

Empowering Patients with Data to Improve Health Equity

Grace Cordovano, Patient Advocate
Sara Abrams, Rochester RHIO
Craig Behm, CRISP
Deven McGraw, Invitae
Dan Porreca, HealtheLink

August 22, 2022

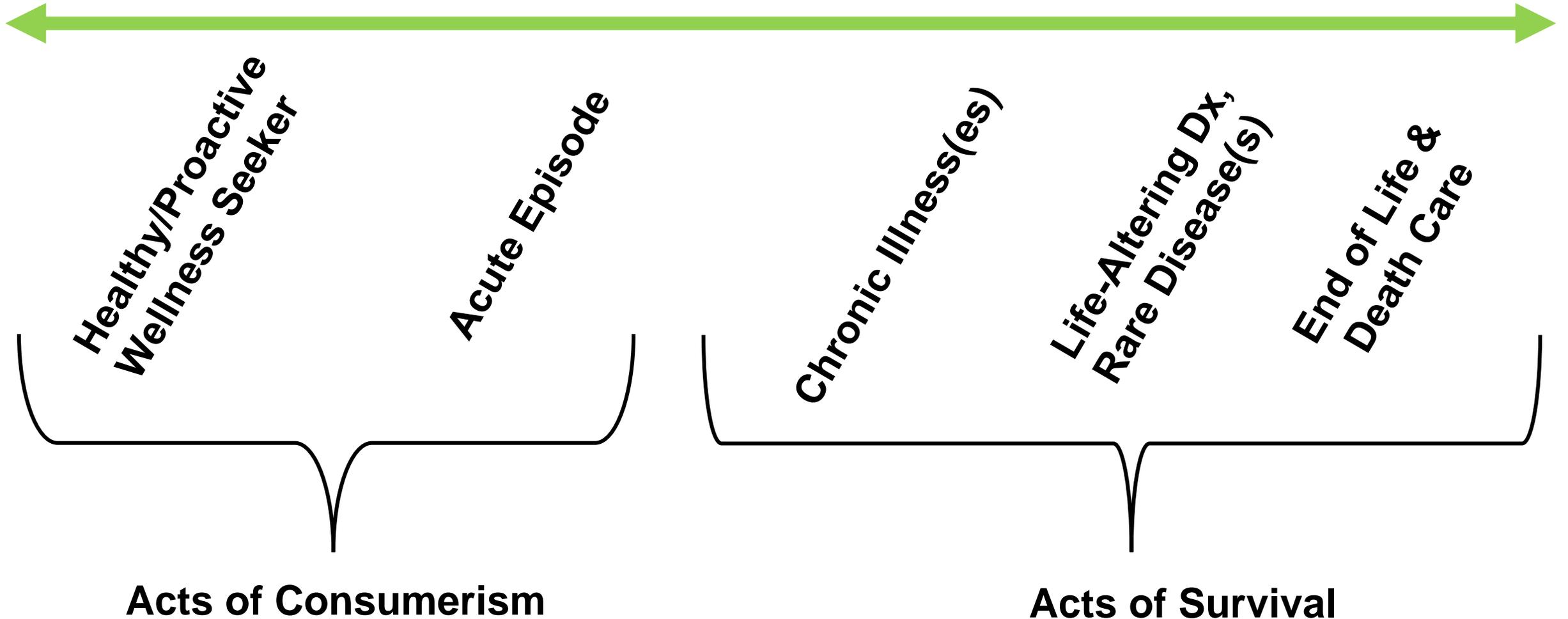
#Together4Health2022



