Interoperability
MATTERS
an initiative of The Sequoia Project

Consumer Engagement Strategy Workgroup

Kick-Off Meeting

April 23, 2024

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Meeting Agenda

- Welcome and Introductions

- Overview of March meeting

- Review the Workgroup Charter

- Outline of Workgroup Process

- Meeting objectives

- How HIT policy enables personal access to data – Evolution of right of access

- PHRs IRL – Lessons from the frontlines of creating a patient PHR

- Open Discussion

- Introduction of Workgroup worksheet

# 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
- Jeff Coughlin, American Medical Association
- Tammy Coutts, EHRA
- Dave Debronkart, HL-7 Patient Engagement

- Yssa DeWoody, Ring14
- Cathriona Dolphin-Dempsey, Stanford Health Care
- John Gaines, MatchRite
- Eddie Gonzalez-Loumiet, Ruvos
- Mike Graglia, Cure SynGAP1
- Thomas Grannan, Azuba Corporation
- Joe Hernandez, BluIP
- Jen Horonjeff, Savvy Cooperative
- 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
- Desla Mancilla, BCBSA
- Shamekka Marty, Patient/Caregiver Advocate

- Josh Mast, Oracle
- Elizabeth McElhiney, Verisma
- Chrissa McFarlane, Patientory
- 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
- Stacey Tinianov, Patient Advocate/ Consultant
- Jaffer Traish, FindHelp
- Janice Tufte, Hassanah Consulting
- Brian Van Wyk, Epic
- Diana Warner, MRO Corporation
- Duncan Weatherston, Smile Digital Health
- Carol Zinder, inTandem Health

