



Consumer Engagement Strategy Workgroup

Meeting Eight

November 19, 2024

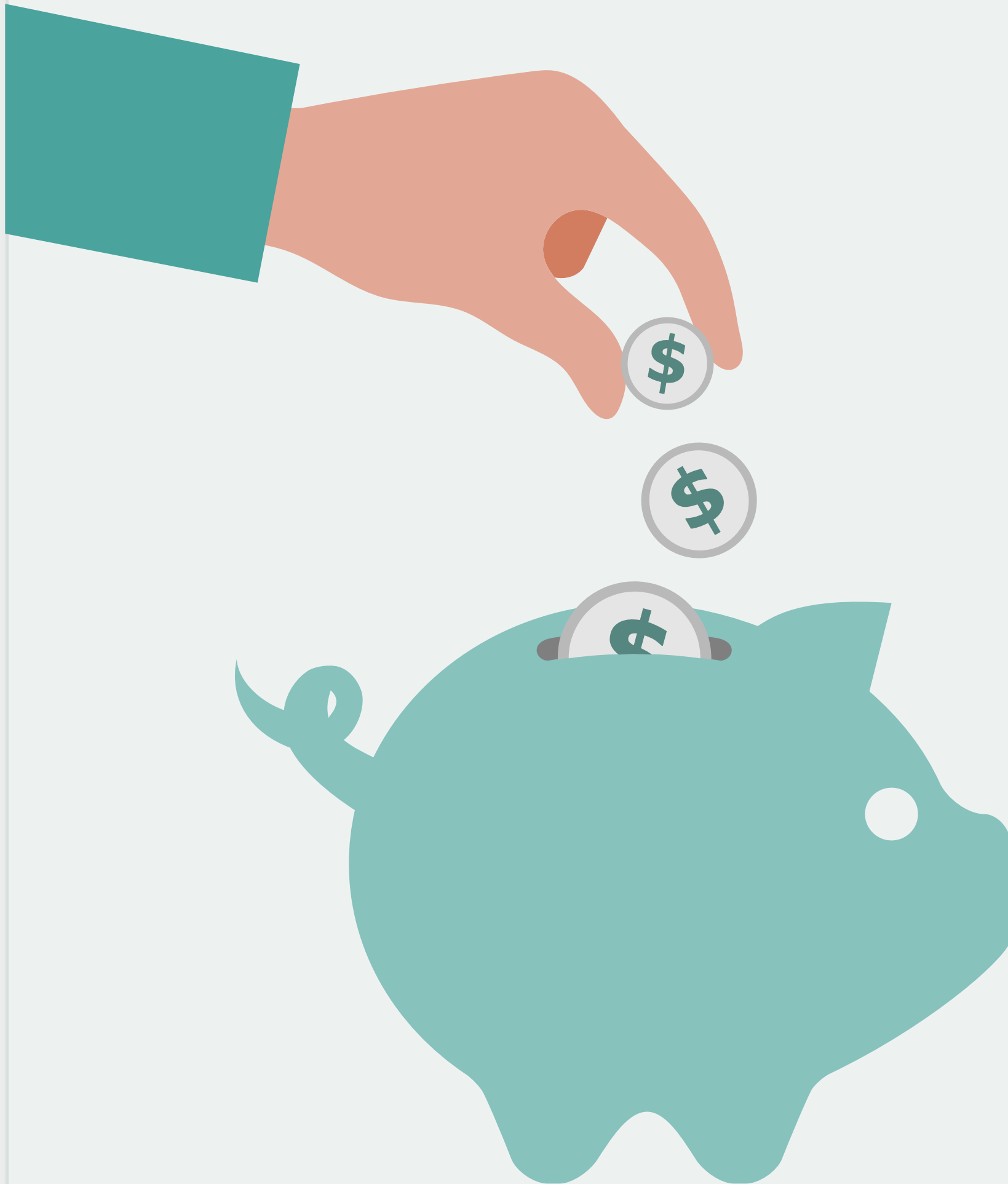
CESWG Meeting Agenda – November 19, 2024

- Welcome – and workgroup charge
- Overview – Workgroup action plan
- The curious case of the super engaged, highly knowledgeable, empowered, well connected patient and information blocking
- Audit results
- Patient pathways to information and data
- Discussion and group input
- Group activity review – Best Practices and Toolkit Worksheet
- 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, Patient Engagement Evangelist/epatientdave.com
- 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



Deadline Approaching!
- November 29!

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



*Save
the Date*

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

Sponsorships Available!

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

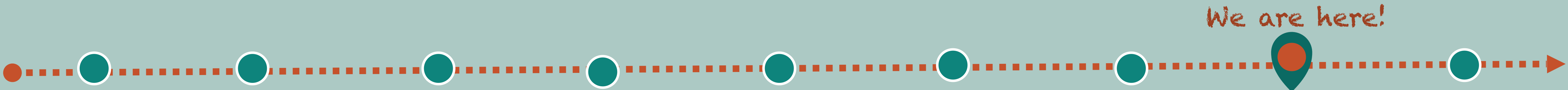
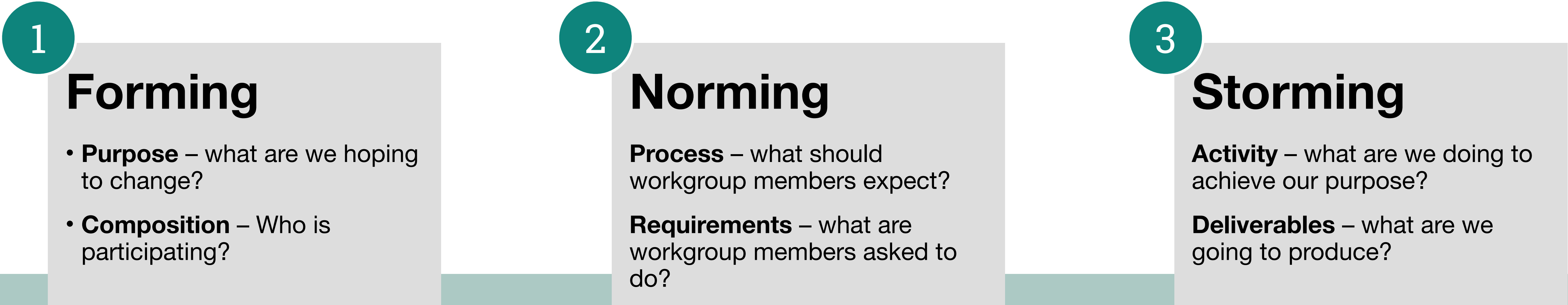
I understand my rights to data access, how and by whom my data is used and can advocate for myself and others

