



Health Information Exchanges

Health Data Utilities: Comprehensive Health Data on Whole Communities

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September 25, 2024

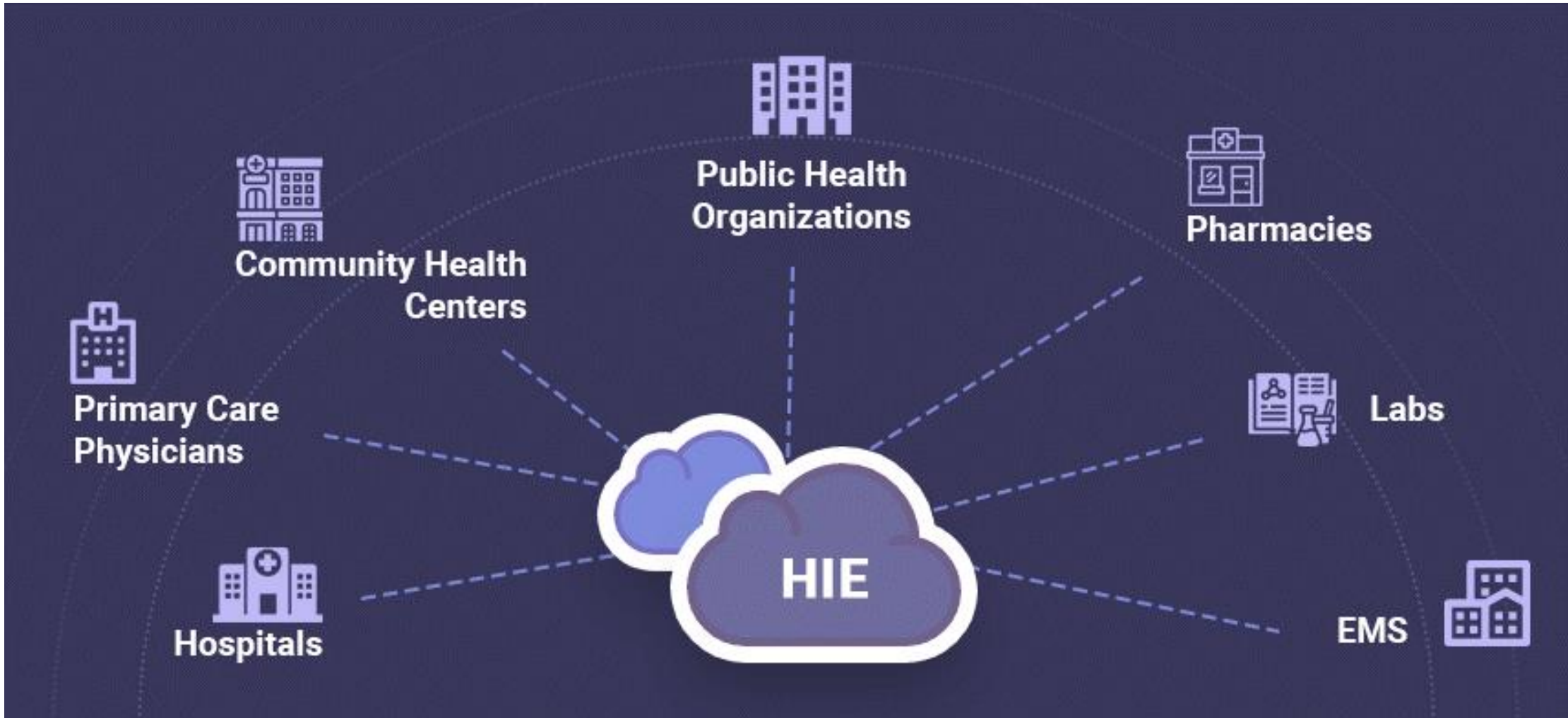
Disclaimer

- **Some of the work** presented on this slide deck was supported by Task Order **75F40123F19010** under Master Agreement **75F40119D10037** from the U.S. Food and Drug Administration (FDA).
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Agenda

