

Empowering Patients with Access to Their Medical Records through Nationwide Networks

- Uncovering Success and Barriers



Glenn Keet – Selfii
A. John Blair III, MD – MedAllies
Marcos Domiciano – CLEAR
Jenn Searls – Connie

Tuesday, October 15, 2024



Agenda

- 1 Introductions
- 2 Centering the Patient
- 3 Patient Access Background
- 4 Barriers Across the Landscape
- 5 Trying a New Path
- 6 Lessons Learned
- 7 Roadmap to Realize IAS
- 8 Q & A



**A. John Blair,
III, MD, F.A.C.S**
CEO at MedAllies

23 years MedAllies CEO

15 years president of Taconic IPA

26 years medical practice



**Marcos
Domiciano**

Senior Director of Healthcare
Business Development at
CLEAR

16+ years in Health Tech

Helped commercialize start-ups such
as Zocdoc, TytoCare and Vitals with
a focus on patient access &
experience



Jenn Searls
Executive Director
at Connie

25+ years in Health Tech

Former COO at clinically integrated
network of 5 hospitals

Former CIO at ProHealth
Physicians, now owned by Optum



Glenn Keet
General Manager,
HIE at Selfii

Health IT for 38 years

Founder of Axolotl 1995 – 2010

Clinical Trial software, NLP/AI

Centering *the Patient* in "Patient Access"

Selfii's Origin Story

- Anil Sethi's drive for healthcare innovation stems from his sister Tania's late-stage cancer diagnosis in 2017
- Anil became her full-time caregiver, navigating 2,200 pages of records from HIPAA access and 40+ pages in patient portals
- He realized there needed to be a better use for this unstructured medical data

What We're Solving

- Tackles fragmented data challenges, working to harness the full power of health data
- Allows patients to gain meaningful insights into their health journey
- Helps data holders comply with regulations like the 21st Century Cures Act
- Ensures seamless access to complete medical records

The logo for Selfii, featuring the word "Selfii" in a blue, cursive script font with a period at the end.

#Civitas2024

History 101 – Patient Access

Key Milestones:

- Microsoft Health Vault – 2007
- iPhone 2007
- HITECH 2009
- Cures Act 2017 (implemented 2021; fines 2023)
- CA DxF QHIOs & TEFCA first QHINs – late 2023

Patient Access Background

ONC Cures Act Final Rule

- Mandates patient access to all EHI at no cost and in a format convenient to the patient
- Prohibits information blocking by HIEs and HINs (*there are only a few who fit one of the remaining applicable exemptions defined by the ONC/ASTP.*)

Carequality & TEFCA

- Facilitates patient access across a network of networks



Barriers Across the Landscape

- **Structural Barriers:** Despite significant investments in interoperability, patients and healthcare stakeholders continue to struggle with fragmented records and limited access to essential information.
- **Complex Regulatory Landscape:** Navigating evolving federal and state data sharing regulations can be burdensome on organizations.
- **Data Privacy and Security:** As patients become more aware of data risks, the demand for secure and compliant access to their information is more urgent than ever.



CT's Mandate

•Goals for statewide HIE include:

- Allow real-time, secure access to patient health information and complete medical records across all health care provider settings;
- Provide patients with secure electronic access to their health information;
- Allow voluntary participation by patients to access their health information at no cost.

Source: [Conn. Gen. Stat. § 17b-59d \(2017\)](#)

Trying a New Path



- Selfii runs largest network for patient access in the country - Cures Gateway connects 20 HIEs covering 128M patients
- Selfii connects to Carequality and TEFCA via MedAllies
- Selfii has a free personal health app for any patient who wants it, and provides free IdP via Clear
- Selfii recently acquired TripleBlind, a privacy preserving encryption solution that renders anonymization moot.