Workgroup Charter
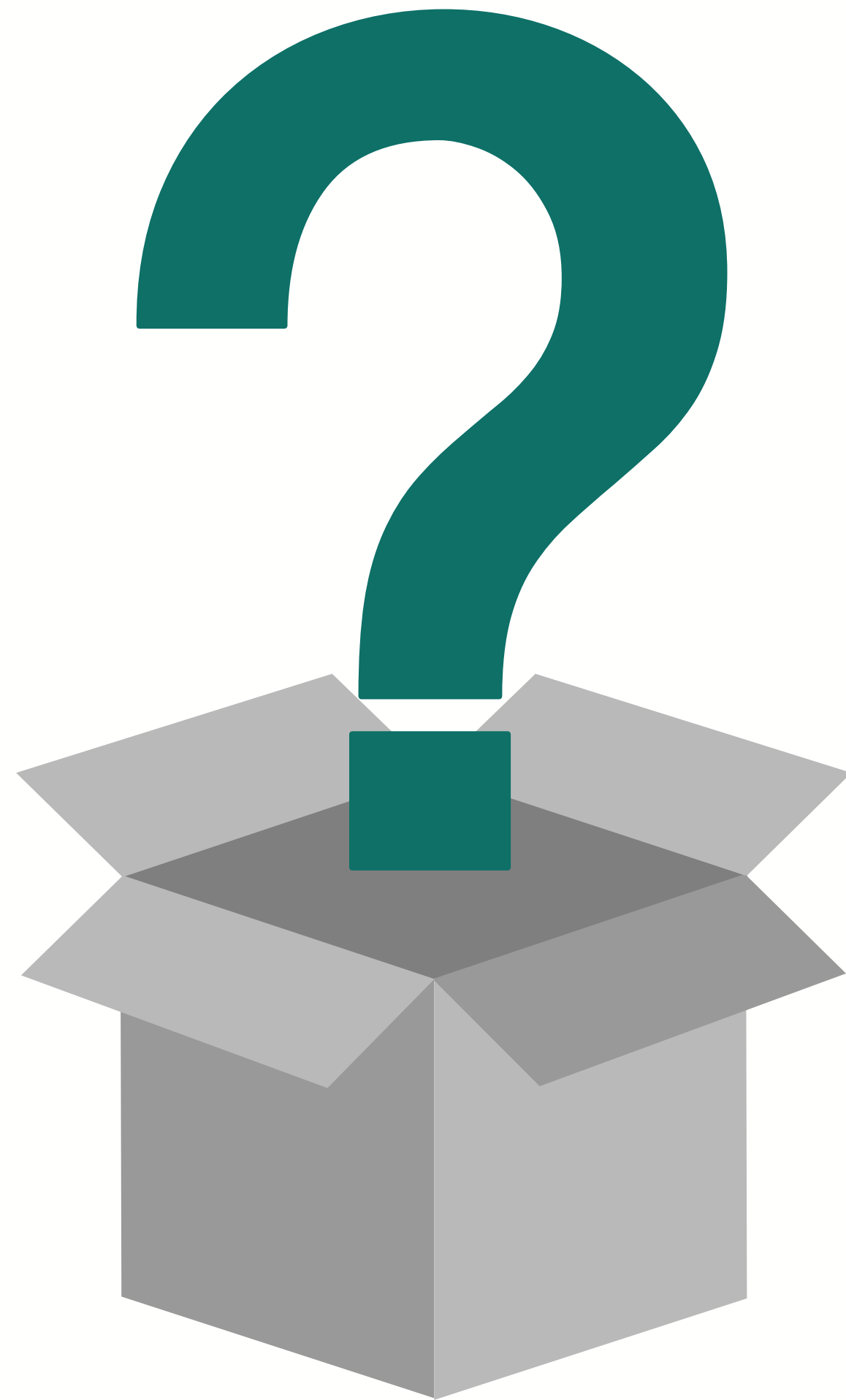
Broad Workgroup Charter
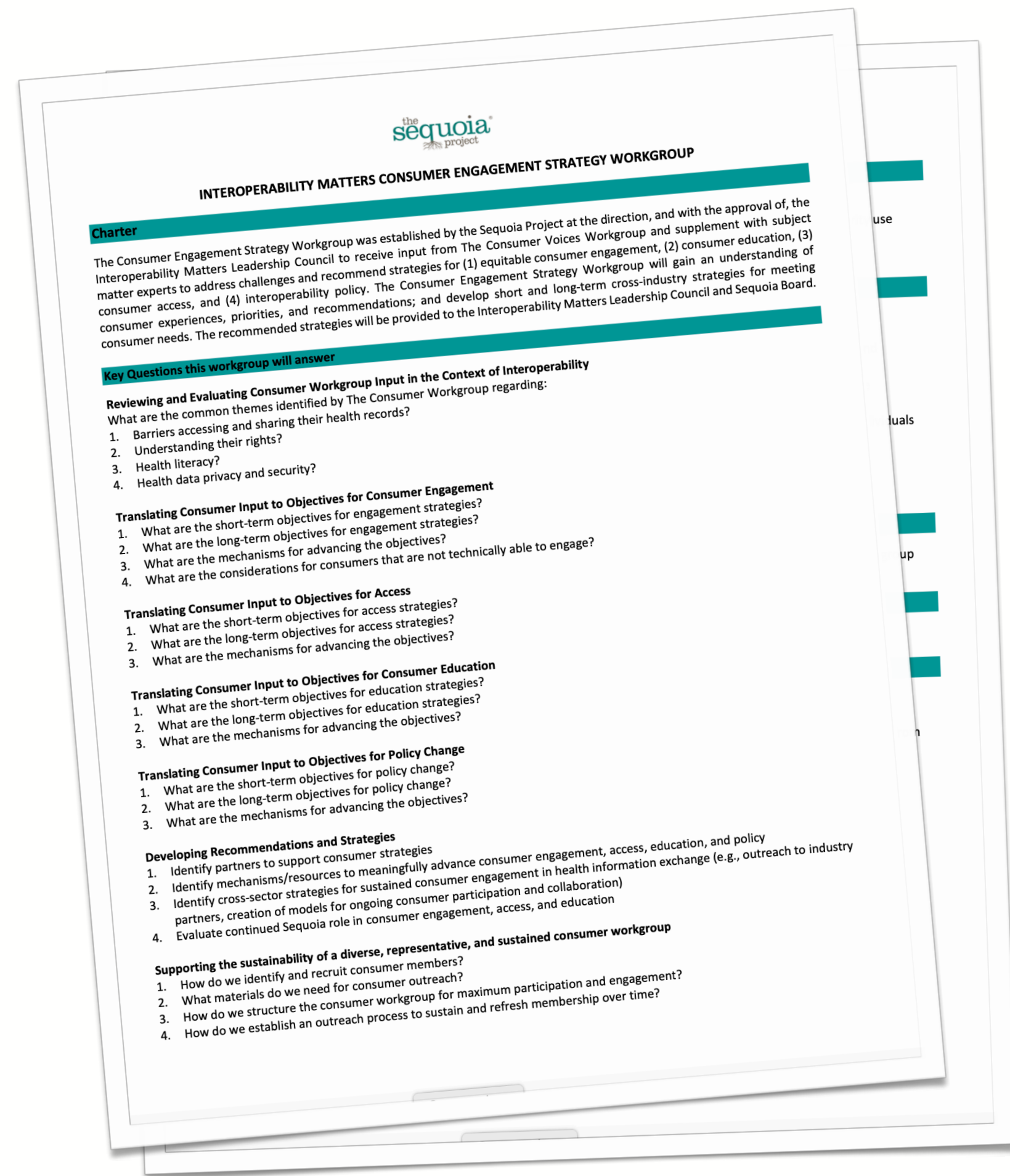
"The Consumer Engagement Strategy Workgroup will gain an understanding of consumer experiences, priorities, and recommendations; and develop short and long-term cross-industry strategies for meeting consumer needs."

Charter identifies key questions for the workgroup to explore
- Reviewing consumer workgroup input in the context of interoperability
- Translating consumer input into objectives for:
  - Consumer engagement
  - Data access
  - Consumer education
  - Policy change
- Developing recommendations and strategies
- Supporting the sustainability of consumer engagement in Sequoia work

Workgroup Deliverables

- Charter doesn't specify workgroup deliverables
- Our mandate is to make an impact that matters
  - ✓ Specific
  - ✓ Achievable
  - ✓ Measurable
  - ✓ Time-limited

Workgroup Process

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.