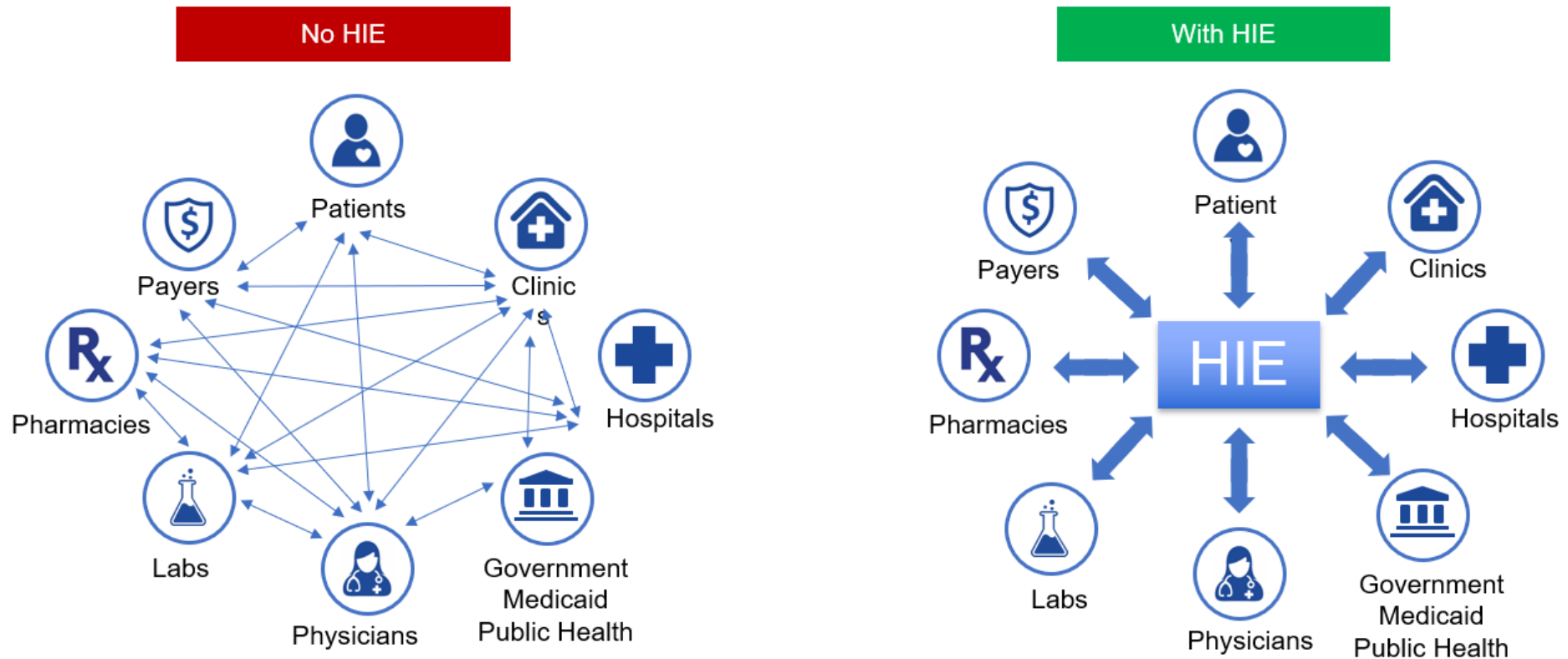
- Health Information Exchange (HIE)
 - Data Elements
 - Nationwide Coverage
 - Unique Data Source
- Health Data Utility (HDU)
 - Introduction
 - HIEs Evolving into HDUs
- MyHealth Access Network
 - Data Fragmentation
 - SDOH Data Capture
 - Data Quality
- Data characterization exercise with Sentinel
 - Description
 - Results

