



Consumer Engagement Strategy Workgroup Meeting Four

June 25, 2024

Meeting Agenda

- Welcome – 2 minutes
- Workgroup charge – 5 minutes
- Meeting Three Recap – 10 minutes
- Presentation – Jennier Blumenthal and Brendan Keeler – 20 minutes
- Open Discussion and Q&A – 15 minutes
- Meeting wrap up and next steps – 5 minutes

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, BlulP
- 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 Charge

Consumer Engagement Strategy Workgroup



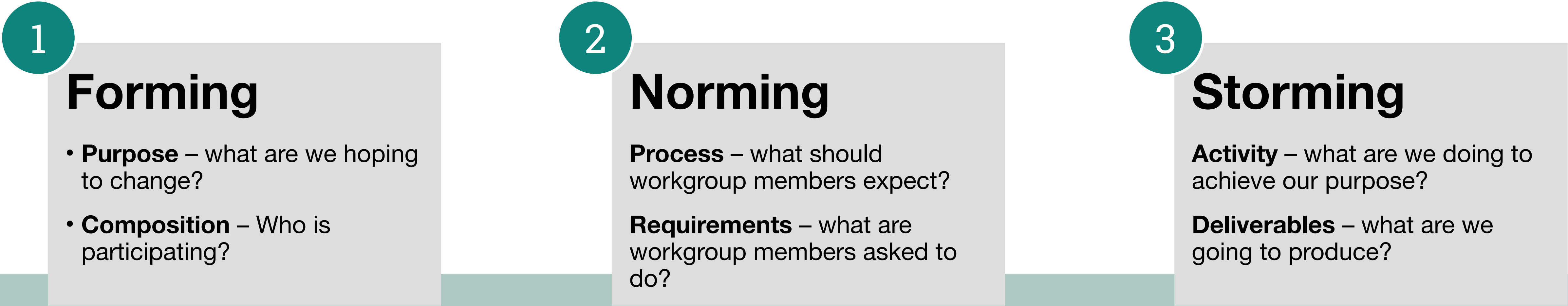
Workgroup Vision

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.

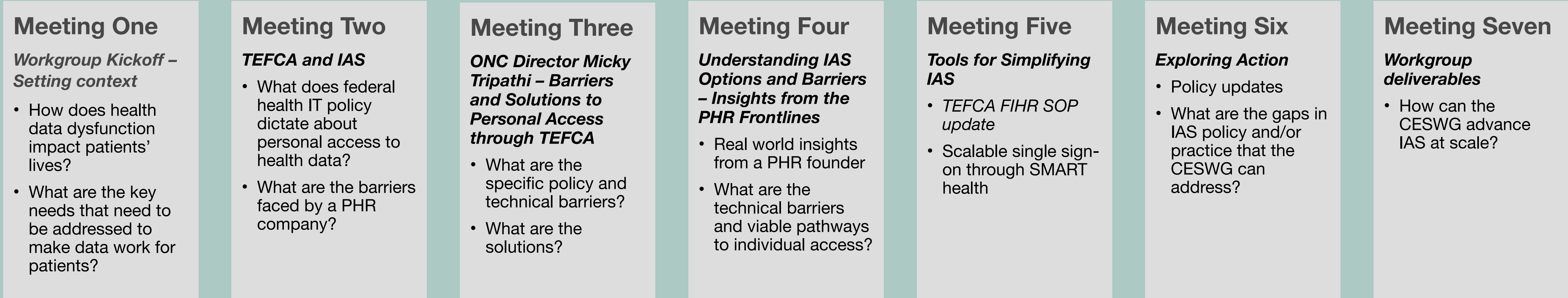
Consumer Engagement Strategy Workgroup – Our Evolving Roadmap



We are here!