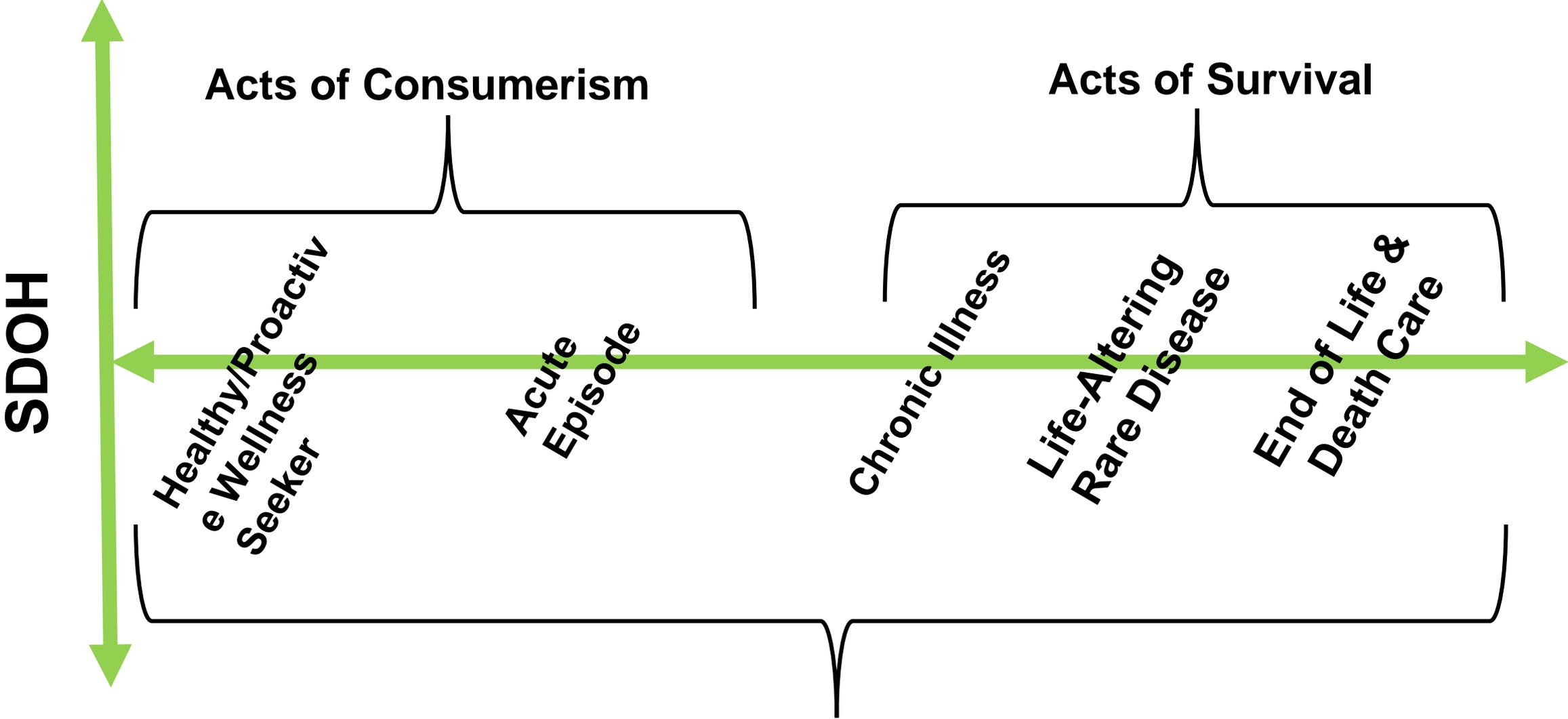
We will fill all patients!
We will fill all beds!



Patient Life Experience Spectrum



Patient Life Experience Spectrum



Acts of Survival



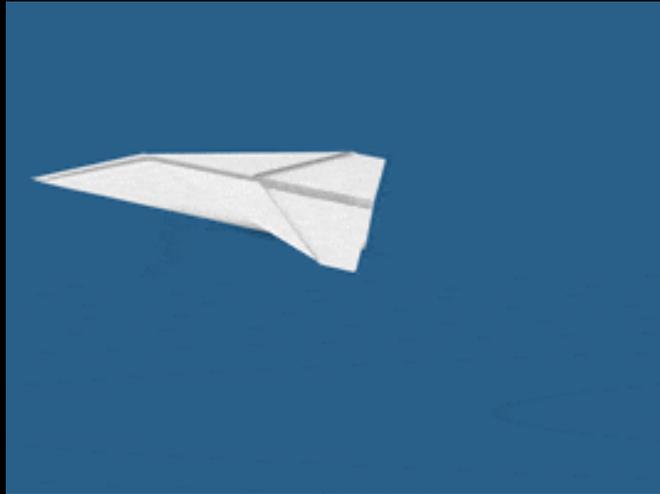
Grace Cordovano, PhD, BCPA @GraceCordovano