Introduction to HIEs



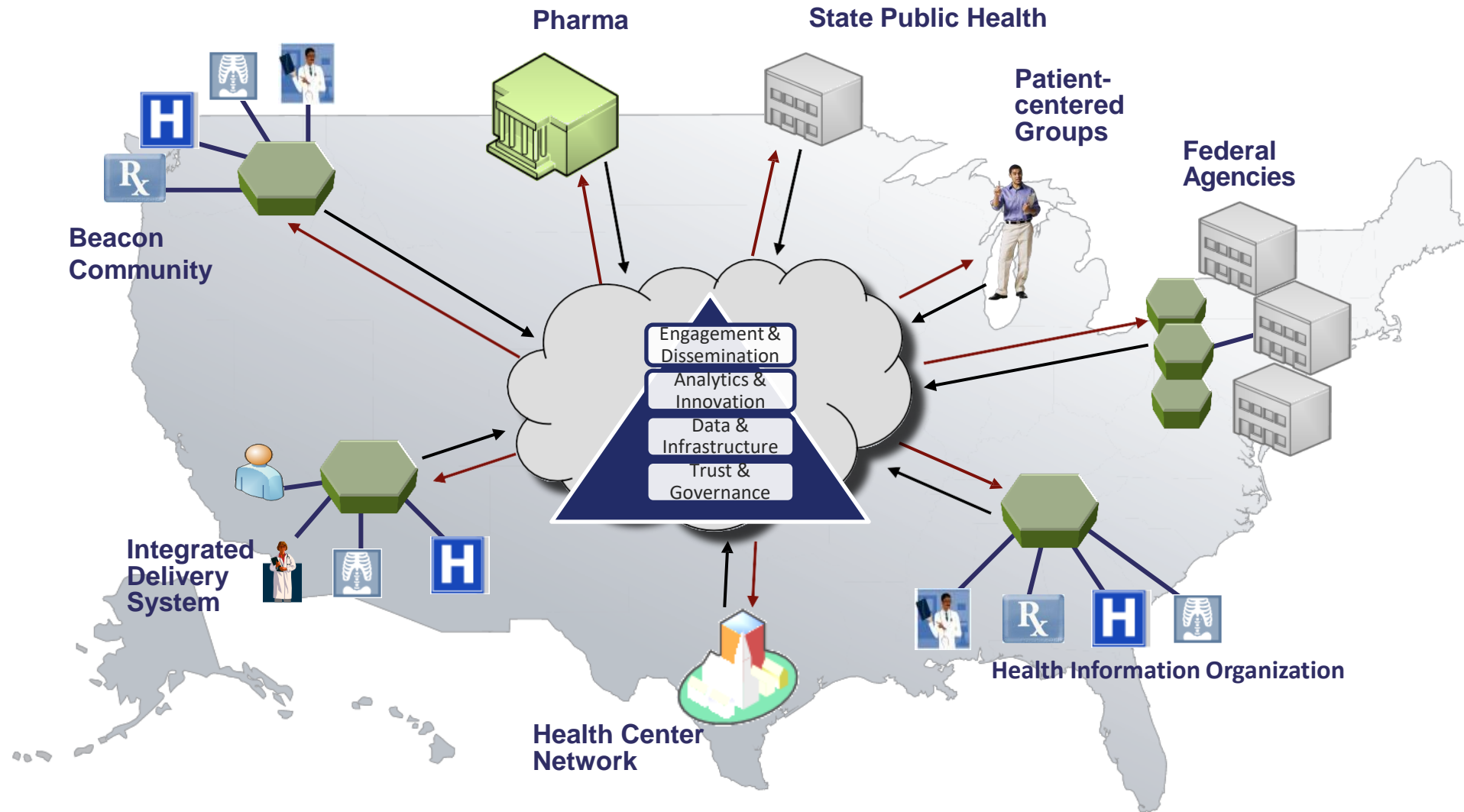
Introduction to HIEs

Health Information Exchanges (HIEs) securely share vital medical information among healthcare and social service providers in real-time. HIEs standardize data, link records across providers, manage consent, and store data for population level analysis and insights.



HIE Services: Master patient ID; Longitudinal patient data; Role-based access; Hospital admit/discharge alerts; Secure data exchange; Consent management; Population data