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



March	April	May	June	July	August	September	November	December
Meeting One <i>Workgroup Kickoff – Setting context</i> <ul style="list-style-type: none">How does health data dysfunction impact patients' lives?What are key needs to make data work for patients?	Meeting Two <i>TEFCA and IAS</i> <ul style="list-style-type: none">What does federal health IT policy dictate about personal access to health data?What are the barriers faced by a PHR company?	Meeting Three <i>Meeting Three ONC Director Micky Tripathi – Barriers and Solutions to Personal Access through TEFCA</i> <ul style="list-style-type: none">What are the specific policy and technical barriers?What are the solutions?	Meeting Four <i>Understanding IAS Options and Barriers – Insights from PHR Frontlines</i> <ul style="list-style-type: none">Real world insights from a PHR founderWhat are barriers and pathways to individual access?	Meeting Five <i>Policy Updates for IAS under TEFCA</i> <ul style="list-style-type: none">TEFCA July 1 SOP update	Meeting Six <i>Exploring Action</i> <ul style="list-style-type: none">Epic - IAS through TEFCAHTI-2's impact on patientsGroup discussion – what's next?	Meeting Seven <i>Workgroup deliverables</i> <ul style="list-style-type: none">Aligning on program elementsCrafting tactical plan	Meeting Eight <i>Workgroup deliverables</i> <ul style="list-style-type: none">Audit resultsBest practices discussionTool kit development	Meeting Nine <i>Workgroup deliverables</i> <ul style="list-style-type: none">Best practicesTool kit development

The curious case of the super engaged,
highly knowledgeable, empowered, well
connected patient and information
blocking

Seriously... how is this still a thing?

It's me! Hi!



2 X health tech startup
founder

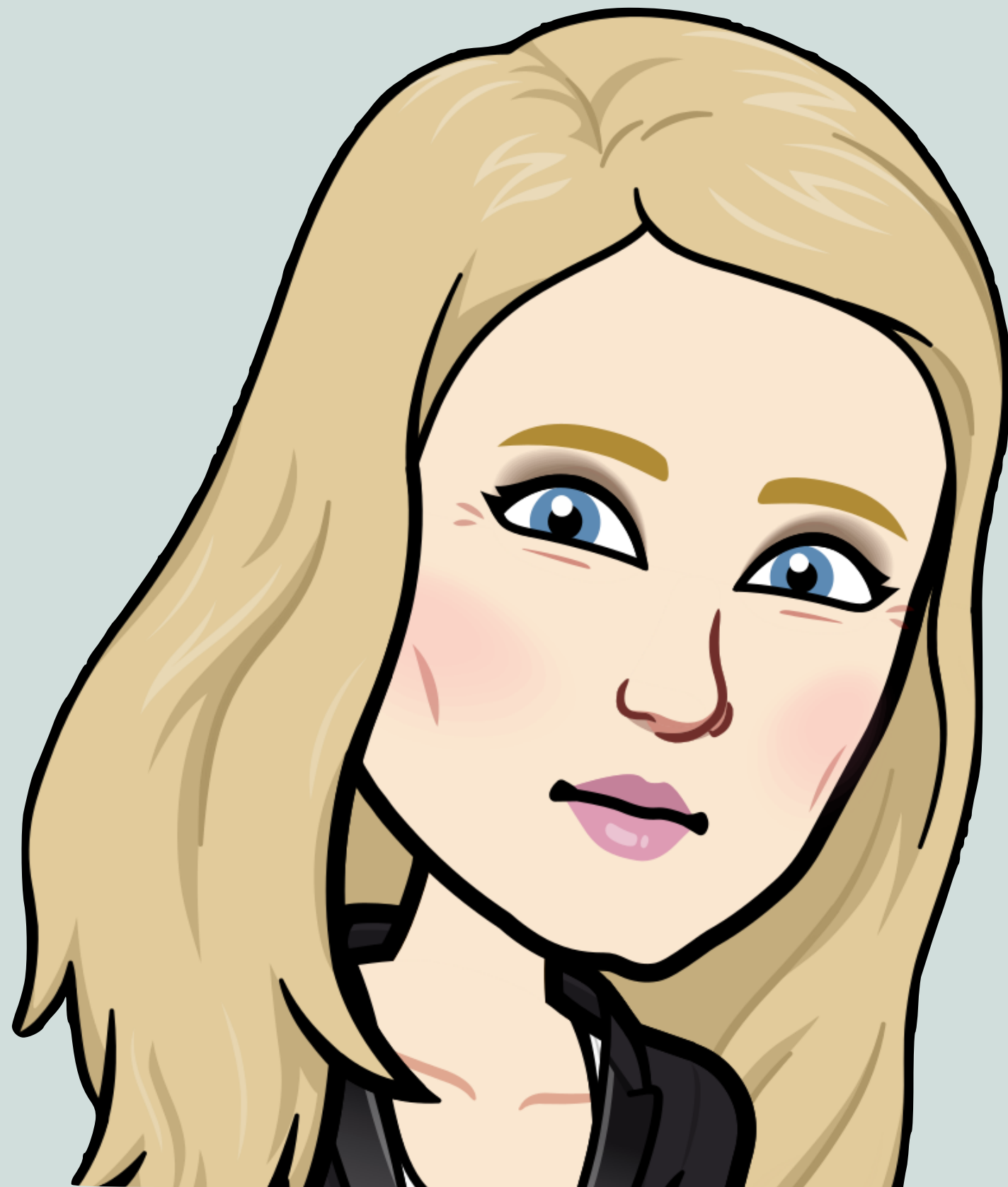
Co-Founder patient hacker
#WeAreNotWaiting mvmt