**FACT: Patients want to live their
best life with a diagnosis**

Patient Administrative Burden

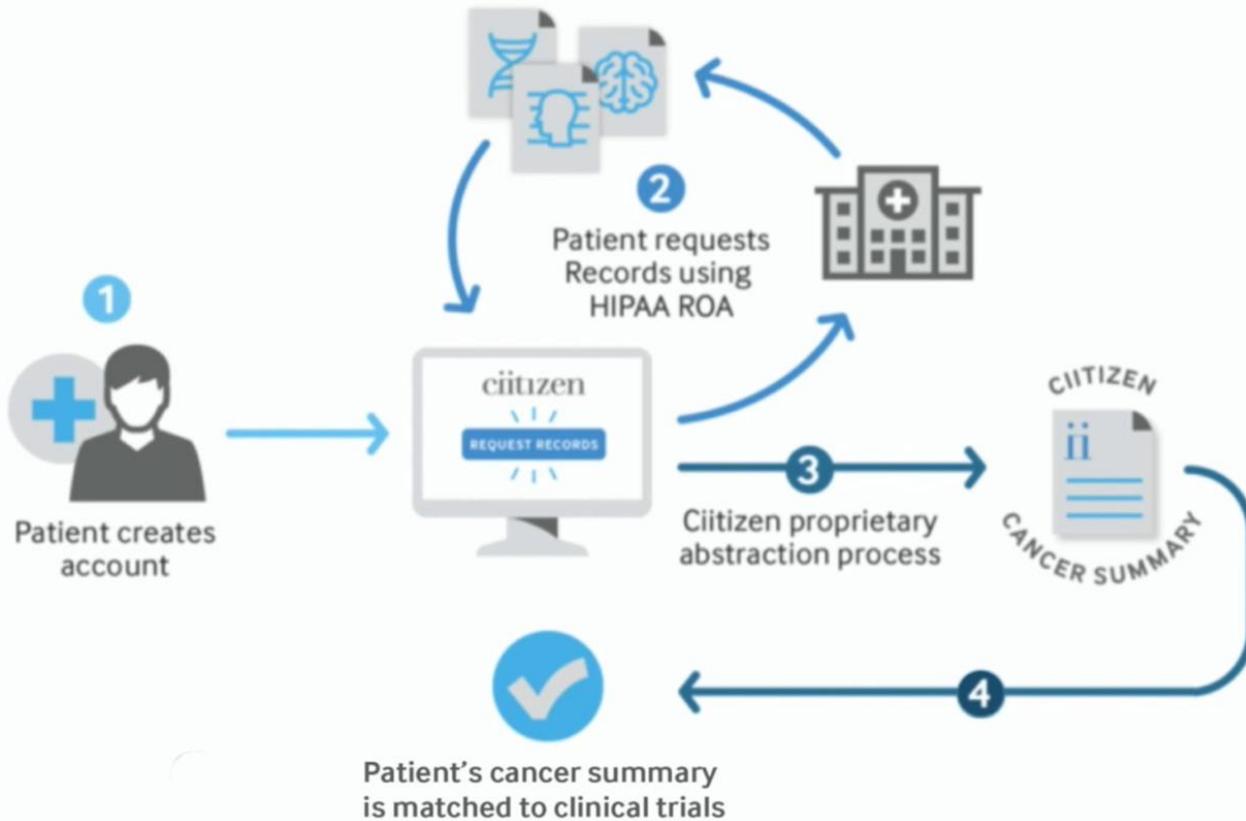


Grace Cordovano, PhD, BCPA @GraceCordovano



**FACT: Patients want & need
access to their health information
using digital tools to help them
live their best life.**

Ciitizen: Helping patients aggregate and control their medical records



1. **Onboard:** Patients can directly sign up for Ciitizen or be referred through partners

2. **Collect Records:** Leveraging patient's HIPAA Right of Access, data is requested on behalf of patients from all institutions they have received care

3. **Automated Data Extraction:** Ciitizen's core ML platform extracts and standardizes data against complex disease models and ontologies

4. **Consent-Based Data Sharing:** Patients retain full control of their data to share for clinical care (care coordination, nth opinion, VTB) or research (clinical trials, real world data generation, natural history)

Early Ciitizen Use Case: Increasing clinical trial enrollment of black breast cancer patients

- Between 2013-2017, the death rate from breast cancer was 40% higher in black women than white women, in part due to higher incidence of Triple Negative breast cancer in black women
- Only 40% of black women with metastatic breast cancer report having been offered enrollment in a clinical trial, while 80% would consider a clinical trial if they learned of one.
- Matching patients to potential clinical trials could help change this dynamic.
- Working with black breast cancer advocates
- Efficient gathering of medical record data for clinical trial matching is a huge challenge.