A National Learning Health System requires Interoperability



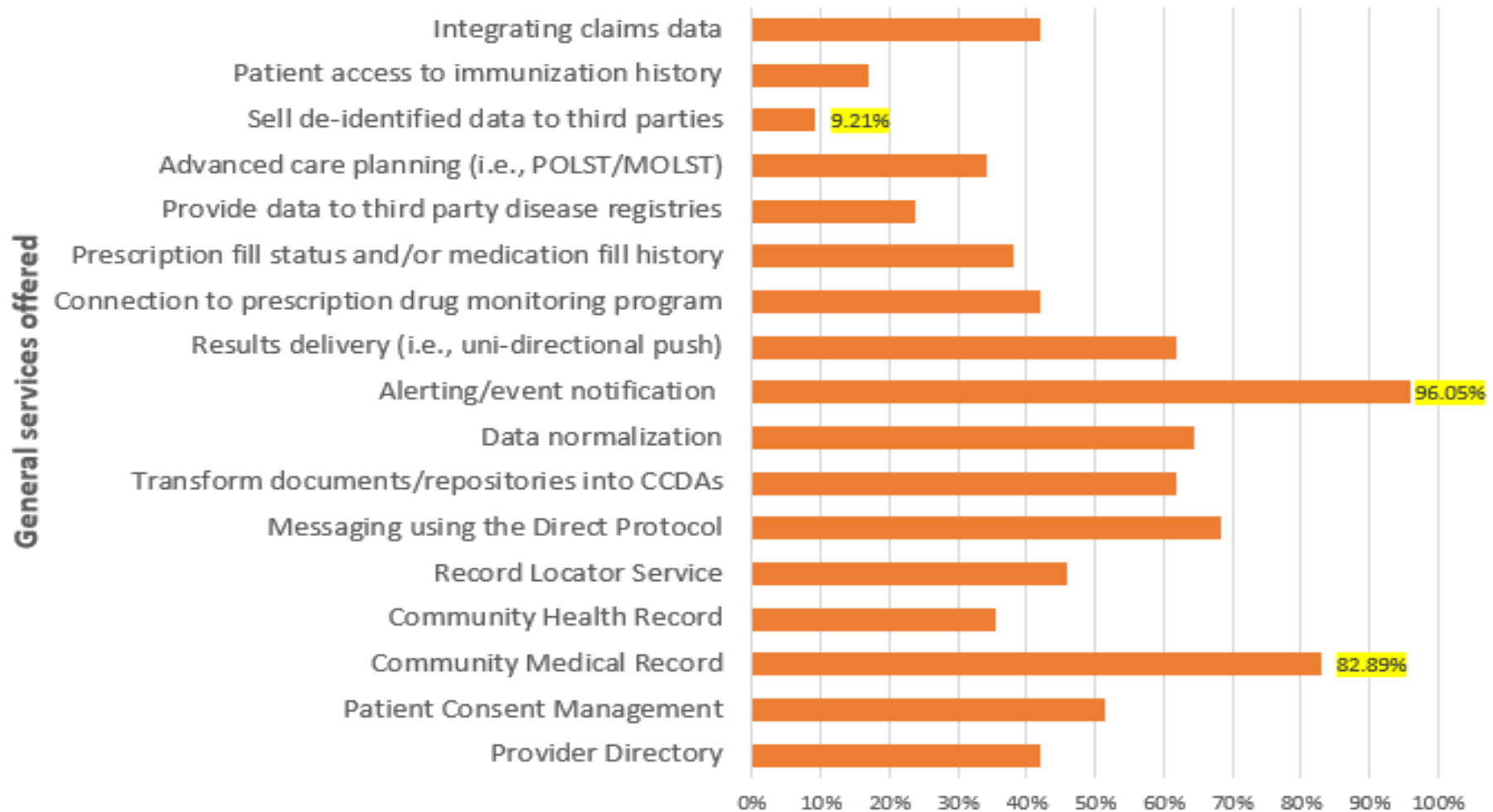
Data Elements in HIEs

The United States Core Data for Interoperability (USCDI) is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange. **HIEs and electronic health records (EHRs) are mandated by Health and Human Services Commission (HHSC) and the Office of the National Coordinator for Health Information Technology (ONC) to use USCDI.** Below is a visual showing the main data elements and tables from USCDI v2 (current requirement)