HITAC Member

Sequoia Board Member

CESWG Workgroup Lead

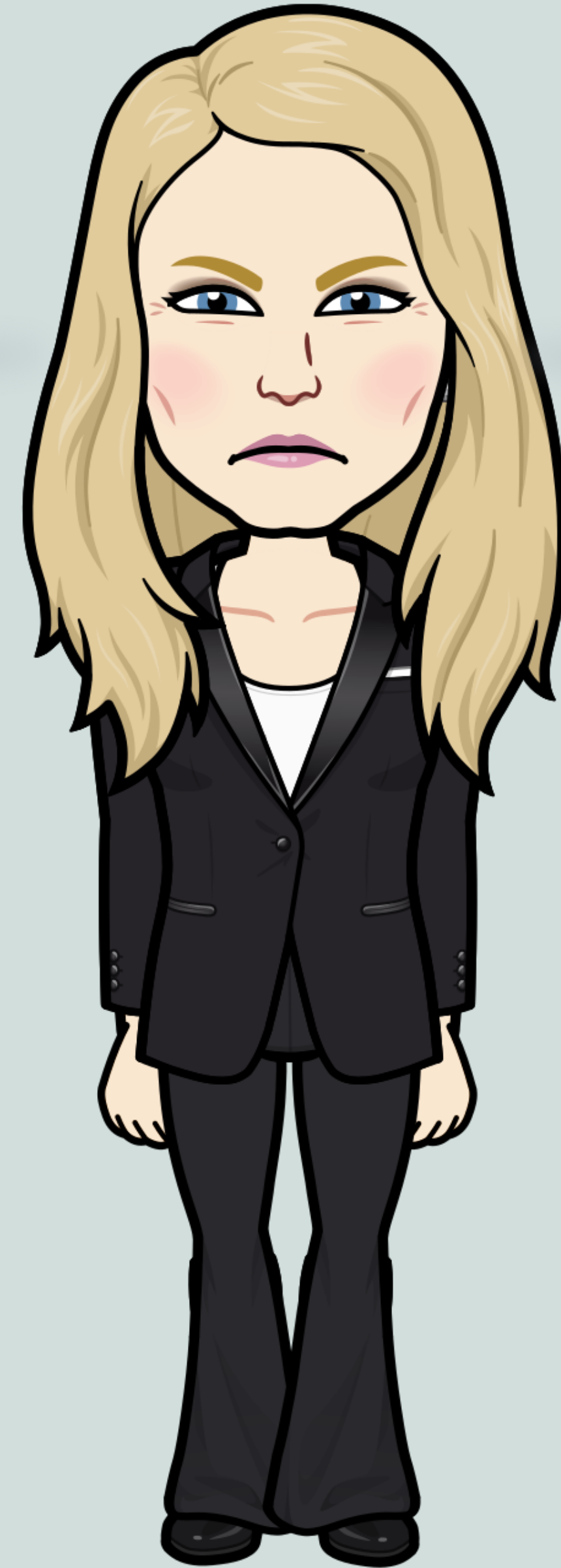
...But I'm NOT the problem



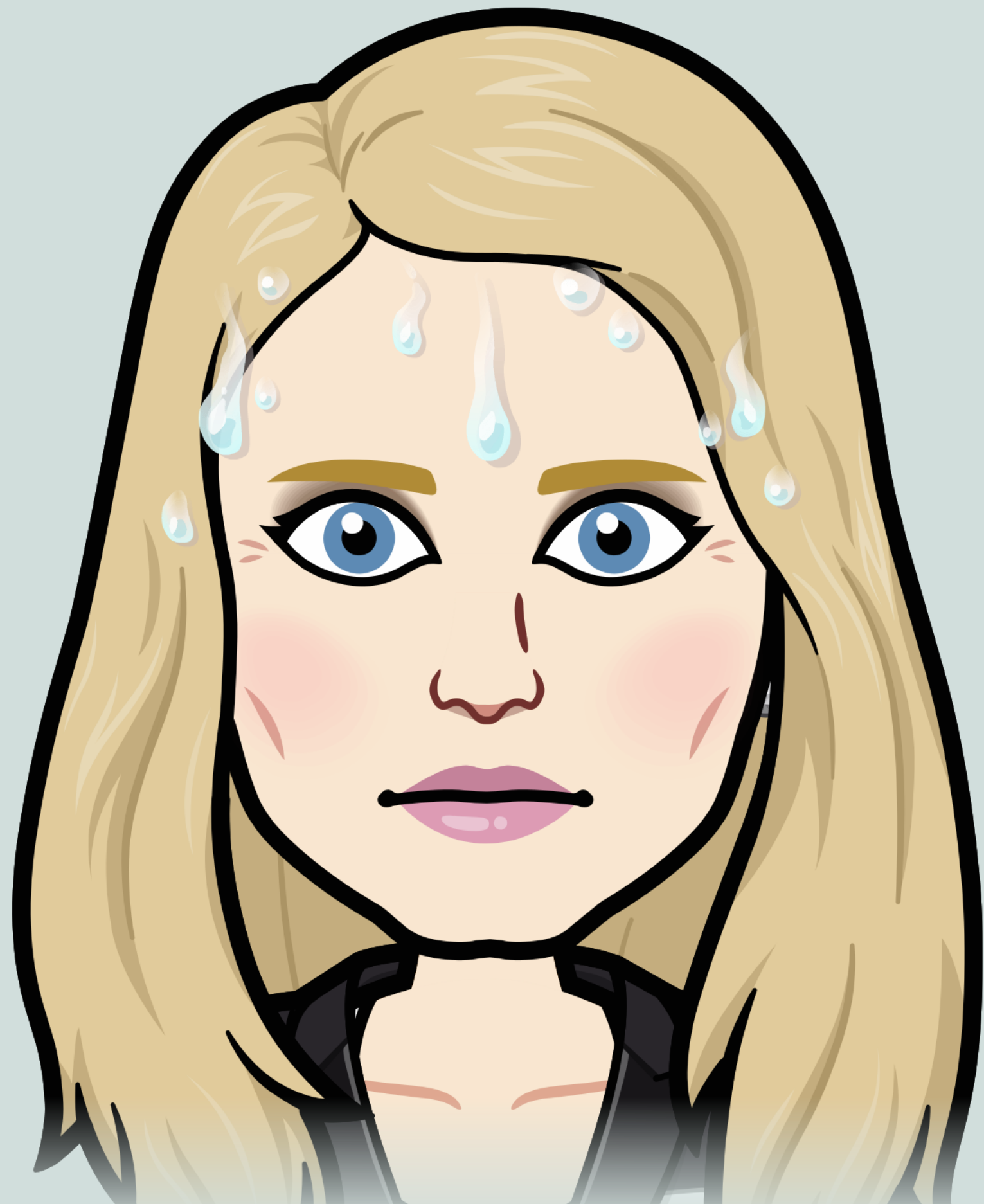
- Urgent, evolving and frightening health issue
- Time sensitive need for access to data
- Difficult family issue
- Busy professional demands
- Other complex health issues
- Desperate need to get a second opinion
- Hesitation about implications of informing doctor about interest in second opinion