Solution: Cures Gateway Service

Citizen Cures Gateway is a new solution for HIEs that enables patients to obtain their medical records in a timely manner and useful format

- Leverages existing data exchange models (i.e. IHE and FHIR) to deliver patients' their medical records
- Provides identity proofing of patients requesting their records (ID proofing alone valued between \$1-5 per patient)
- As simple as adding a link to the HIE website
- Supports the HIE and its downstream participants who may get direct requests for records (hospitals, practices, labs, etc.)
- 24/7 helpdesk provides patient support
- Patients can receive records in their PHA, in a human readable PDF, or get a free PHR to hold and view their records

No cost to early adopter HIEs, and never to patients



Patient Access Options via Cures Gateway

Patient Health Application

- Each 3rd party app is vetted and approved in ways consistent with Cures (ID proofing, consent, & meets definition of PHA)
- Approved apps utilize ID Proofing meeting IAL2 (or contract with Ciitizen to supply ID proofing through its ID proofing vendor)

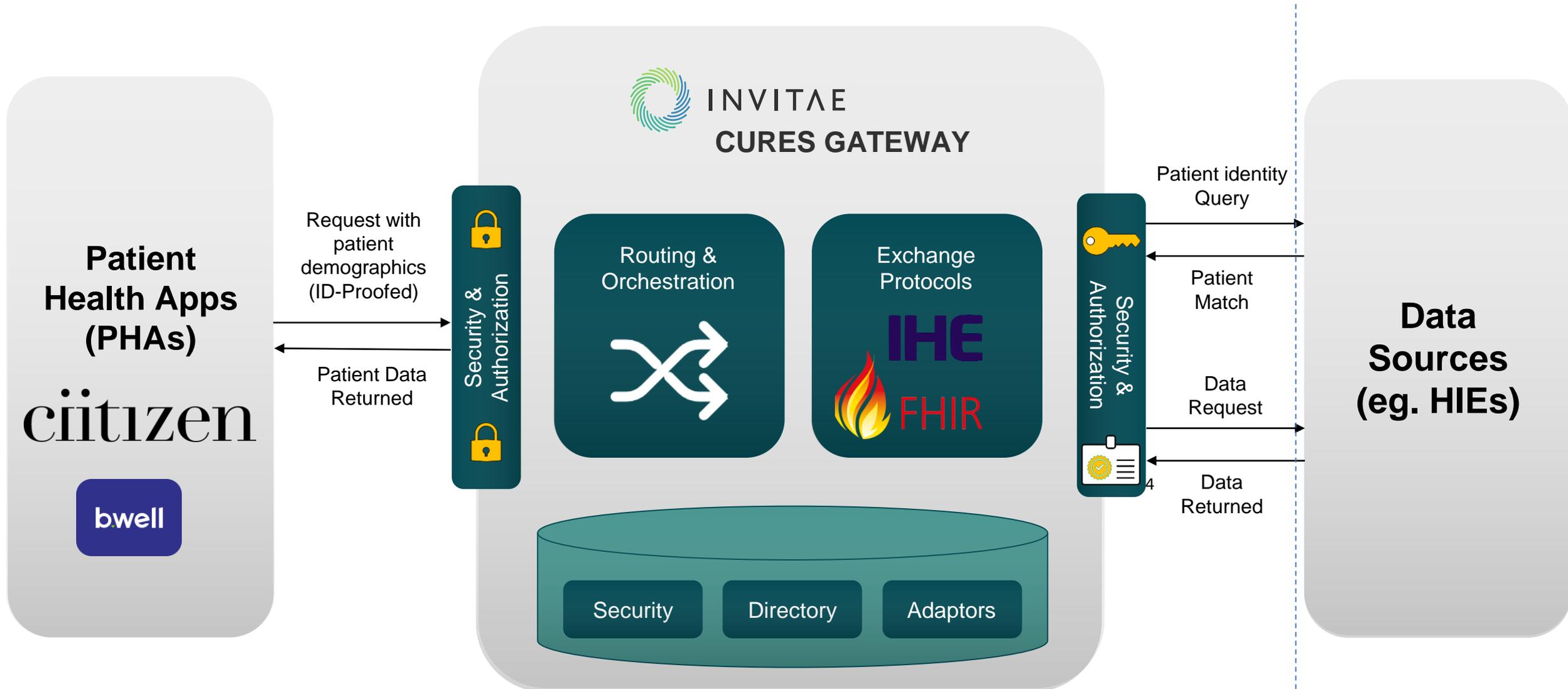
Ciitizen Platform

- One of the PHAs connected to the Gateway
- Does ID proofing for “walk-up” patients
- Helpdesk, first line of patient support
- Offers additional services for patients with certain conditions