Consumer Engagement Strategy Workgroup – How it will work

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?

We are here!

March — April — May — June — July — August — September

Meeting One
Workgroup Kickoff – Setting context
- How does health data dysfunction impact patients' lives?
- What are the key needs that need to be addressed to make data work for patients?

Meeting Two
Deep Dive – Personal Access/Use
- What does federal health IT policy dictate about personal access to health data?
- What are the barriers faced by a PHR company?

Meeting Three
Deep Dive – Care Team Data Access
- What is the current status for interoperability?
- What type of data is being exchanged and is it what we need?

Meeting Four
Deep Dive – Data Usefulness
- Does the data that my HCP and I access serve my needs?
- What would application of best practices produce?

Meeting Five
Deep Dive – Awareness and Education
- What are the specific rights to access and how do patients learn about their rights?
- What can patients do if their rights aren't being fulfilled?

Meeting Six
***Special Guest Facilitator – Barriers and Solutions to Personal Access*
- What are the specific policy and technical barriers preventing consistent personal access?
- What are the solutions?

Meeting Seven
Workgroup deliverables
- Summarize needs, barriers and solutions from worksheet
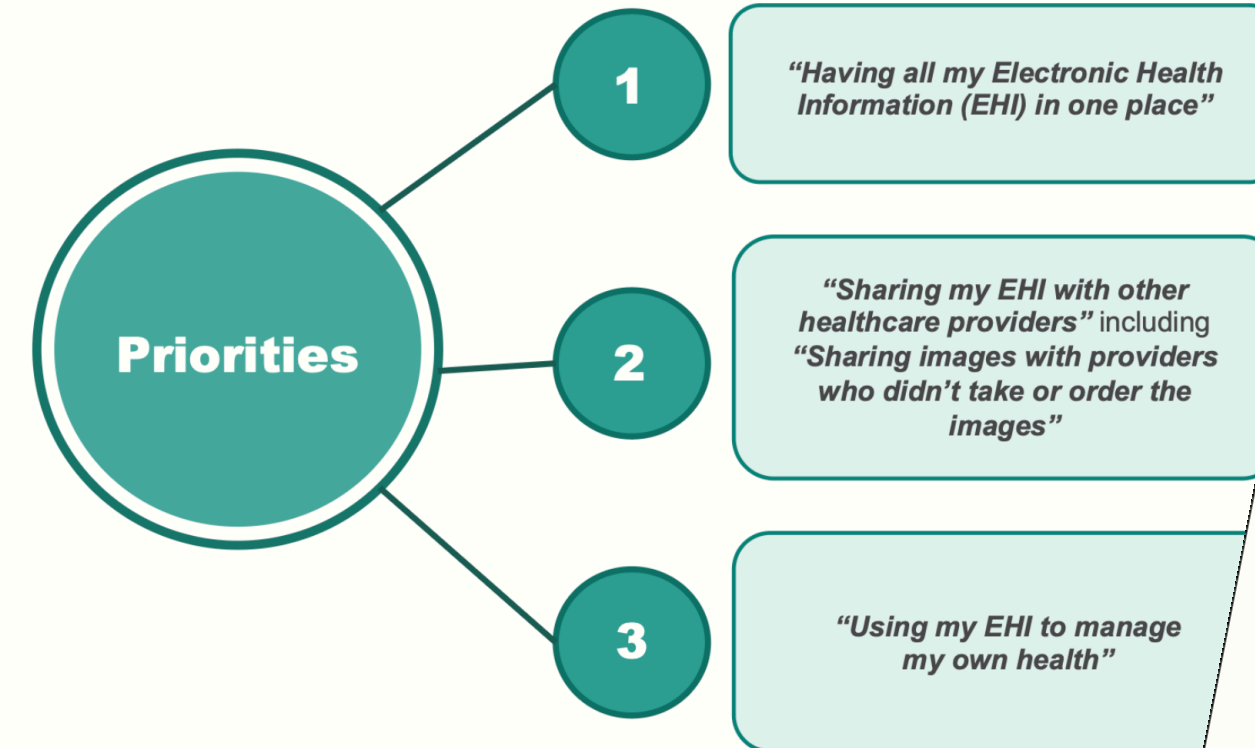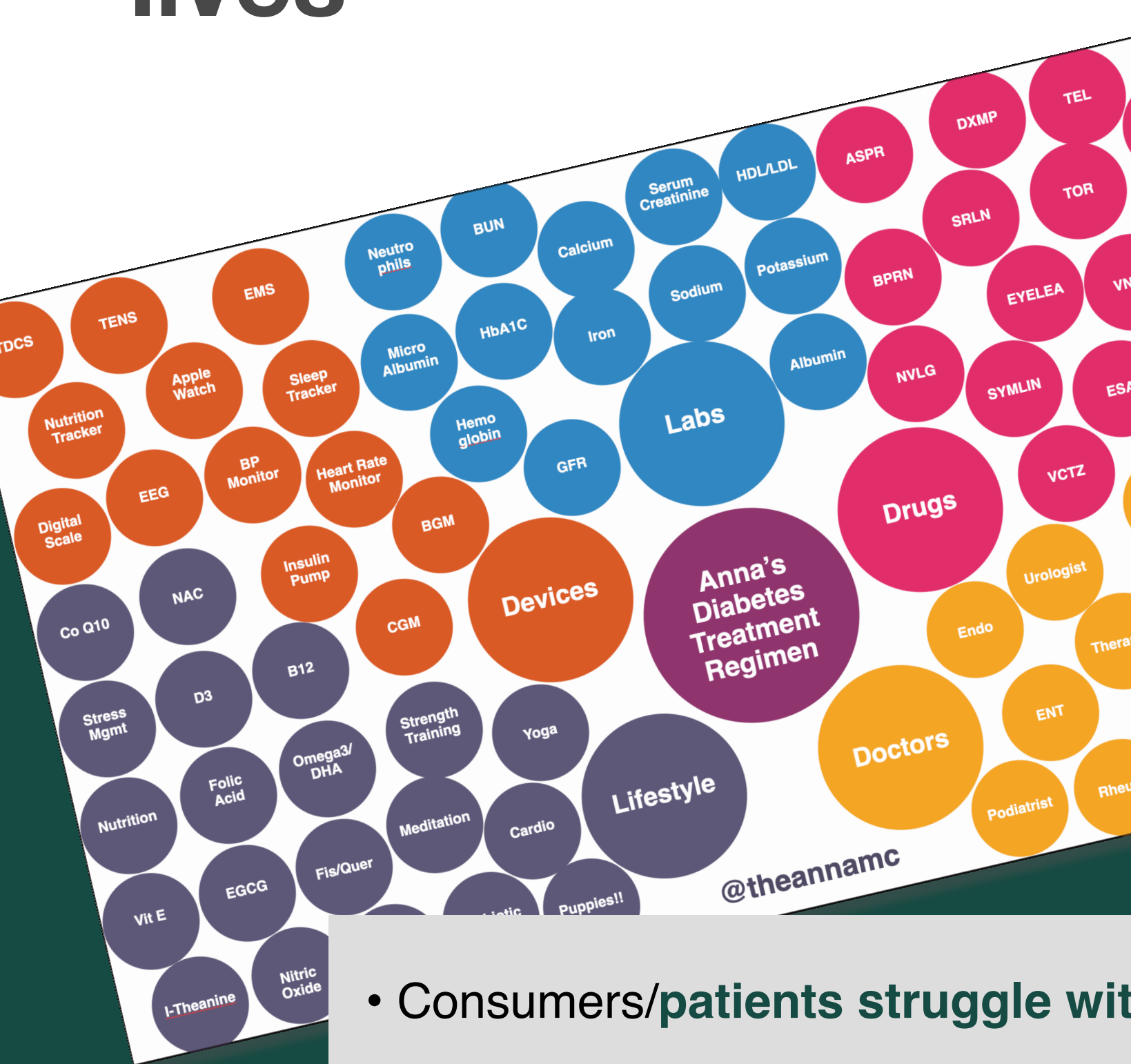- Review and decide upon recommended solutions