THIS is the problem

- No access to data on portal
- Called doctor's office – immediately sent to medical records
- Medical records didn't have the data ... BUT
 - Only option was to go through them
- Medical records “process”
- Complete a form requesting data access
- Mail a check for the fees to the medical records office or drive an hour to hand deliver it
- After the check had cleared, they would have 30 days to provide me with the data
- The doctor had told me the issue needed urgent attention
- My appointment with the new specialist was in less than a week

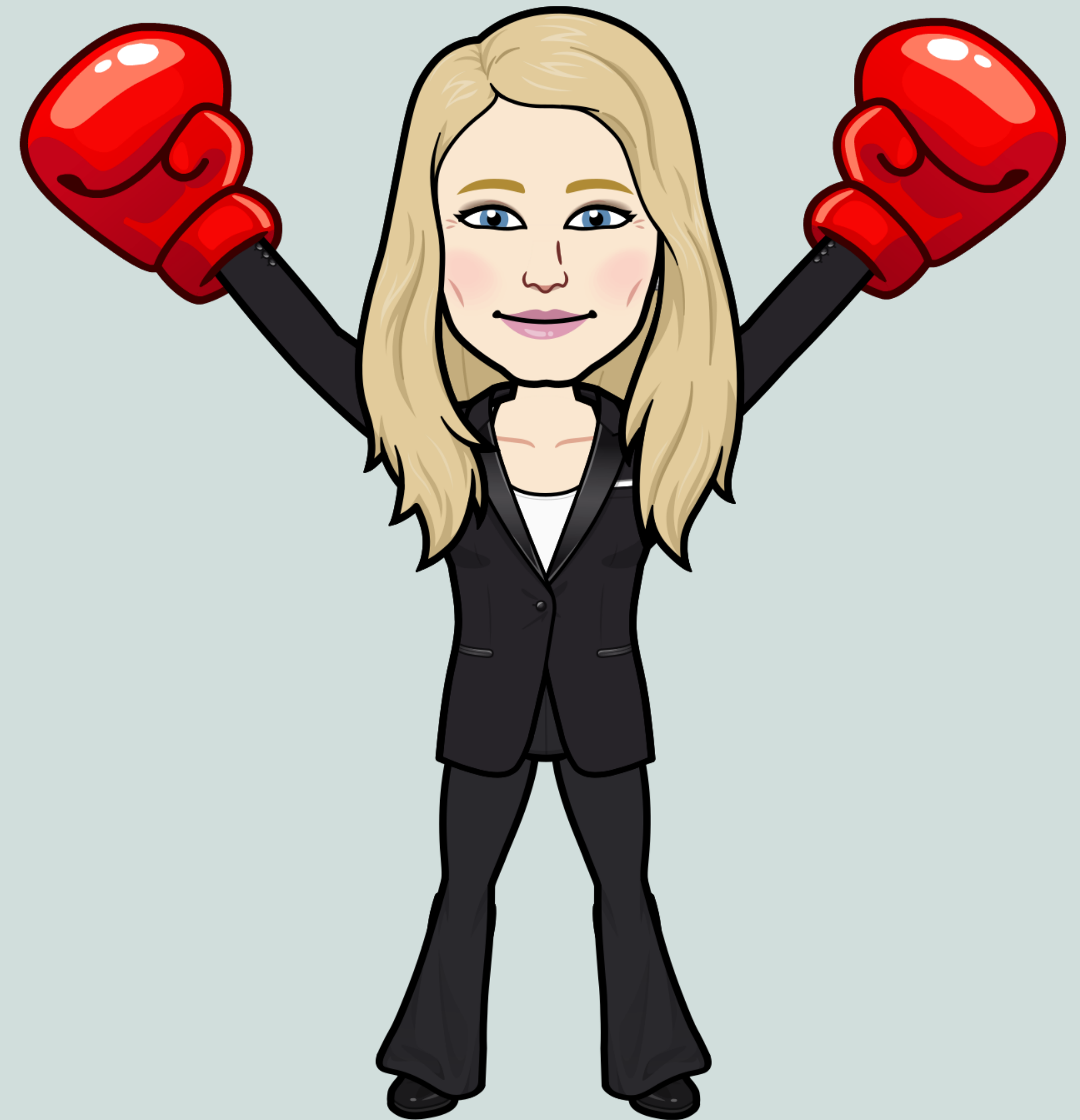


What did it take for me to get my data?



- In-person HITAC – surrounded by people who wrote the regulations
- Close friends and personal cell number for former lead for HIPAA at HHS/OCR
- ChatGPT4 to quickly find specific parts of federal rules around information blocking
- Emails to office manager/medical records threatening to file complaint for information blocking
- Purchasing a USB drive
- Going in-person to doctor's office to oversee process for getting the data downloaded onto the drive
- Uploading the data to a secure dropbox folder
- Sending to my new physician

**WE can
make this
work better!!**



Planning for action

Our path to action...

Consumer Engagement Strategy Workgroup



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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	Care Team Access	Usefulness	Awareness and Education
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Six Meetings focused on personal access!!