Downloading PDFs (“walk-up” patients)

- Patient is still identity proofed
- Ciitizen holds patient’s data for up to 7 days to download

Cures Gateway Architecture



Rochester RHIO Mission

ROCHESTER **RHIO**

Regional Health Information Organization

The mission of Rochester RHIO is to provide the greater Finger Lakes Region (Rochester, Finger Lakes, Southern Tier) with a system for a secure health information exchange that allows for timely access to clinical information and improved decision making. The primary goal is to share patient/consumer health information in a secure environment to improve care and to reduce systems inefficiencies.

Rochester RHIO is a critical link in the Statewide Health Information Network of New York (SHIN-NY), and seeks to collaborate with health information exchange efforts across New York State.

Key Stats

More than 1,000 practices contribute data to Rochester RHIO, including 23 regional hospitals and nearly 300 community-based organizations.

- 347,956 Explore/Explore+ Logins
- 581,875 Patient Record Returns (Searches via Query Portal)
- 450,175 Unique Alerts Sent
- 612,461 DIRECT Messages Sent
- 23,460,360 Electronic Lab Results Delivered
- 105,650,363 Total Incoming Clinical Data Transactions*

*Over a 12-month period (January 2021 – December 2021)

Diversity, Equity and Inclusion

In 2020, the Greater Rochester Black Agenda Group developed a Racism/Health Crisis Declaration.

Rochester RHIO joined 170+ organizations in signing the declaration and is committed to:



<https://blackagendagroup.org/>



- Improving quality of HIE data related to race, ethnicity and gender
- Emphasizing building diversity in governance and workforce
- Focusing on opportunities that address systemic change, advocacy, and leadership development in the community

Empowering Patients with Cures Gateway

- Mission Synergy with Ciitizen – prioritize direct patient access in alignment with CAIRN Alliance Standards
- Rochester RHIO’s commitment to Health Equity is rooted in community collaboration.
- Piloting implementation with Northstar Network’s 2022 Healthcare Business Academy Fellowship Program:
 - Community leaders representing organizations across the healthcare ecosystem in Greater Rochester region
 - Collaboration with key stakeholders who serve patients and communities who are disadvantaged by inequitable systems
 - Ensure Cures Gateway works for ALL patients, not only “default users”