March April May June July August September



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

Meeting Three Recap

Anna's attempt to summarize Micky Tripathi's Master Class on Individual Access rights, options, barriers and pathways for scaling

ONC Overview – Limited, Focused Authority

Office of the National Coordinator for Health IT

- Founded in 2004 by executive order, established in statute in 2009
- ONC is charged with formulating the **federal government's health IT strategy** to advance national goals for better and safer health care through an **interoperable nationwide health IT infrastructure**



Laying the foundation of EHRs across the industry

- \$40B CMS investment to subsidize EHRs for hospitals and ambulatory providers
- ONC certification of EHR systems to support CMS and CDC programs
- ONC certification now covers EHRs used by 97% of hospitals and 86% of ambulatory providers



Leveraging EHRs to drive value

- **Information blocking:** Prohibits providers, technology developers, and health information networks from interfering with access, exchange, and use of electronic health information
- **Standards:** Requires access to information through APIs "without special effort"
- **TEFCA:** Requires nationwide governance for health information exchange networks – Trusted Exchange Framework and Common Agreement

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Key Areas of Focus

Build the digital foundation

- Data standards
- Health IT gaps

Make interoperability easy

- TEFCA
- APIs

Promote information sharing

- Enforce information-blocking rules
- HHS Health IT Alignment policy

Ensure responsible use of digital information

- Health-equity-by-design principles
- Transparency in areas such as AI use

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Limited Budget

- Since 2004...authority and scope have expanded, but
- Budget has not kept pace
 - Starting budget in 2004 – \$52 million
 - Current budget in 2024 – \$65 million