Allergies and Intolerances <ul style="list-style-type: none"> • Substance (Medication) • Substance (Drug Class) • Reaction 	Diagnostic Imaging ★ <ul style="list-style-type: none"> • Diagnostic Imaging Order ★ • Diagnostic Imaging Report ★ • Diagnostic Imaging Narrative → 	Laboratory <ul style="list-style-type: none"> • Tests • Values/Results • Laboratory Report Narrative → • Pathology Report Narrative → 	Problems <ul style="list-style-type: none"> • Problems • Date of Diagnosis ★ • Date of Resolution ★ 	Vital Signs <ul style="list-style-type: none"> • Diastolic Blood Pressure • Systolic Blood Pressure • Body Height • Body Weight • Heart Rate • Respiratory Rate • Body Temperature • Pulse Oximetry • Inhaled Oxygen Concentration • BMI Percentile (2-20 Years) • Weight-for-length Percentile (Birth-36 Months) • Occipital-frontal Head Circumference Percentile (Birth-36 Months)
Assessment and Plan of Treatment <ul style="list-style-type: none"> • Assessment and Plan of Treatment 	Encounter Information ★ <ul style="list-style-type: none"> • Encounter Type ★ • Encounter Diagnosis ★ • Encounter Time ★ 	Medications <ul style="list-style-type: none"> • Medications 	Procedures <ul style="list-style-type: none"> • Procedures 	
Care Team Members <ul style="list-style-type: none"> • Care Team Members • Provider Name ★ • Provider Identifier ★ 	Goals <ul style="list-style-type: none"> • Patient Goals 	Patient Demographics <ul style="list-style-type: none"> • First Name • Last Name • Previous Name • Middle Name (incl. middle initial) • Suffix • Birth Sex • Date of Birth • Race • Ethnicity • Preferred Language • Current Address • Previous Address • Phone Number • Phone Number Type • Email Address 	Provenance <ul style="list-style-type: none"> • Author Time Stamp • Author Organization 	
Clinical Notes <ul style="list-style-type: none"> • Consultation Note • Discharge Summary Note • History & Physical • Procedure Note • Progress Note 	Health Concerns <ul style="list-style-type: none"> • Health Concerns 		Smoking Status <ul style="list-style-type: none"> • Smoking Status 	
	Immunizations <ul style="list-style-type: none"> • Immunizations 		Unique Device Identifier(s) for a Patient's Implantable Device(s) <ul style="list-style-type: none"> • Unique Device Identifier(s) for a Patient's Implantable Device(s) 	

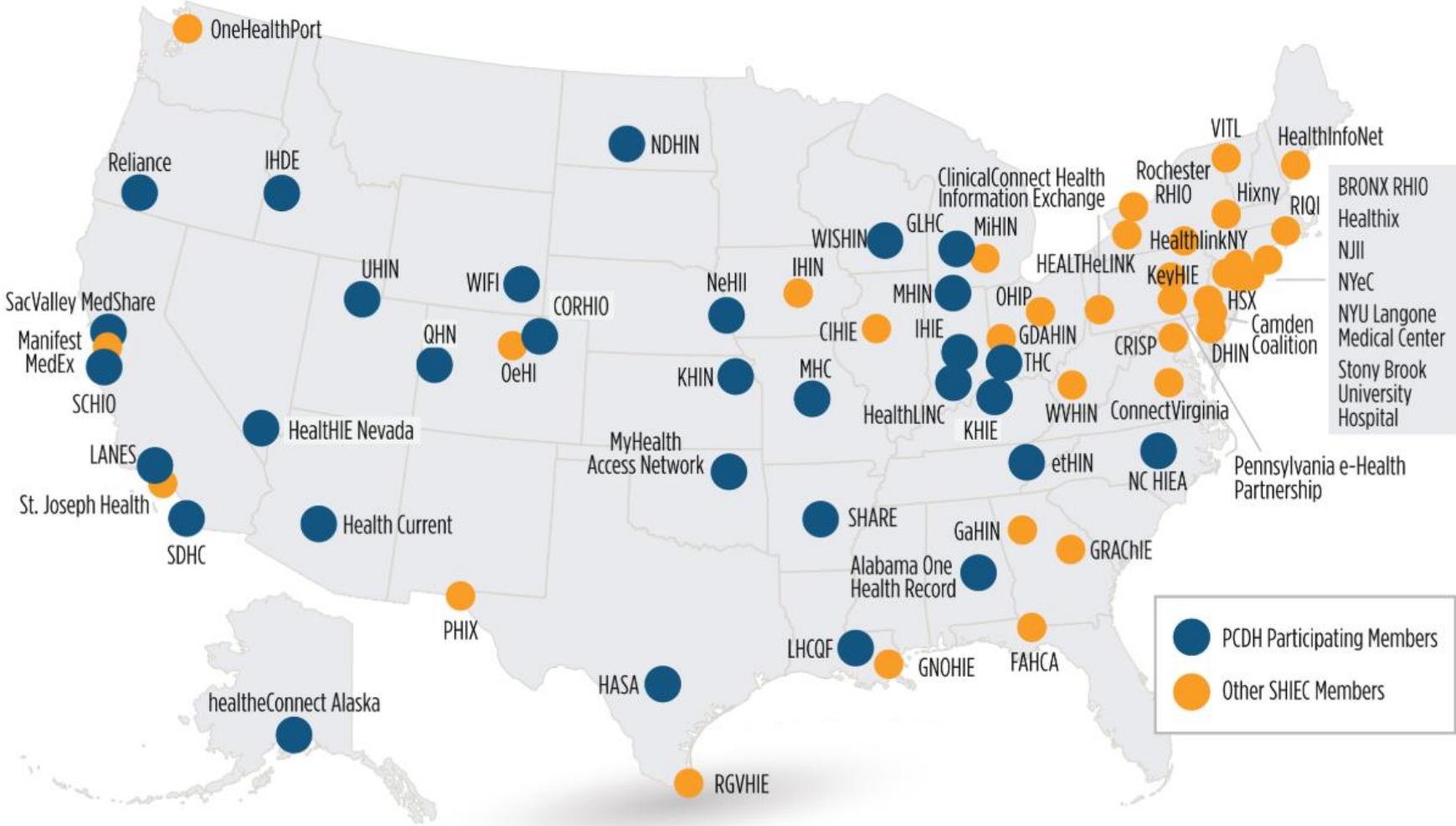
Key ★ New Data Class or Element
 → Data Element reclassified