354

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

Revised

Goal

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

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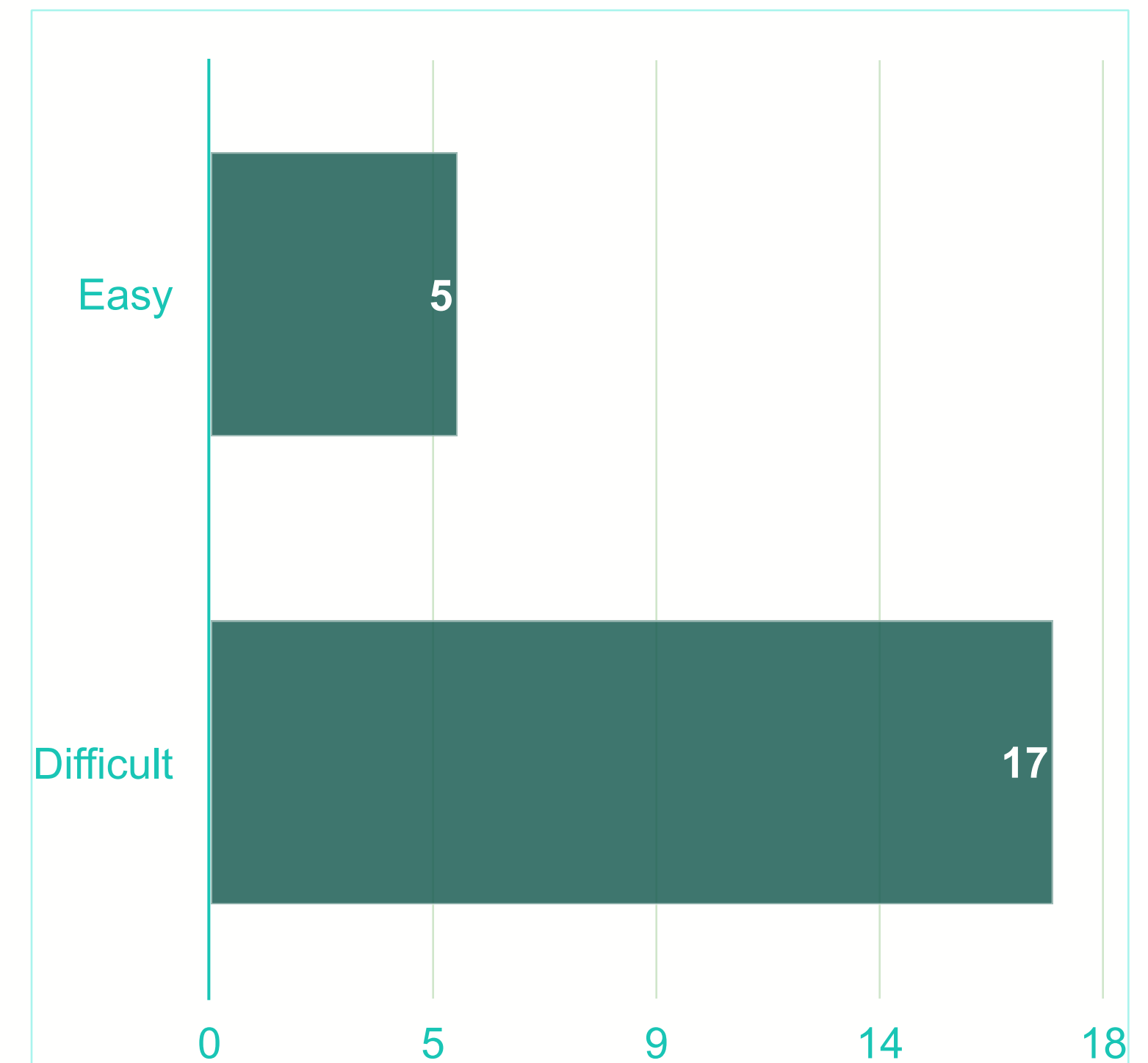
Create recommendation to ASTP/ONC to require placement of information in obvious, accessible location in EHR for all certified HIT

- Identify core patient need
- Map patient process for seeking data
- Identify barriers/needs for improving
- Draft best practices for industry adoption
- Draft list of needed resources for workgroup toolkit

Workgroup Audit Results

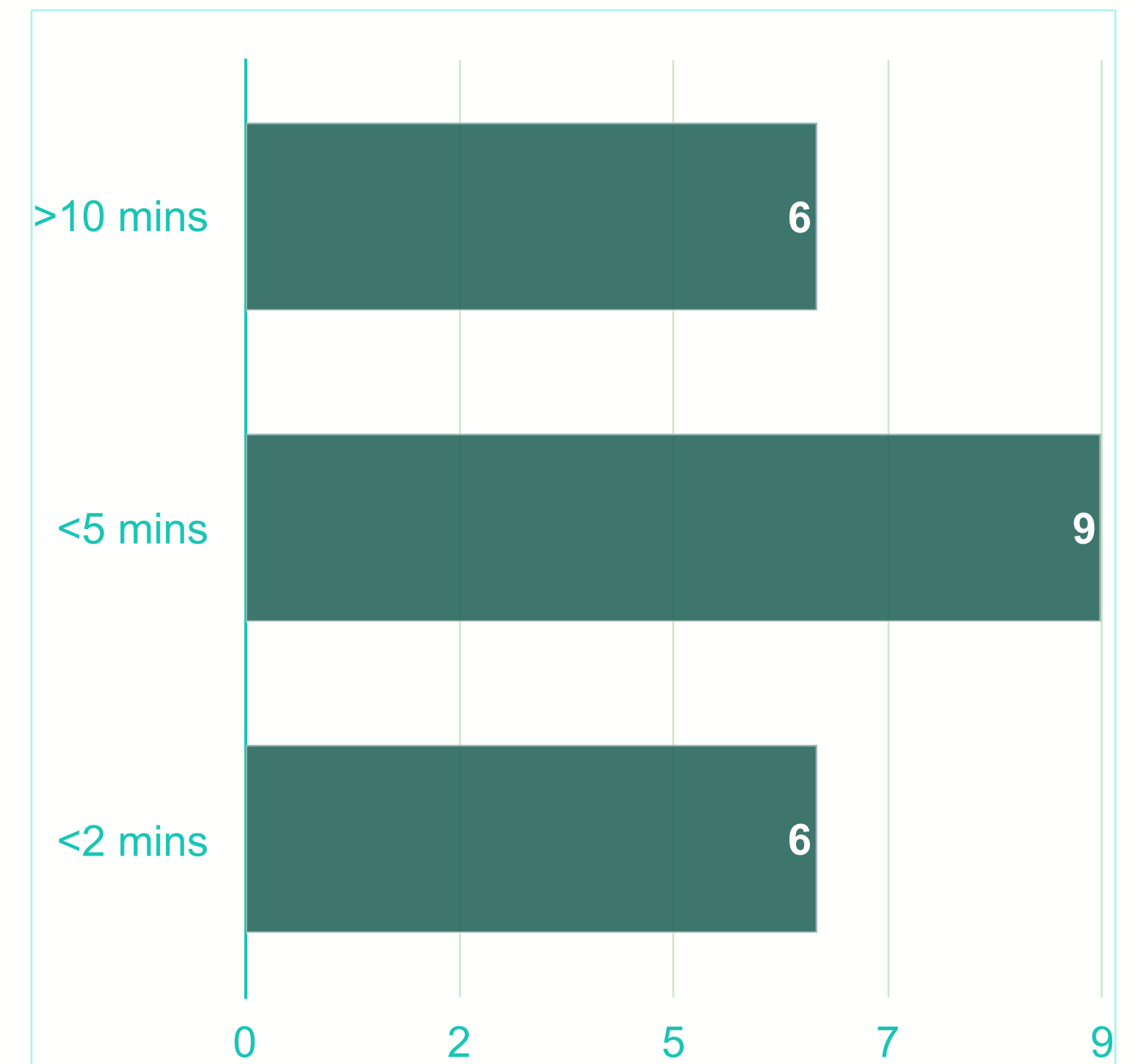
How easy/difficult was it to find information about your data access rights?