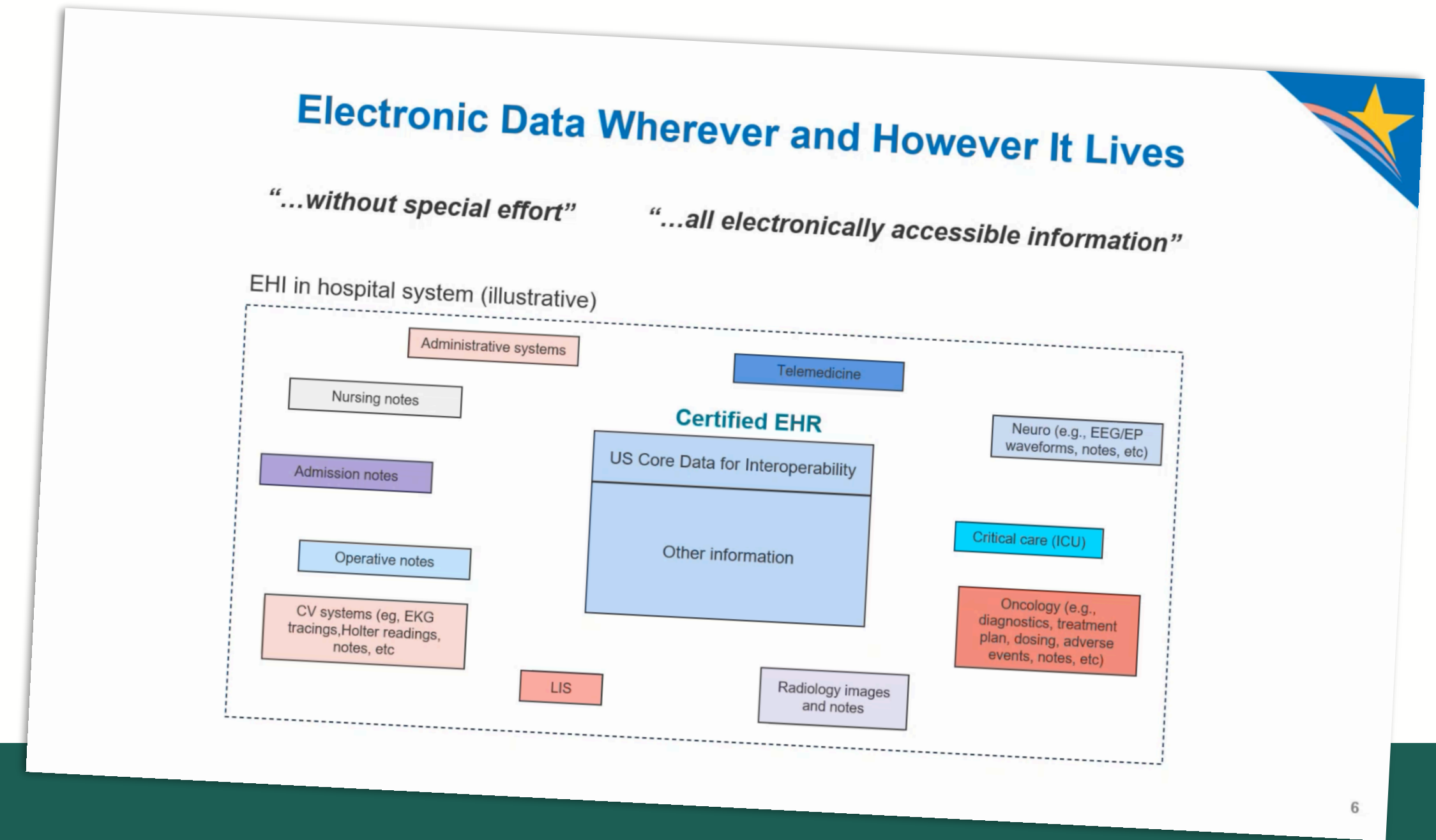
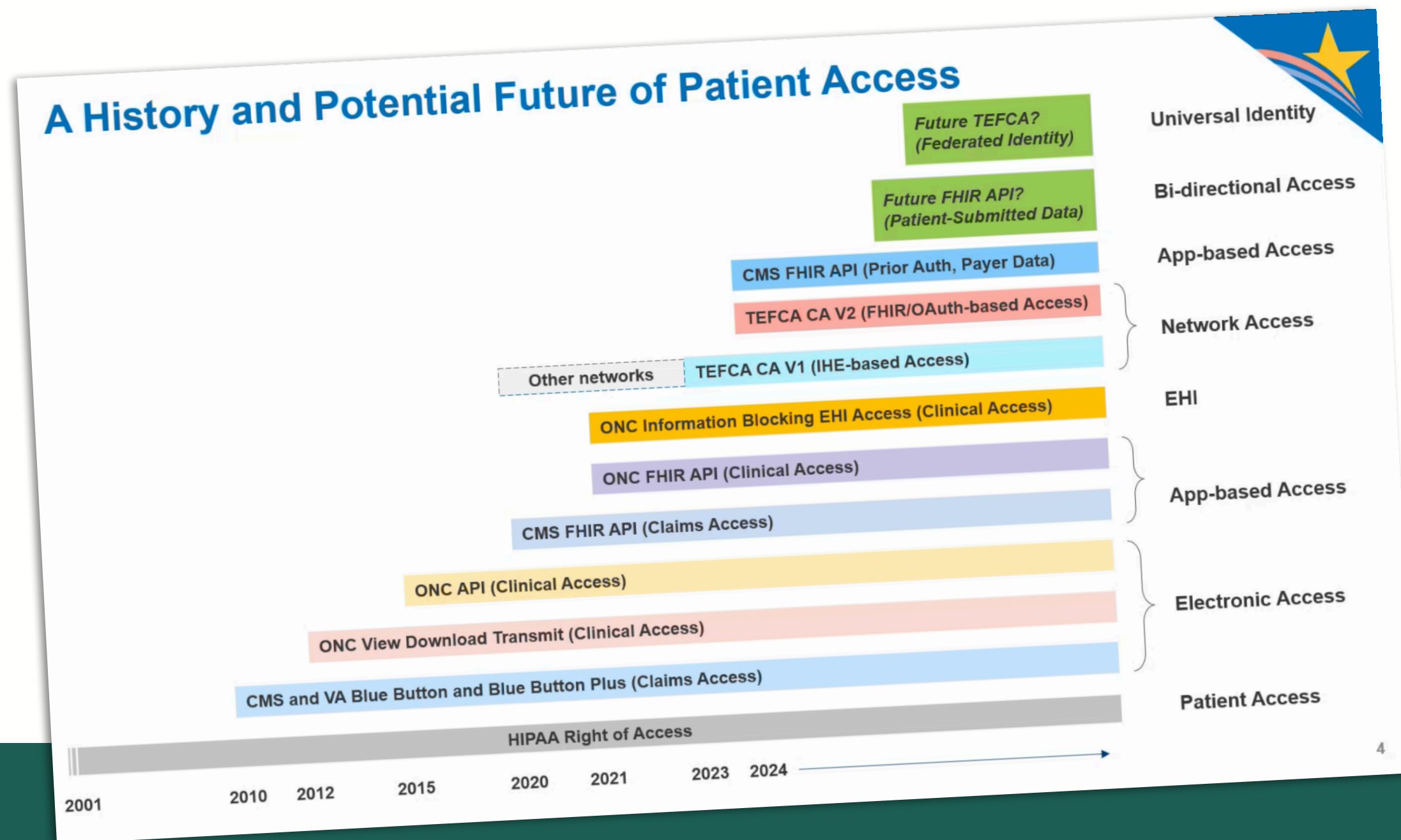
Limited Authority