- CLEAR is a connected health identity powering trusted experiences across airports, healthcare and consumer partnerships
- 26M active members across the U.S.
- 200M identity verifications to date
- IAL2/AAL2, SOC 2 Type2, HIPAA and cybersecurity certifications
- Powering hospitals, HIE's, apps and healthcare data platforms



- Independent nonprofit organization
- Incorporated in 2019 to be the designated statewide HIE for state
- Connected to all of the health systems in the state and more than 2,000 other healthcare organizations
- 5M unique patients in our MPI
- >70,000 patient queries each month







- MedAllies is a health IT company focused on secure, interoperable health data exchange
- A key partner in nationwide interoperability efforts with TEFCA
- Serves over 700 hospitals, 5,000 organizations, and 125,000 healthcare providers

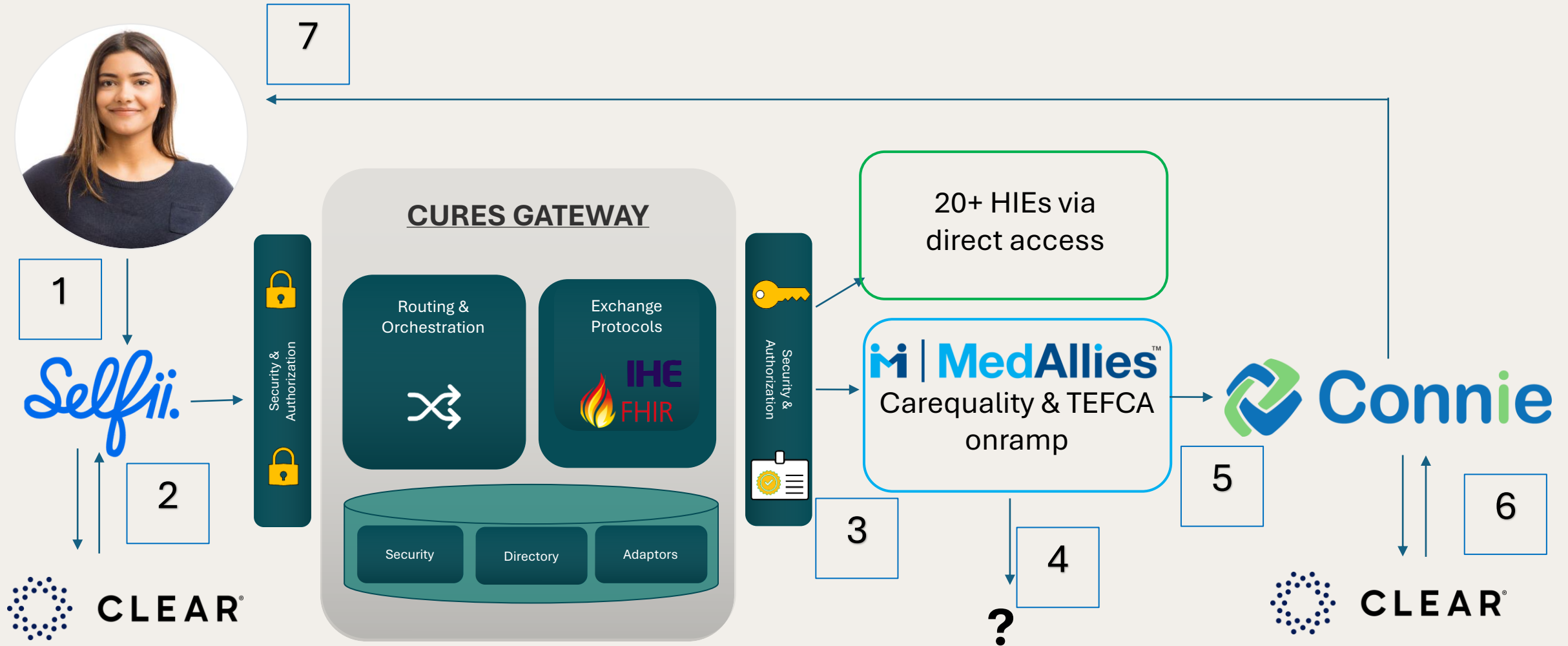
Addressing New Security Requirements

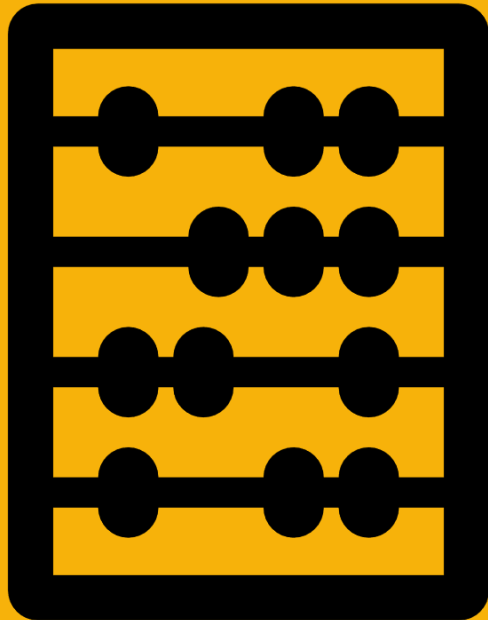
- Carequality implements change to rules in July 2023
 - Kantara certified vendor for IAL2 and AAL2