- 17 of 23 respondents indicated finding this information was difficult



How much time did you spend attempting to find the information/How long did the process take?

- 6 of 23 respondents indicated finding this information in 2 or fewer minutes
- 9 respondents indicated less than 5 minutes
- 6 respondents indicated spending more than 10 minutes
- 2 respondents did not share a time



Common ways to find information

Organization website search

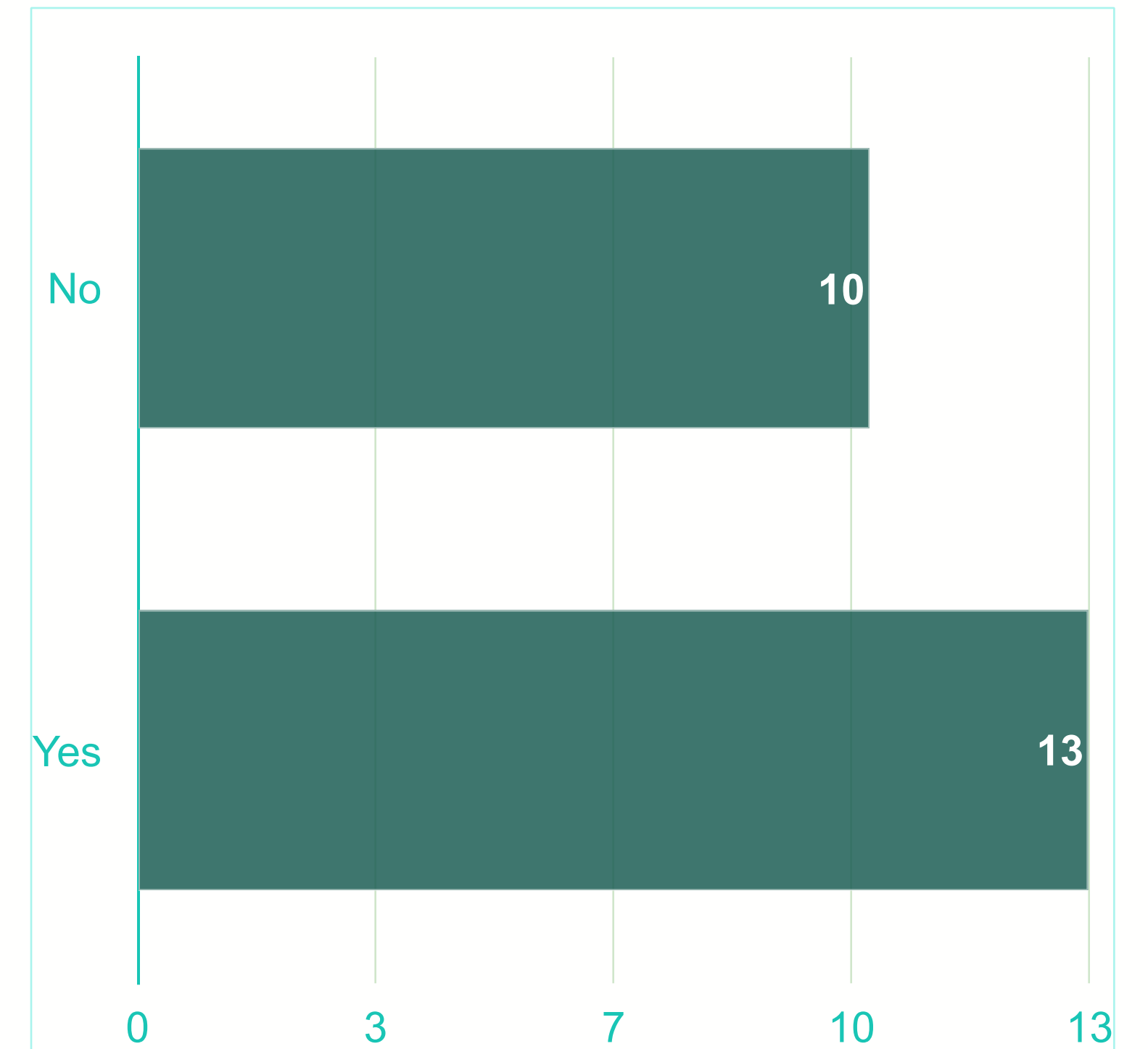
- Cures Act, 21st Century Cures Act, Health Records, Individual Access, Patient Rights and Responsibilities, Patient Information and Rights, Medical Records, Notice of Privacy Practices, HIPAA Privacy Notice, Authorization for Use and Disclosure of Medical Information, Sharing Your Health Data