- Defined authorities
 - Certification of EHR systems
 - Define standards
 - Information blocking

Key Areas of Focus

- Build the digital foundation
- Make interoperability easy
- Promote information sharing
- Ensure responsible use of data

Individual Right to Data Access – Emergence and Definition



Patient Access

- Right to access data has emerged and evolved over decades
- Combination of legislation and regulatory action
- ONC works closely with CMS to define and expand
- ONC defines standards/process
- CMS incentivizes

What data can we get?

- Statute – all electronic health information (EHI)

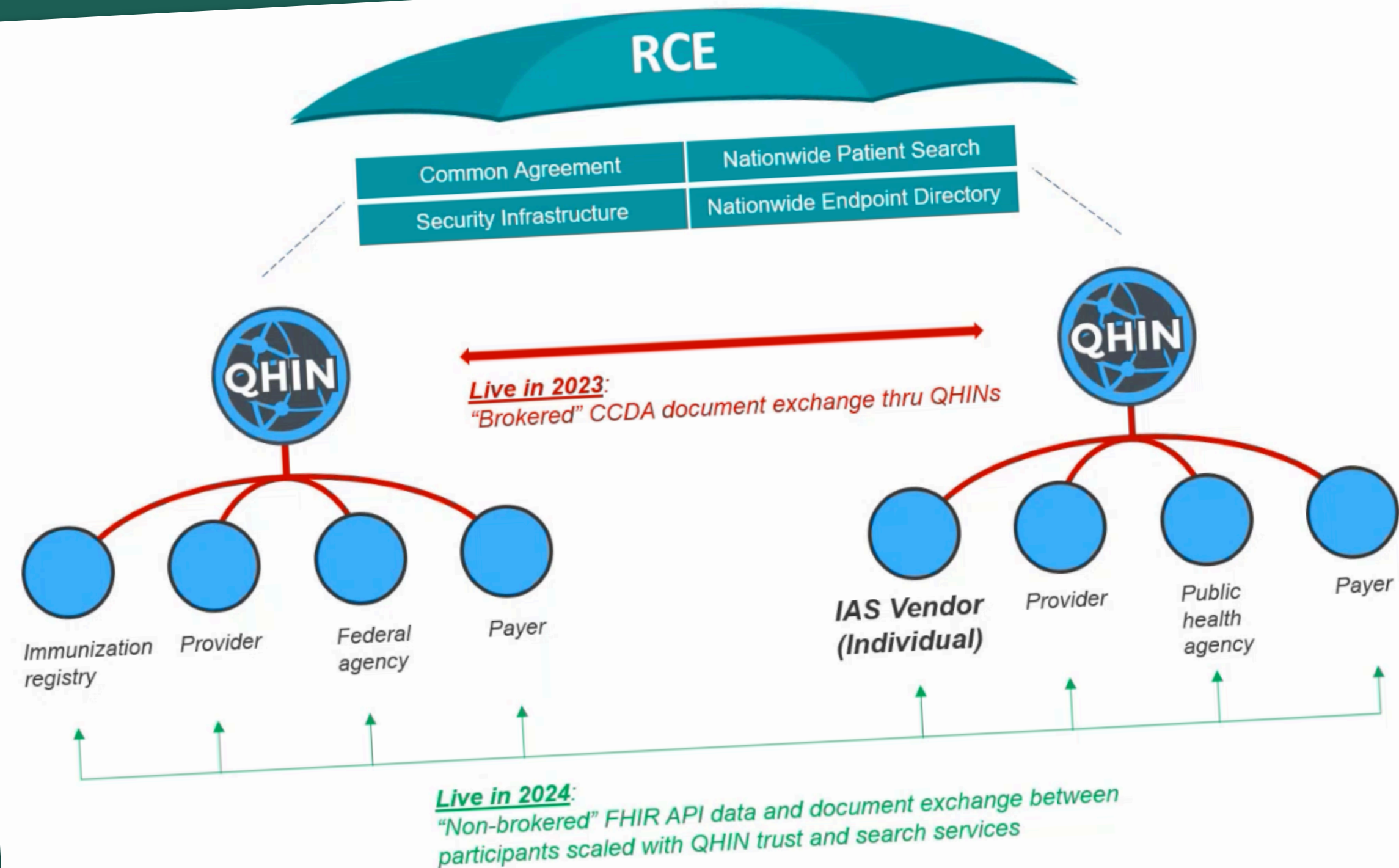
But...

