions.
- Portal Data Access
  - List and description of the various types of data that is readily accessible through most patient portals.

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Thank You!!

Contact Us

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For additional information visit our website.