Worksheet Contributions

Meeting One Recap

Setting the context for the workgroup activity

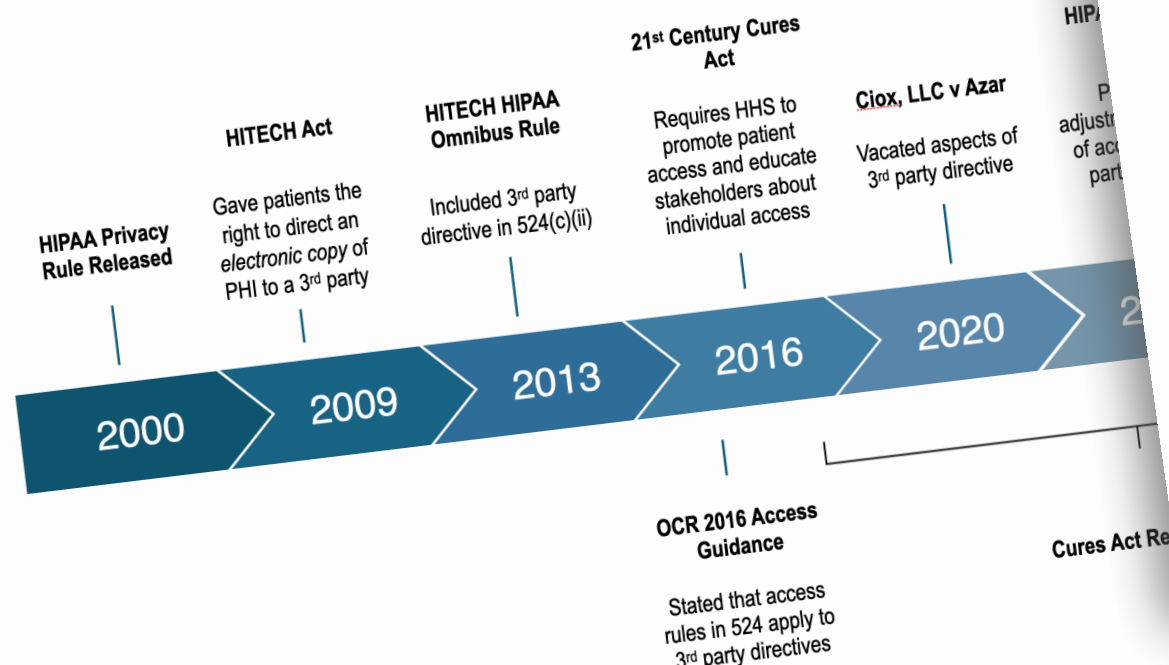# Meeting One Recap – How data dysfunction impacts patient lives