- Not all EHI is in EHR
- USCDI – required
- Other EHR data elements can vary
- Categories drawn from HIPAA rule
- Providers determine what data is in the defined category – can vary
- Many data types not in EHR

Additional challenges

- Ban on national patient ID number
- HHS OCR/HIPAA policy on impermissible access
- ONC limited authority
- B2B facilitates B2C
- Without Trust, nothing is shared

IAS Through TEFCA



TEFCA

- Voluntary
- Based on TRUST
 - RCE
 - Other network participants
- All participants must adhere to TEFCA requirements to participate in exchange
- If rules too onerous or a participant loses trust, they can drop out

Participant Requirements

- Must adhere to HIPAA
- Must exchange data for any of six defined purposes (more coming)
- Includes Individual Access Services (IAS)
 - PHRs
 - Consumer-focused apps

TEFCA V1

- Live in December, 2023
- CCDA exchange through QHINs

TEFCA V2

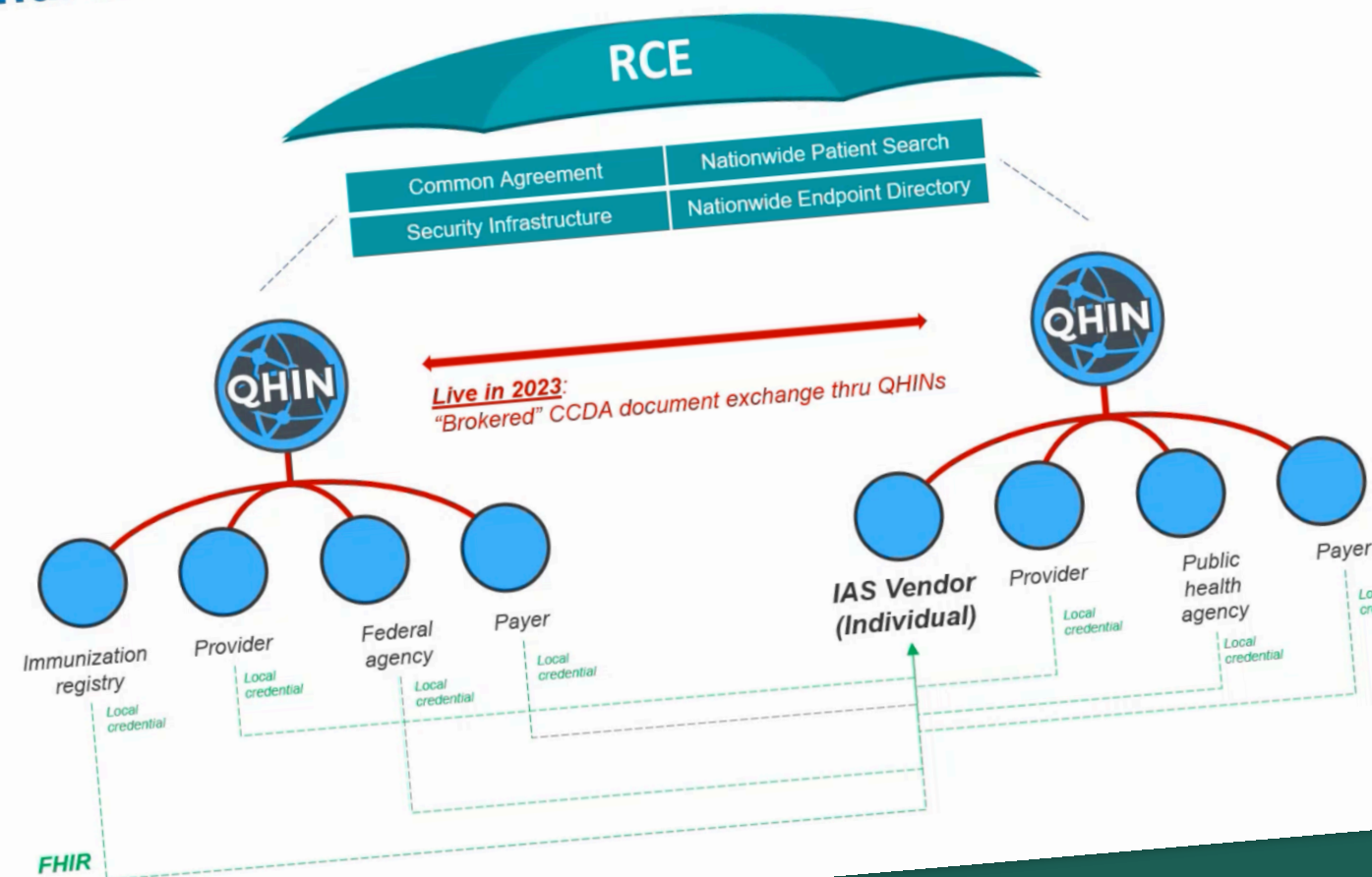
- Live in May 2024
- FHIR exchange directly among participants
- Awaiting release of SOPs for FHIR exchange