Organization website navigation

Patient Portal

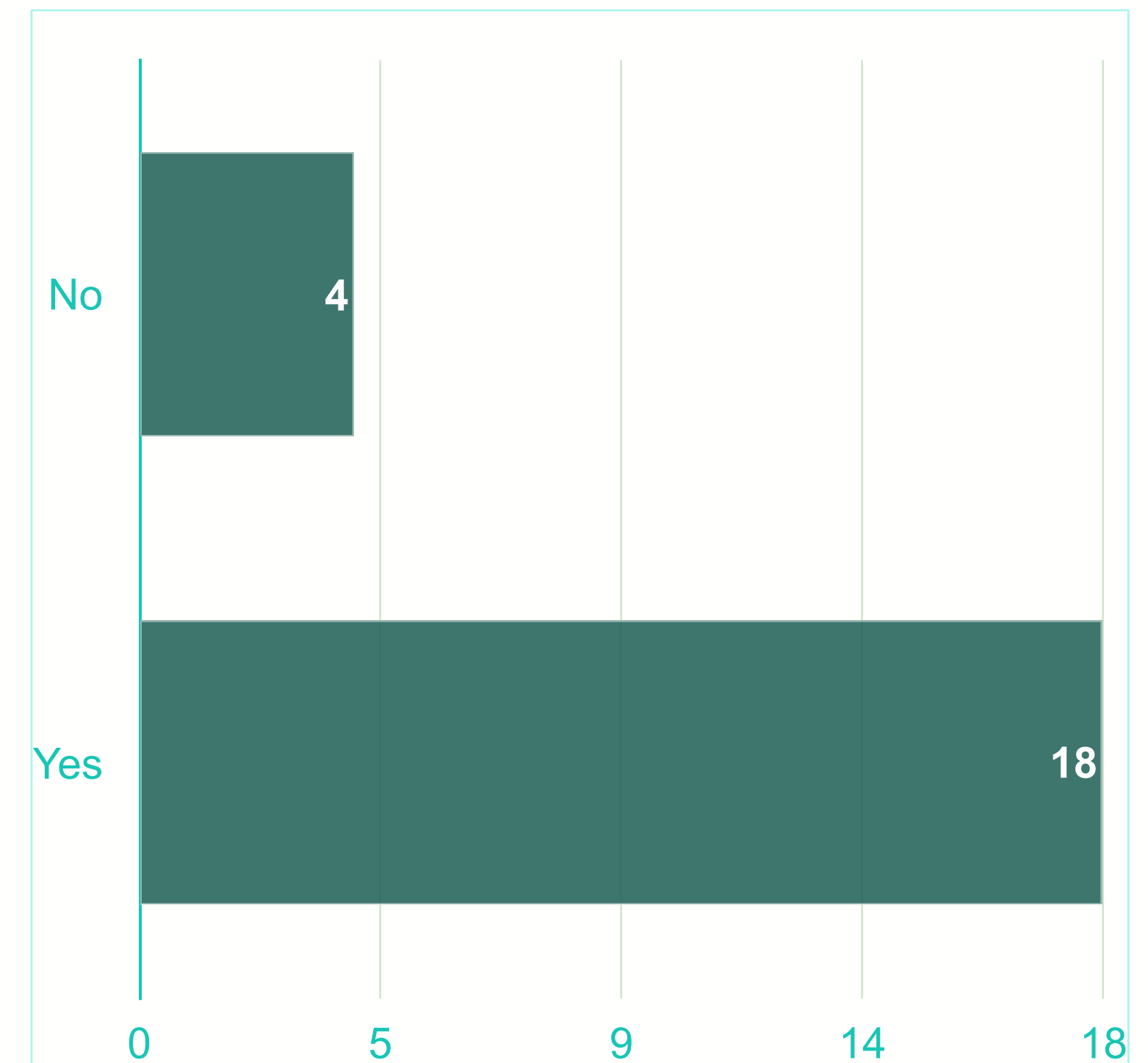
Did the institution provide any descriptions of the types of data that you could access?

- 13 of 23 respondents indicated there were descriptions of the data types available



Did the institution provide any information about whom you should contact if you were having issues accessing your information?

- 18 of 23 respondents indicated there was a way to contact for more questions
- Many of these options were only via a form or only via phone



Summary of audit results:

How easy/difficult was it to find information about your data access rights?	17 of 23 respondents - Difficult
How much time did you spend attempting to find the information/How long did the process take?	6 of 23 respondents <2mins 9 of 23 respondents <5 mins 6 of 23 respondents >5 mins
Common ways to find information	Organization website search: Cures Act, 21 st Century Cures Act, Health Records, Individual Access, Patient Rights and Responsibilities, Patient Information and Rights, Medical Records, Notice of Privacy Practices, HIPAA Privacy Notice, Authorization for Use and Disclosure of Medical Information, Sharing Your Health Data Organization website navigation Patient Portal
Did the institution provide any descriptions of the types of data that you could access?	13 of 23 respondents indicated there were descriptions of the data types available
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Patient Needs and Pathways

Core patient needs

When a patient is facing a health crisis and needs access to their data to facilitate care, what do they need to ensure timely access?

- Clear, obvious information about how to get their data
- Information about the type of data they can access
 - What is the data to which they have a right of access?
 - What is the data that is available on their portal?
- If data isn't available on their portal, what do they need to do?
 - Whom do they contact and how?
 - What is the required process?
 - What are the fees?
 - What is the projected timeline?
 - What's the process for escalating timeframe for time-sensitive needs?
- Process for time sensitive requests
 - Who can the patient contact if the articulated process doesn't happen in a timely manner?

Pathways to access

What are the ways that patients seek access to their data?



Ask the doctor

What happens?

- May not have the answer
- Might create awkwardness if goal is to get second opinion
- Likely defer to support staff
 - Directed to portal
 - Directed to medical records

Pathways to access

What are the ways that patients seek access to their data?



Provider Website

What happens?

- Search for information yields incomplete and inconsistent information
- Difficult to find how to access – obvious search terms don't get you to what you need
- Little to no information on right of access
 - Types of data available - EHI
 - May reference HIPAA
 - No reference to information blocking rules
- Inconsistent information on process to access
- Limited clarity on what patient needs to do

Pathways to access

What are the ways that patients seek access to their data?



Patient Portal

What happens?

- Portal access can be cumbersome - requires special code or provider action
- Portal data is limited – not all EHI
 - No images
 - Lacks some specialty data and diagnostics
 - EKGs, Genetic testing, EEGs, etc.
- Inconsistent information on what to do to get EHI not in portal

Pathways to access

What are the ways that patients seek access to their data?

Telephone Call to
Provider

What happens?