HIE Services



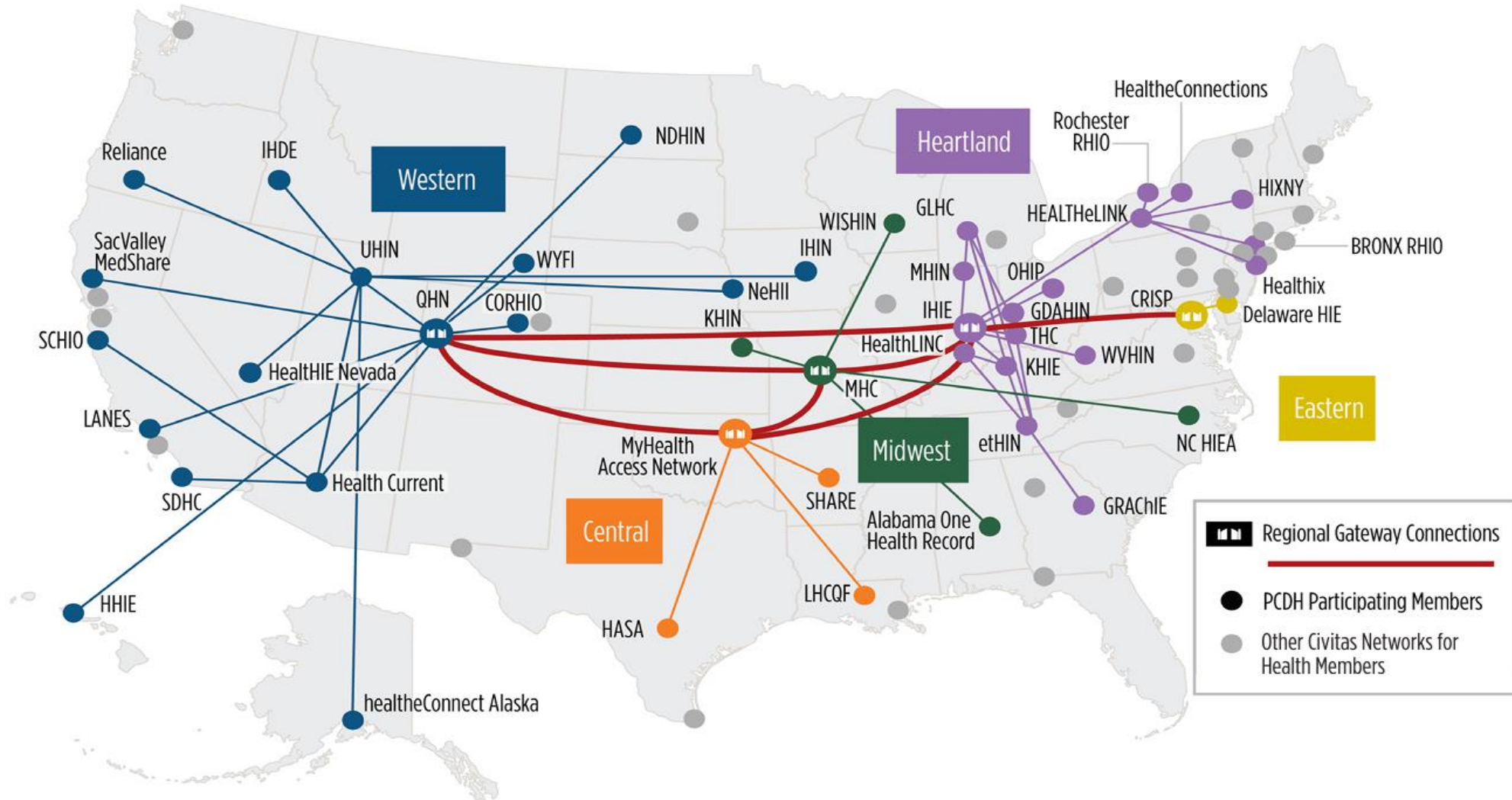
Civitas and UCSF conducted the 2023 National HIO survey, which included nationwide state and local HIEs/HDUs/HIOs involved in electronic health exchange as of 1/1/19.