21st Century Cures Act

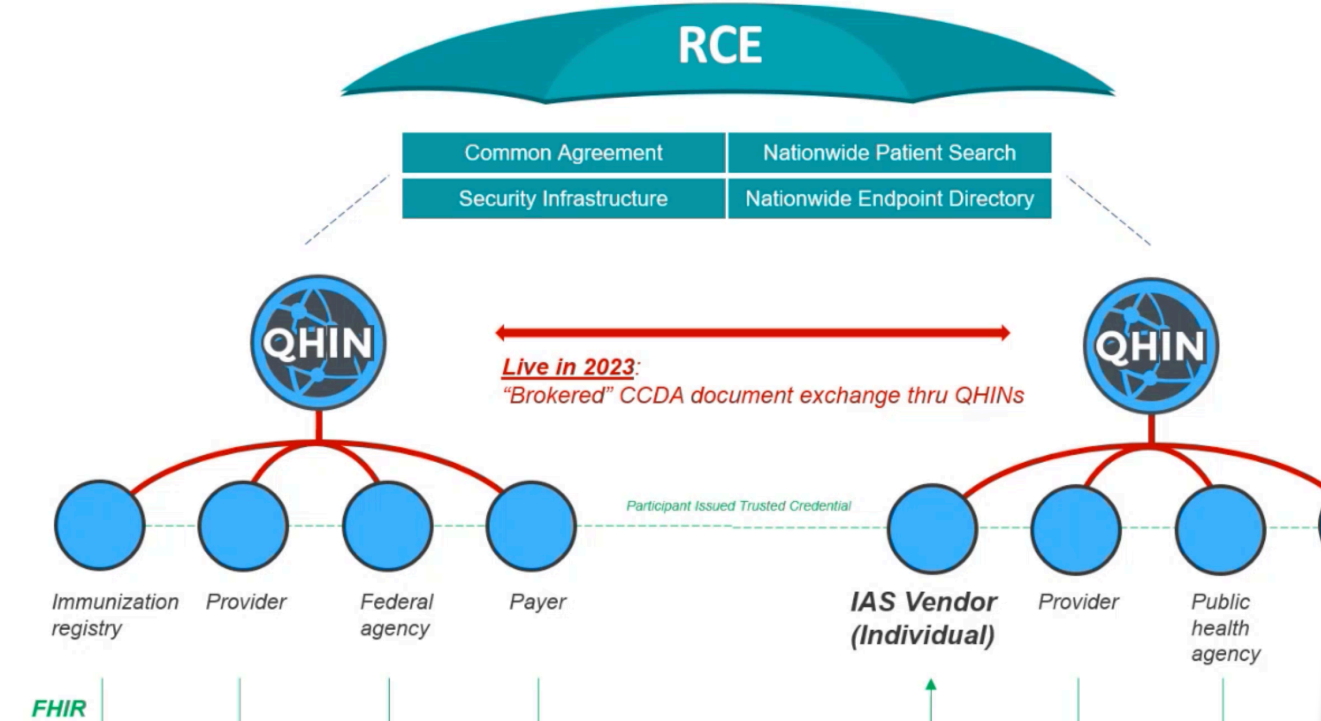
"[T]he National Coordinator shall convene ... stakeholders to develop or support a **trusted exchange framework** for trust policies and practices and for a **common agreement** for exchange between health information networks."