What workgroup participants most wanted from hea...

Priorities

1 — *"Having all my Electronic Health Information (EHI) in one place"*

2 — *"Sharing my EHI with other healthcare providers"* including *"Sharing images with providers who didn't take or order the images"*

3 — *"Using my EHI to manage my own health"*

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Consequences of Gaps in Interoperability

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- 57% said trying to get medical records was stressful, time-consuming, or confusing
- 43% had hesitancy to switch doctors for fear of losing medical history
- 43% experienced a hospital emergency and with no record of meds, allergies
- 43% experienced duplicating tests / images because they weren't shared between providers
- 43% said they had to go in-person to pick up medical records
- 43% said spending time getting medical records took time away from self-care / caregiving
- 29% (n=8) had to cancel appointments because medical records weren't available

- Increased burden of disease
- Duplicate tests
- Canceled appointments
- Fear and frustration
- Medical errors
- Unnecessary hospitalizations

@theannamc

- Consumers/**patients struggle with accessing data** how and when they need it
- Hurdles to data access **increase patient workload,** which is cumulative across different doctors, institutions and portals
- Even in best-case scenario, **patients must serve as "HIE of One"** to assemble data and ensure each HCP has the data they need
- Consequences of hurdles to data access can **significantly impact patient health, care and outcomes**
- Even most sophisticated, **data savvy patients struggle with complexity of data access and assembly,** especially amidst health crisis
- **Few patients are aware of their rights to data access** and/or what to do if data rights are not honored
- Complexity of accessing usable data **leads to frustration, burnout and resignation, along with missed appointments, medical errors and unnecessary hospitalizations**

Meeting One Recap – Overview of federal policies on data access rights

HIPAA

- Establishes right of access
- Right to give access to "third party"

21st Century Cures – ONC/ CMS Regs

- Requires certified HIT to provide API-based access
- Requires health plans to make data accessible via API
- Establishes Individual Access Services (IAS)

Ciox Health v Azar

- Vacated aspects of 3rd party directive
- Removed limits on charging patients for access
- In response, HHS/OCR NPRM proposes re-instating limits to charging patients for access – still awaiting final rule

OCR Right of Access Enforcement

- Launched in 2019
- Fines for not giving patients access to data
- 44 settlements and two civil monetary penalties

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

Today's Objectives

- *Gain insights into issues and opportunities related to personal data access*

- *Begin identifying specific needs, barriers and action steps*

Personal Health Data – *What Patients Need*

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How does federal HIT policy enable personal data access?