CRISP is a regional HIE... and an HDU

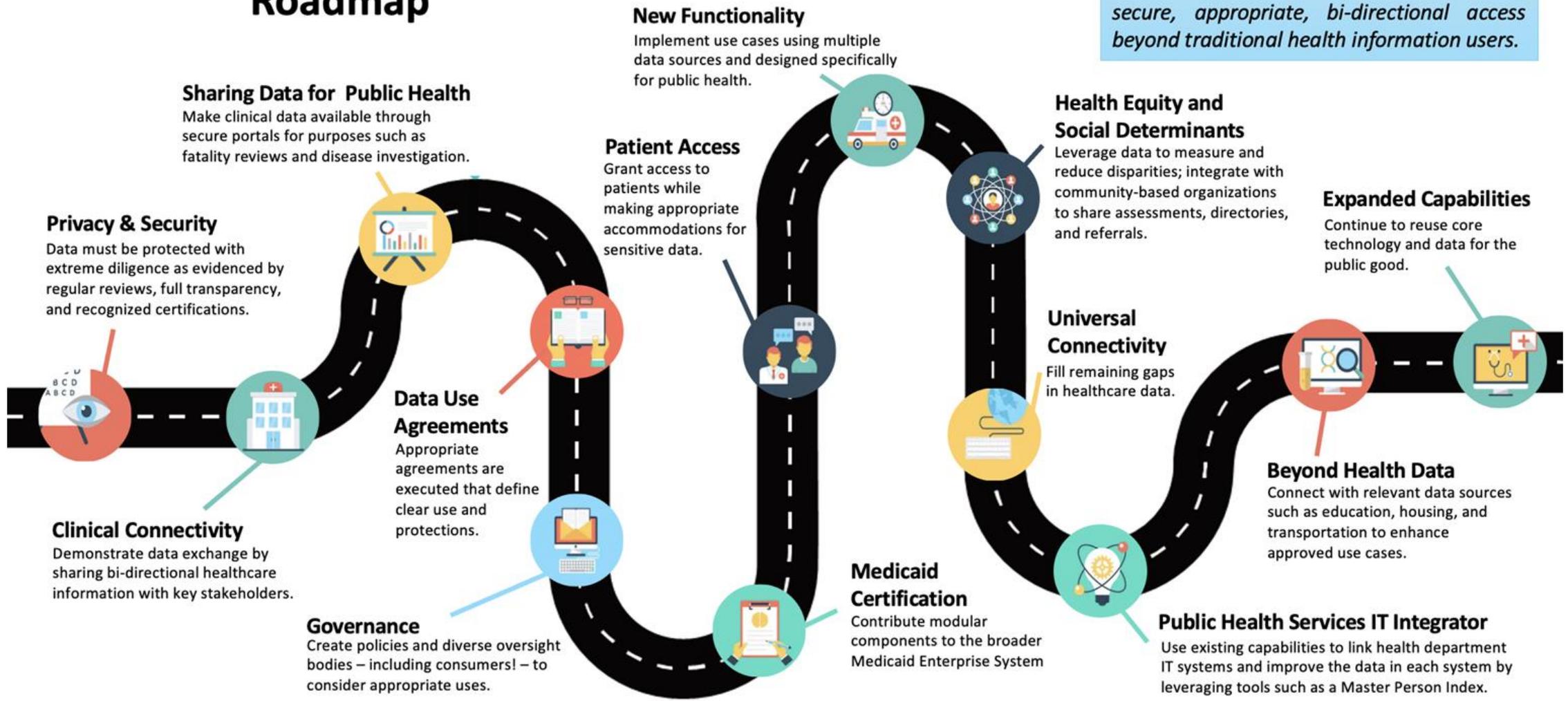
HB1127 requires the State-Designated HIE (CRISP) to operate as a Health Data Utility (HDU) for the State. Purposes include:

1. The collection, aggregation, and analysis of clinical information, public health data, and health administrative and operations data to assist the Department, local health departments, the Commission, and the Health Services Cost Review Commission in the evaluation of public health interventions and health equity;
2. The communication of data between public health officials and health care providers to advance disease control and health equity; and
3. The enhancement and acceleration of the interoperability of health information throughout the State.

Source: <https://mgaleg.maryland.gov/2022RS/bills/hb/hb1127T.pdf>

Health Data Utility Roadmap

A Health Data Utility advances equity and wellness by combining and enhancing data across the public health system and enabling secure, appropriate, bi-directional access beyond traditional health information users.



Value to Patients

 I want to see my health data in one place

 I want to understand my individual health risks

 I want all of my care providers to see my data, wherever I am and whenever I receive care

 I want to know how much my health services will cost

 I want to understand what human services may apply to me

 I want to be in control of my privacy

 I want my data to be secure

 I want my individual environment and resources to be considered in my care

 I want to understand how to prevent health issues specific to me

 I want the option to share my data securely for research purposes

Privacy
Data must be accurate, complete, and secure. It must be collected, stored, and used in a way that respects individual privacy and autonomy.

Clinical
Demonstrate the value of data sharing to improve patient care and health outcomes.

New Functionality

Implement use cases using multiple data sources and designed specifically for public health.

Patient Access

Grant access to patients while making appropriate accommodations for sensitive data.

Medicaid Certification

Contribute modular components to the broader Medicaid Enterprise System

Value to the HDU

- Increased transparency builds confidence across all HDU efforts
- More opportunities to find and fix potential data quality issues
- New stakeholders gain direct value from the HDU
- Opens new use case possibilities such as updating demographics and controlling consent
- Potential to improve health care for our community

A Health Data Utility advances equity and wellness by combining and enhancing data from multiple, appropriate, bidirectional access beyond traditional health information users.