IAS Through TEFCA – Individual Access at Scale

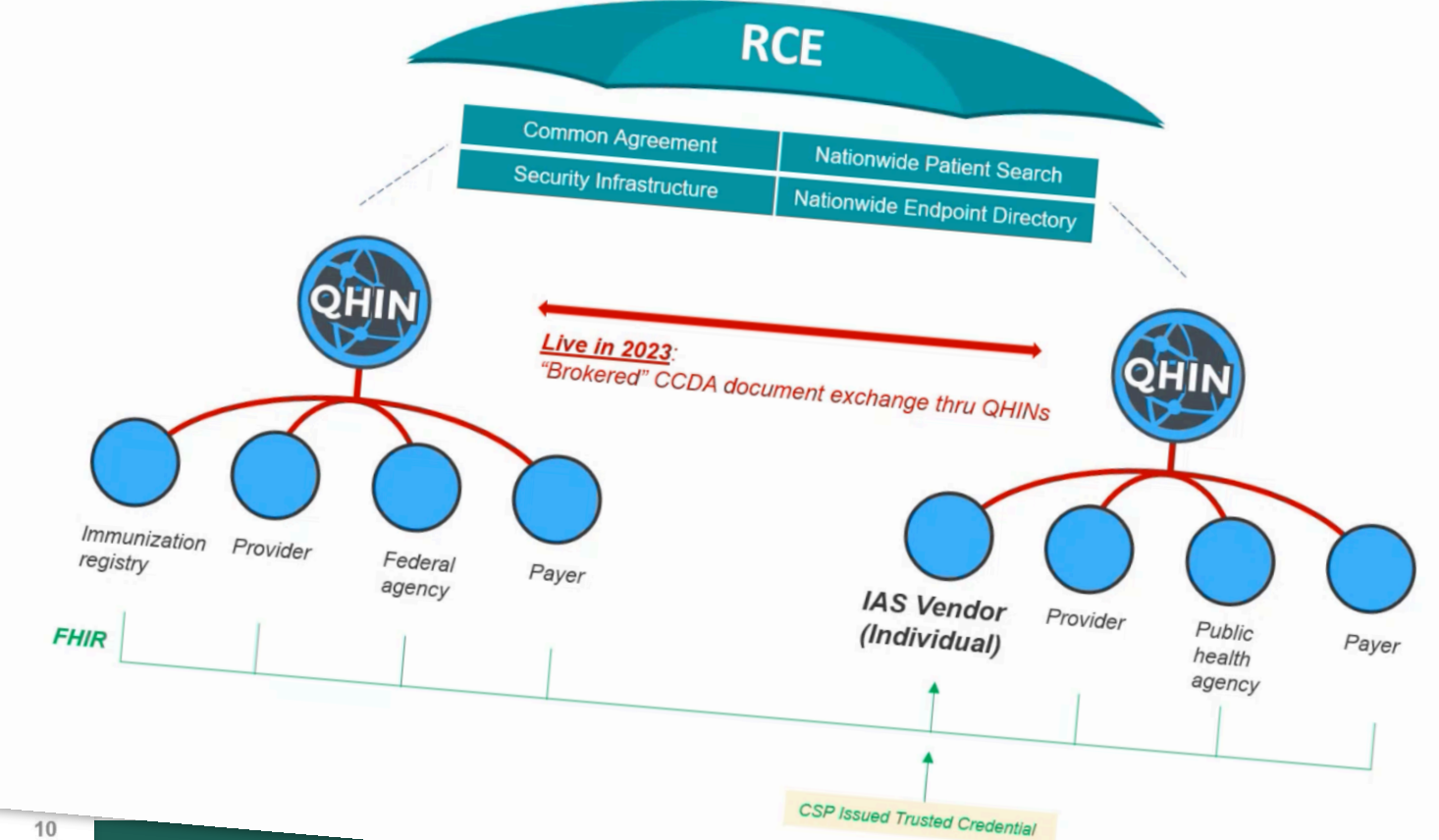
Individual Access initial level: Participant-Issued Credentials