- Endless phone trees and wait times
- That absurd message about calling 911!!!
- When you speak with human...
 - They don't know what to tell you
 - They send you to medical records

Pathways to access

What are the ways that patients seek access to their data?



Medical Records

What happens?

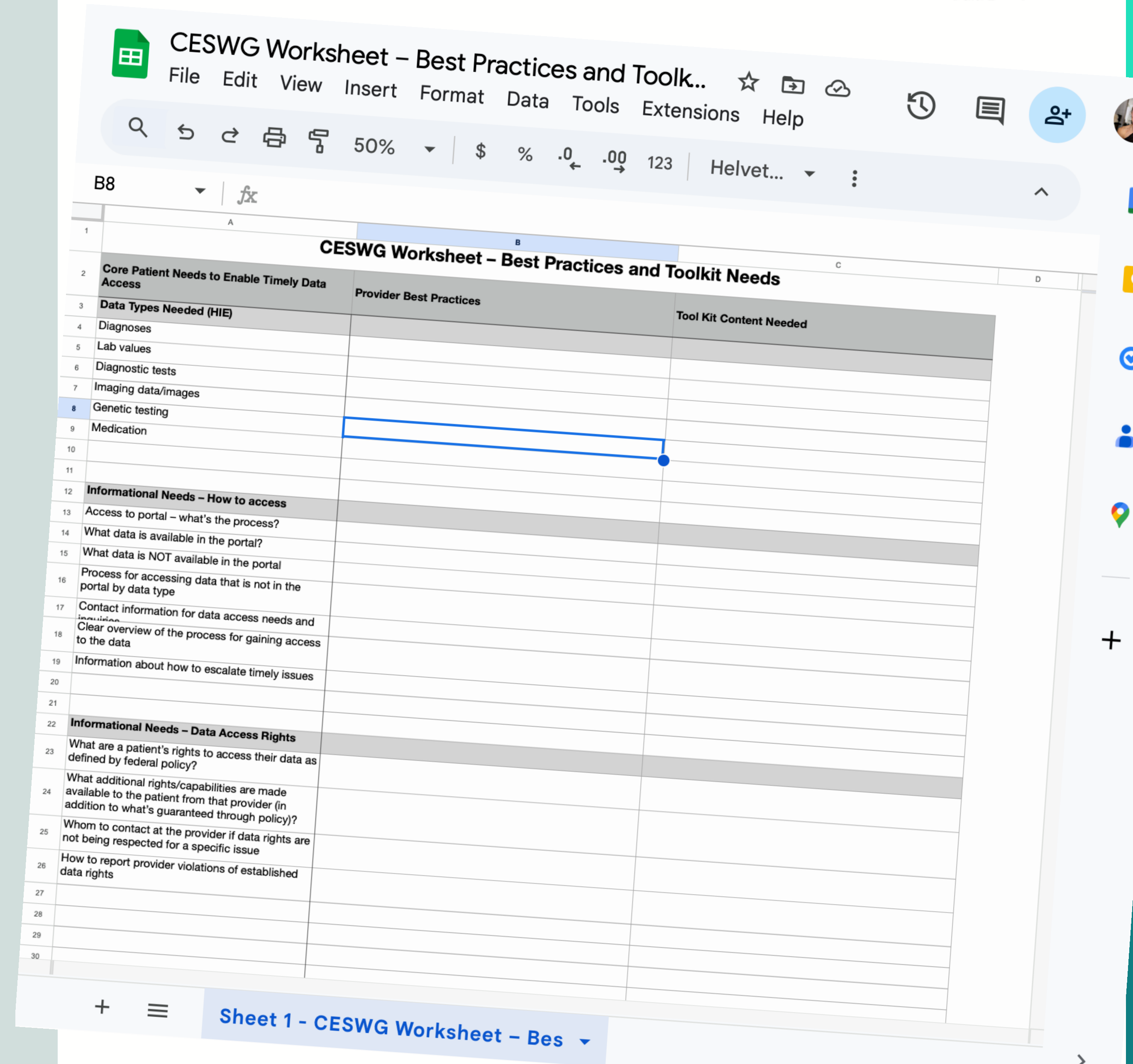
- Who/if call is answered depends on provider or ROI vendor
- Medical records contact and process based off of current rules related to HIPAA right of access
- Anecdotally... no awareness of information blocking requirement for timely access

On your mark, get set ... GO!

Group Assignment

- 1 Review DRAFT worksheet
- 2 List core patient needs – what type of data, information and resources do patients need to gain timely access to data (Column A)
- 3 Identify what providers need to do to fulfill core patient needs (Column B)
- 4 Suggest tool kit elements that would be helpful to assist providers in providing patients with timely access to data

[Worksheet Link](#)



The screenshot shows a Google Sheet titled "CESWG Worksheet – Best Practices and Toolkit Needs". The sheet is divided into three main columns: "Core Patient Needs to Enable Timely Data Access", "Provider Best Practices", and "Tool Kit Content Needed". The rows are numbered 1 through 30. The first column (A) lists various data types and informational needs. The second column (B) is for provider best practices. The third column (C) is for tool kit content. A blue selection box is visible around row 9, column B. The sheet is titled "Sheet 1 - CESWG Worksheet - Bes" at the bottom.

	A	B	C
1			
2	Core Patient Needs to Enable Timely Data Access	Provider Best Practices	Tool Kit Content Needed
3	Data Types Needed (HIE)		
4	Diagnoses		
5	Lab values		
6	Diagnostic tests		
7	Imaging data/images		
8	Genetic testing		
9	Medication		
10			
11			
12	Informational Needs – How to access		
13	Access to portal – what's the process?		
14	What data is available in the portal?		
15	What data is NOT available in the portal?		
16	Process for accessing data that is not in the portal by data type		
17	Contact information for data access needs and inquiries		
18	Clear overview of the process for gaining access to the data		
19	Information about how to escalate timely issues		
20			
21			
22	Informational Needs – Data Access Rights		
23	What are a patient's rights to access their data as defined by federal policy?		
24	What additional rights/capabilities are made available to the patient from that provider (in addition to what's guaranteed through policy)?		
25	Whom to contact at the provider if data rights are not being respected for a specific issue		
26	How to report provider violations of established data rights		
27			
28			
29			
30			

Thank You!!



Contact Us

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amccollister@sequoiaproject.org

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