Evolution of Policy to Promote Patient Access to Health Information

Policy Tension

HIPAA: Keep Data Private and Secure (but with patient right of access)
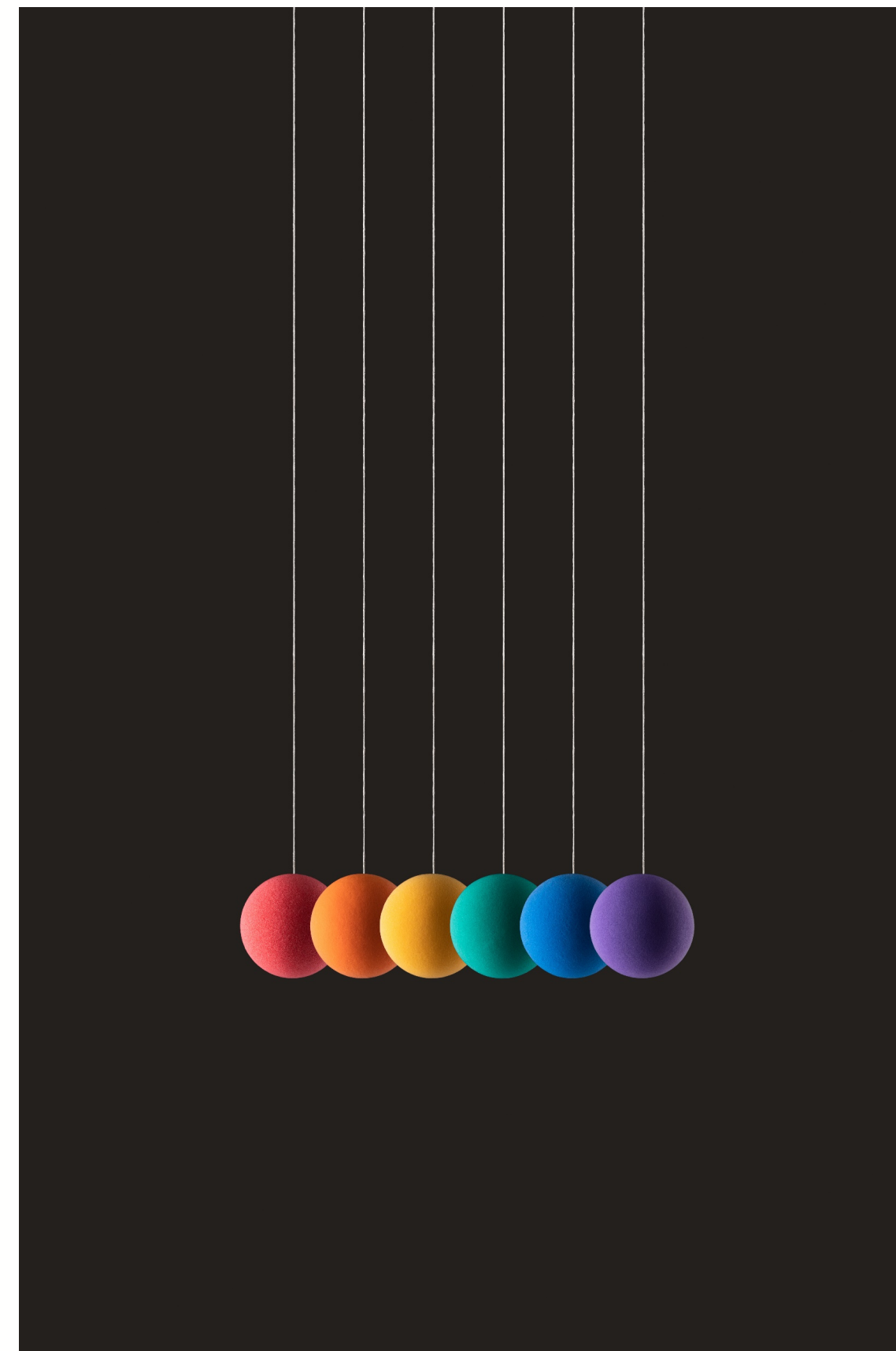
HITECH and 21st Century Cures: Information Sharing "Without Special Effort"

Patient Access to Health Information – Policy Evolution

Digitizing Health Care
2006-2015

HIPAA Transaction Standards and Electronic Submission of Claims

Meaningful Use and Adoption of Electronic Health Records (EHRs)

Laying the Groundwork
2016-2023

ONC 21st Century Cures Act Final Rule includes Application Programming Interfaces (APIs) for EHRs (2020)

CMS Interoperability and Patient Access Final Rule includes APIs for certain health insurers (2020)

ONC Continues to Refine Rules for Information Sharing

Looking Forward
2024+

Continued refinement of payer APIs to include information on Prior Authorizations

"Go Live" for the Trusted Exchange Framework and Common Agreement (TEFCA)

Interoperability MATTERS

Why APIs?

- Allow access to medical records from third-party organizations "without special effort"
- Enable use of health apps
- Bring medical records technology in line with common internet-based standards
- ONC research indicates that individuals are using apps to access their records
- Reality check: Only 2% of patients used an app to combine medical information from different patient portals or online medical records in 2022.

Strawley C. and Richwine C. Individuals' Access and Use of Patient Portals and Smartphone Health Apps, 2022. Office of the National Coordinator for Health Information Technology. Data Brief: 69. 2023
Individuals' Access and Use of Patient Portals and Smartphone Health Apps, 2022 (healthit.gov)