Individual Access potential next level: Trusted Participant Credentials



Individual Access potential next level: Patient-Controlled Credential



Level One

- Provider accounts
- Username and passwords for each institution or network
- Requires patients/IAS providers to enable sign-ons for each institutions
- If network member unsure if it's the right patient, can refuse
- HIPAA/OCR policy on impermissible disclosures

Level Two

- Network member issued credential
- Single trust credential issued by one provider shared across all providers/institutions
- Technically possible now – SMART HEALTH vaccine credential system
- Requires framework and trust

Level Three

- Credential service providers
- Clear or ID Me
- Would require credential service providers to be part of trusted network

Patient Access: Intent vs Implementation

Jennifer Blumenthal, Founder and Product Director, One Record
Brendan Keeler, Advisor FlexPa

Placeholder – Presenter Slides

Jennifer Blumenthal, Product Director, OneRecord

<https://www.linkedin.com/in/jenniferblumenthal/>

Jennifer Blumenthal is Product Director, OneRecord, at Milliman IntelliScript, where she oversees the developing solution to deliver electronic health records (EHR) with consent for insurance underwriting and clinical trials.

As an expert in everything related to patient access and the 21st Century Cures Act, she also helps consumers access, aggregate, and share their healthcare data with the people and organizations they trust using the OneRecord app. Jennifer sits on the board of directors for the Sequoia Project, is Chair of Consumer-Facing Technology at Carequality's Steering Committee, and Chairs the Privacy and Security Committee at the CommonWell Health Alliance and is an active member of the CARIN Alliance.

Brendan Keeler, Adviser, Flexpa

<https://www.linkedin.com/in/brendan-keeler/>

<https://healthapiguy.substack.com/>

Brendan Keeler has a strong background in product management and advisory roles within the healthcare industry. Brendan currently serves as the Head of Product at Flexpa, where they have been since September 2022. Before that, they worked as an Advisor at Flexpa from April 2022 to September 2022.

In addition to their role at Flexpa, Brendan has also held advisory positions at various companies, including Vitalize Care, Revero, Elion, and Azra Care, all starting in 2022. Brendan has provided their expertise and guidance to these companies in implementing effective healthcare solutions.

Prior to their advisory roles, Brendan worked at Zus Health as a Senior Product Manager from September 2021 to September 2022. Before that, they held the position of Product Manager at Zus Health from April 2021 to February 2022.

Brendan also has experience as a Product Manager, Product Owner, and Solutions Engineer at Redox, a healthcare API company. Brendan joined Redox in October 2018 and held various roles until April 2021. As a Solutions Engineer, Brendan played a significant role in enabling software integration with electronic health records and improving the quality of patient care.

Before joining Redox, Brendan was a member of the Carequality Advisory Council at The Sequoia Project from December 2020 to April 2021. Brendan also worked as a self-employed Integration Consultant from May 2018 to October 2018, providing integration services to healthcare organizations.

Brendan's early career includes significant experience at Epic, a leading healthcare software company. Brendan served as the Integration Product Lead, Europe from March 2016 to May 2018, the Integration Manager, International from December 2013 to May 2018, and the Integration Manager from August 2012 to December 2013. These roles involved managing and overseeing the integration of Epic's software with various healthcare systems.

Overall, Brendan Keeler has a diverse and extensive background in product management, advisory roles, and integration consulting within the healthcare industry.

Brendan Keeler attended the University of Notre Dame from 2008 to 2012, where they obtained a Bachelor of Science (B.S.) degree in Computer Engineering. In 2010, they also briefly attended The University of Western Australia, although it is unspecified whether they obtained any degree or field of study from there. Additionally, Brendan Keeler has obtained several certifications from Epic, including Care Everywhere in April 2015, Radiant in February 2014, Ambulatory in October 2012, and Bridges in October 2012.

Questions, Answers and Discussion

Thank You!!



Contact Us

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

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