 - Required to submit a token containing verified credentials
 - Optional validation of token by data responder (HIE, provider)
- TEFCA aligning with Carequality security directions

Kantara-Initiative full service certified providers

Company	Class of Approval	Name of the service	Assurance Levels
 1KOSMOS BlockID	NIST 800-63 rev.3	BlockID Verify and Authenticate Service	IAL2; AAL2
 CLEAR [®]	NIST 800-63 rev.3	High Assurance Mobile Verification & Authentication (CLEAR Verified)	IAL2; AAL2
 ID.me	NIST 800-63 rev.3	Identity Gateway	IAL2; AAL2
 EXOSTAR [®] We build trust.	NIST 800-63 rev.3	Exostar OTP	IAL2; AAL2

New Workflow End to End





Findings & Advice

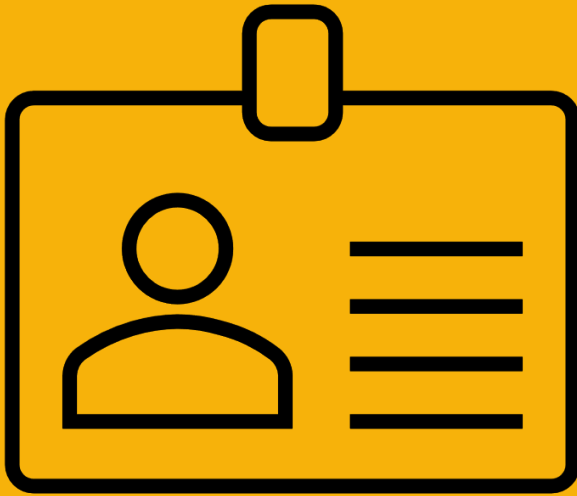
- Token expires in 5 minutes
 - Many hops can lead to delays
 - Start without validating token
 - Only add validation after other errors are addressed

Findings & Advice



- Test smart! Can only get token for real people, so:
 - Manually compare ID with MPI
 - Have they moved recently?
 - Ask if cell phone in their name
 - Common corroboration check
 - Favors run out after 10th try!