Health Equity and

Leverage data to measure and

Expanded Capabilities

Connectivity

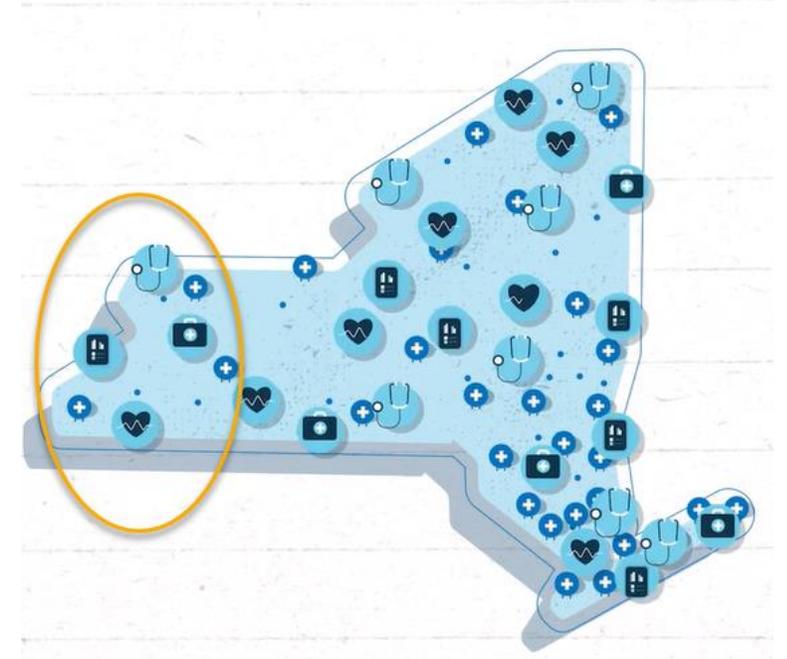
Connect with relevant data sources

Public Health Services IT Integrator

Use existing capabilities to link health department IT systems and improve the data in each system by

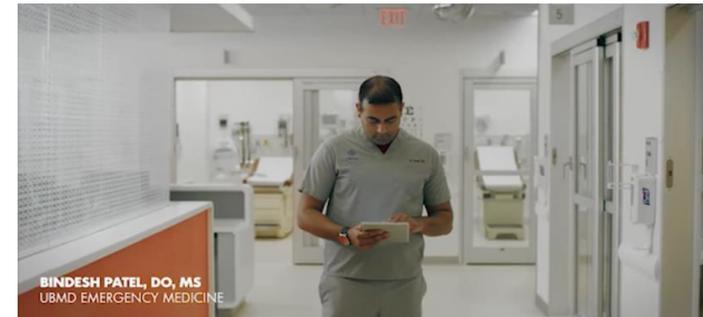
About HEALTHeLINK

- Collaborative partnership since 2006
 - Founding members include region's major payers and hospitals
- Supports 8 western counties of NYS
- Part of the Statewide Health Information Network for New York (SHIN-NY) – certified by NYS DOH as a Qualified Entity
- One of the founding members of Strategic Health Information Exchange Collaborative (SHIEC) – now merged into Civitas Network for Health
- *Recent merger announcement of HEALTHeLINK becoming the RHIC for WNY*



Marketing Efforts

- Nearly 15 years of branding and education about HEALTHeLINK
- Targeting both providers and patients
- Includes TV, radio, billboard, print ads...



Patient Desire for Access

- Evidence includes:
 - Approximately 70% of our breach investigations were related to patient/care giver access
 - Patient looking up own or a loved one's data
 - Co-worker looking up data on patient's behalf
 - 40% of phone calls from patients are related to access to their data
 - The majority of inquiries on our Infoline (website comment section) are patients asking about access

Challenges

- Identity proofing
- Inconsistency of the data from different data sources
 - Duplicative data from multiple data sources
- Overcome perception that we are completely replacing the provider's patient portal
- Concern on the timing of data availability to patient
- How is it sustained?
- Improving Health Literacy in communities most impacted by Health Equity challenges

Thank you!

Grace Cordovano

enlighteningresults@gmail.com
@GraceCordovano

Sara Abrams

sara.abrams@grrhio.org | 585-481-2952
RochesterRHIO.org

Craig Behm

craig.behm@crisphealth.org | 410-207-7192
crisphealth.org



Thank you!

Deven McGraw

deven.mcgraw@invitae.com

www.citizen.com/curesgateway

Dan Porreca

DPorreca@wnyhealthelink.com

www.wnyhealthelink.com