Panel A: Methods individuals used to access their online medical records, 2022

- Don't know, 1%
- Accessed using app only, 19%
- Accessed using web only, 48%
- Accessed using both app and website, 32%
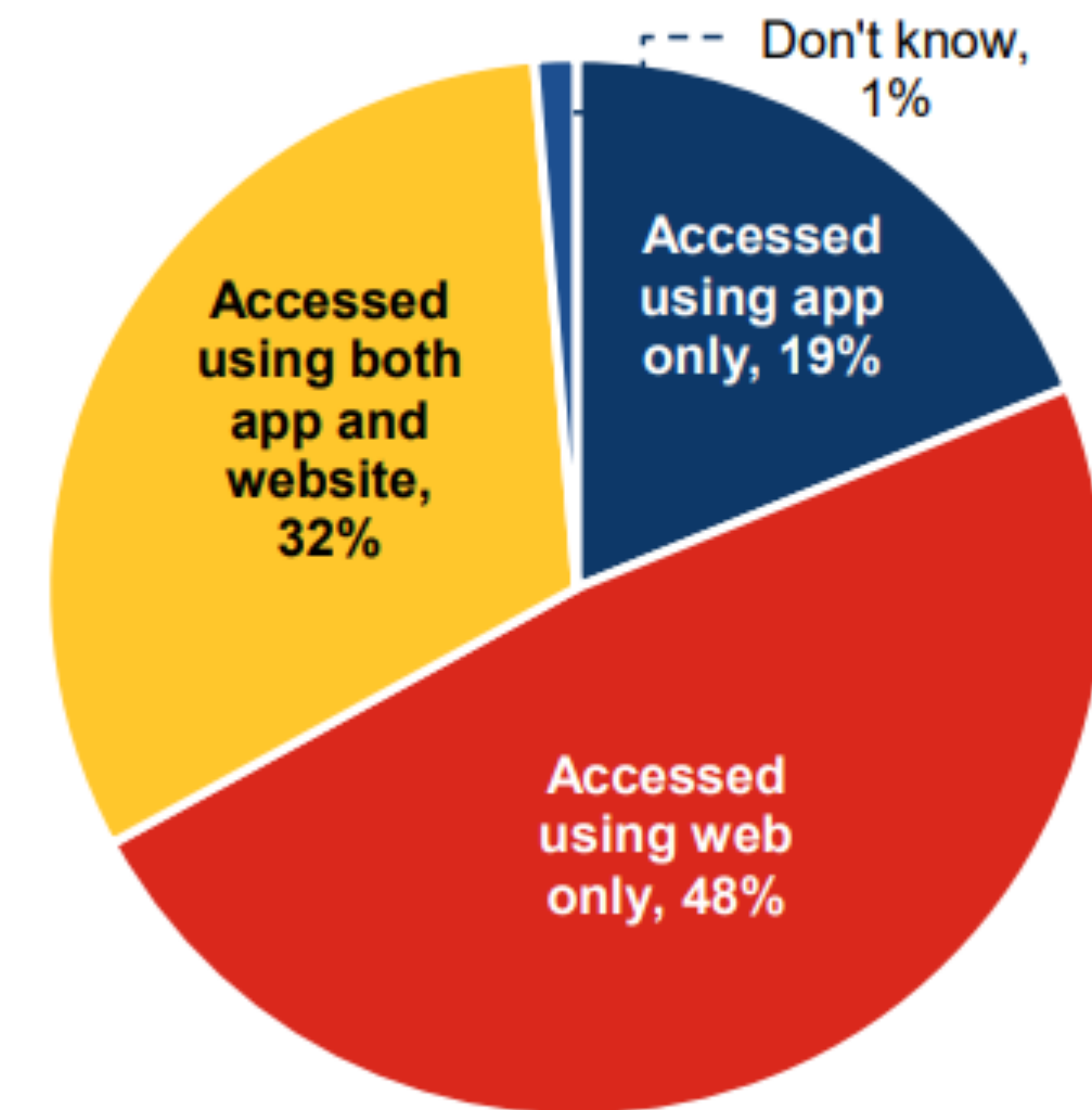
Patient Identification

How Do We Match Patients to Their Records?

- We do not have a national patient ID
  - HIPAA called for one, but it has never been implemented
  - Legislators have blocked implementation through budget policy
    - Patient Matching and Transparency in Certified Health IT (Match IT) Act of 2024 introduced in February by Representative Mike Kelly (R-PA) and Representative Bill Foster (D-IL)
- Insurers and health care providers maintain their own identifiers, but they only apply to that specific entity
  - Insurance coverage details are shared with providers to facilitate claims but they change when you change plans or insurers
  - Providers maintain their own "master patient indexes" or medical record numbers, but have trouble with duplicates
- A single ID would also have challenges

Patient Matching

- Match on demographic variables
- Dependent on having good quality data: accuracy, completeness and formatting differences
- Industry has focused on data collection and use of data standards to increase accuracy
- TEFCA requires use of all available data in standardized formats to improve matching

GAO-19-197, Health Information Technology: Approaches and Challenges to Electronically Matching Patients' Records across Providers

Figure 1: Examples of Data Quality Issues That Can Affect Patient Record Matching

DEMOGRAPHIC INFORMATION[a]

Legal name: Johnathan Michael Smith
Nickname: Mike
Sex: Male
Date Of Birth (DOB): September 7, 1970
Current address: 174 Main Drive Springfield, NV 87064
Current phone: 500-555-5309
Old address: 145 Party Drive Springfield, NV 87064
Email address: mike_smith1@xyz.com
Social Security Number (SSN): 123-45-6789

EXAMPLES OF HOW COLLECTION OF DEMOGRAPHIC INFORMATION CAN VARY ACROSS PROVIDERS

PRIMARY CARE DOCTOR'S RECORD
Name: Johnathan M. Smith
Sex: M
DOB: 07/09/1970
Address: 145 Party Drive Springfield, NV 87064
Phone: 5005555390
Email: mike_smith1@xyz.com
SSN: XXX-XX-6789