Findings & Advice

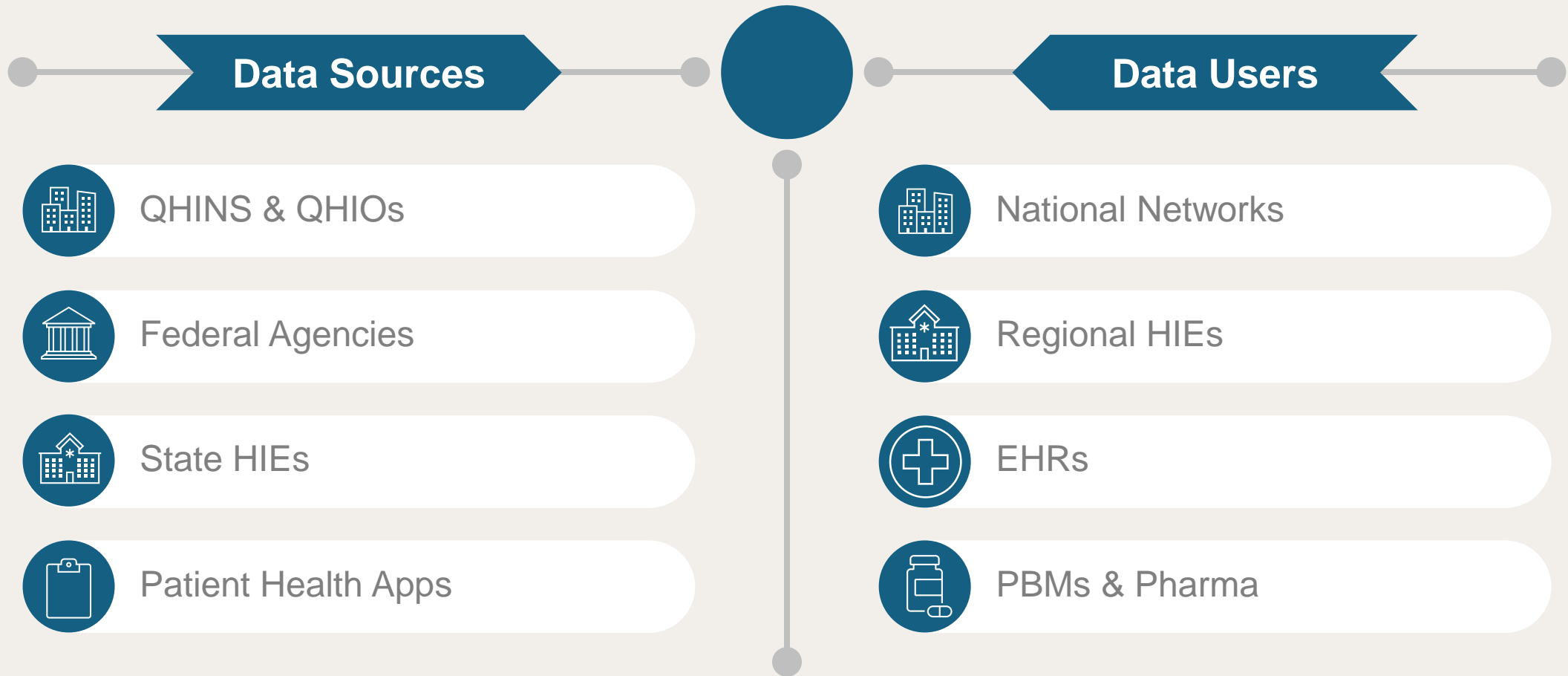


- Demographic match weights
 - set the cell phone high
 - set address low
- Demographic matching (given above) is quite successful

Where to go from here?

- The country needs more Carequality responders
 - >55,000 respond to treatment PoU
 - <1,500 respond to Patient Request PoU
- Advanced Patient Matching Logic
 - Works very well when tuned, high hit rate, 0 mismatches
- Addressing Security Concerns
 - IAL is nearly impossible to spoof; treatment is easy to abuse
 - Responding to a covered entity doesn't really protect you more
- Epic and Individual Access
 - Permissions for individual access through MyChart

Key Players & Who's Missing



Enhancing Policy Levers



Federal Influence

- Policy Enforcement
- Funding to Incentivize Adoption



State-Level Efforts

State Regulations and Policy (ex: DxF)
State HIE Adoption and Support



Public and Private Partnerships

Crucial infrastructure and technology to achieve government policy



Open Discussion + Questions & Answers





Selfie.com

Thank you!