Accuracy
- Phone number incorrect
- Address not current

Completeness
- Full middle name not included
- Does not contain full SSN

Formatting
- Sex abbreviated
- Phone number does not contain dashes
- DOB formatted as DD/MM/YYYY

CARDIOLOGIST'S RECORD
Name: Smith Mike
Sex: Male
DOB: 09/07/1970
Address: 174 Main Dr. Springfield, NV 87064
Phone: 500-555-5309
Email: mike_smith1@xyz.com
SSN: Not collected

Accuracy
- Nickname entered rather than legal name

Completeness
- SSN not collected

Formatting
- Street type abbreviated
- Phone number contains dashes
- Last name listed first

ALLERGIST'S RECORD
Name: Jonathan M. Smithe
Sex: UNK
DOB: 09071970
Address: 174 Main Drive Springfield, NV 87064
Phone: 500-555-5309
Email: Not collected
SSN: 999-99-9999

Accuracy
- First and last name spelled incorrectly

Completeness
- Sex, email address, and SSN not collected

Formatting
- Special characters removed from DOB
- SSN missing and denoted with placeholder value

LAB RESULTS RECORD
Name: Smith, Johna.
Sex: 1
DOB: 09/07/1971
Address: 17 Main Drive Springfield, NV 87046
Phone: Not collected
Email: Not collected
SSN: Not collected

Accuracy
- Address entered incorrectly

Completeness
- First name is abbreviated to fit on label
- Phone number, email address, and SSN not collected

Formatting
- Sex coded with numerical variable

Source: GAO analysis. | GAO-19-197

[a]Demographic information refers to both the demographic and personally identifiable information used in patient record matching. Demographic information may include sex or age. Personally identifiable information may include name, date and place of birth, or Social Security number.

PHRs IRL

Lessons from the frontlines of creating a patient PHR

ciitizen ⊡

- Platform enabling patients – in particular patients with rare disorders - to gather, use and share their comprehensive health information
  - Information, once in the Ciitizen profile, is under the control of the individual – who can share, or not, as they please
- Leverage the HIPAA Right of Access to obtain information for the Ciitizen profile.

Potential routes for patient access ("IAS")

- Written requests submitted to physician and hospital Health Information Management departments/offices (& Release of Information Vendors)

- Patient connects to FHIR APIs at each location where they have received care.

- Patient sends query through HIEs or national networks

- IAS request via TEFCA

State of HIPAA Access Compliance (HIM route)

- Ciitizen maintains scorecard measuring compliance (and potential compliance) with the HIPAA Right of Access - updates automatically with each request.
- Initially published a white paper based on responses to actual patient requests and survey of telephone responses to questions about access processes (@3000 hospitals)
- **Goal is to improve patient's ability to seamlessly access their health information**
- www.ciitizen/scorecard (white paper at https://www.medrxiv.org/content/10.1101/19004291v1)

THE PATIENT RECORD SCORECARD

The majority of medical record providers are not compliant with the HIPAA Right of Access.

Survey of ~3,000 top medical record facilities from August 2018-May 2019.

VIEW SCORECARD

ciitzen

Scorecard Star Rating Key

NON-HIPAA COMPLIANT	HIPAA COMPLIANT Substantial Intervention	STAR RATING - Collapse Requirements HIPAA COMPLIANT Minimal Intervention	HIPAA COMPLIANT Seamless Process	HIPAA COMPLIANT Patient Focused
★	★★	★★★	★★★★	★★★★★
Accepts Requests by Email or Fax	Multiple Supervisor Interventions	One Supervisor Intervention	No Supervisor Intervention	No Supervisor Intervention Accepts External Request Forms Sends Records in 5 Days or Less No Fees

State of HIPAA Access Compliance

- Scorecard & Survey initially revealed more than 50% noncompliant – or potentially noncompliant) - numbers have improved but still issues.
  - o Most common issue (both scorecard and survey): failure to send in form/format requested by patients, to designated third party
  - o Fees also potential area of noncompliance (state law reliance misplaced) (but only on survey – scorecard experience was largely positive on fees)
- Front line staff (employed by provider and at records vendors) who deal directly with requests often not well informed of HIPAA obligations
- Challenges to distinguishing between third party requests and those from patients seeking to send to designee (such as an app or personal health record service)

CARIN Alliance Best Practice Recommendations (implementation of patient-facing FHIR-APIs)

- Improve the Knowledge Base
- Improve App Registration
- Improve Sandbox Testing
- Improve Product Configuration and Release Management
- Improve Technical Infrastructure
- Improve Ongoing Support & Maintenance

Challenges of Network Access

- ID proofing/authentication requirements - is this sufficiently easy for patients yet sufficiently rigorous to handle fraud/spoofing risk?
- Consent - how do we know the patient has authorized the query/access?
- Patient Matching!
  o Only verifiable identity attributes may be submitted - does this set the bar too high?
- Education for patients on potential privacy risks?

Open Discussion

Contact Us

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amccollister@sequoiaproject.org

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