How Does the HIE model Scale Nationwide?



PCDH = Patient Centered Medical Home
 SHIEC = Strategic HIE Collaborative

Patient Centered Data Home™ Nationwide Coverage



Uniqueness of HIEs as a Data Source

- More representative and inclusive population-based data
 - *uninsured, underinsured*
 - *out of pocket prescriptions*
 - *rural*
- Access to EHR data without dealing with many health systems
 - *legal*
 - *technical*
- Linkage with specialized clinical data
 - *Imaging**
 - *inpatient labs*
 - *Pharmacies**
 - *long-term care**
- Access to state-level registries that are connected to local HIEs*
- Access to patient-level charts and details, if needed
- Unstructured data from clinical notes*



* Additional capabilities in an increasing number of HIEs

Some HIE Successes

Public Health Reports®



Impact Factor
5-Year Impact Factor

Free access | Research article | First published online April 6, 2020

Improving Notifiable Disease Case Reporting Through Electronic Information Exchange—Facilitating Decision Support: A Controlled Before-and-After Trial

Bhattacharyya et al
BMC Medical Research Methodology (2023) 23:172
<https://doi.org/10.1186/s12874-023-01907-7>

BMC Medical Research Methodology
[and affiliations](#)

RESEARCH Open Access

Comparison of health information exchange data with self-report in measuring cancer screening

Oindrila Bhattacharyya^{1,2,3}, Susan M. Rawl⁴, Stephanie L. Dickinson⁵ and David A. Haggstrom^{6,7,8,9*}

Open Forum Infectious Diseases

MAJOR ARTICLE



Using a Health Information Exchange to Characterize Changes in HIV Viral Load Suppression and Disparities During the COVID-19 Pandemic in New York City

Emma Tucker^{1,*}, Harry Reyes Nieva^{2,3,*}, Kayla Schiffer², Michael T. Yin^{4,*}, Delivette Castor^{4,5}, Peter Gordon⁴, Noémie Elhadad^{2,6} and Jason Zucker^{2,4,9}

¹Vagelos College of Physicians and Surgeons, Columbia University, New York, New York, USA, ²Department of Biomedical Informatics, Columbia University, New York, New York, USA, ³Department of Medicine, Harvard Medical School, Boston, Massachusetts, USA and ⁴Division of Infectious Diseases, Columbia University Irving Medical Center, New York, New York, USA



Drug and Alcohol Dependence
Volume 212, 1 July 2020, 107992



Leveraging health information exchange for clinical research: Extreme underreporting of hospital service utilization among patients with substance use disorders

Jan Gryczynski^a, Courtney D. Nordeck^a, Ross D. Martin^b, Christopher Welsh^c, Robert P. Schwartz^a, Shannon Gwin Mitchell^a, Jerome H. Jaffe^a

RESEARCH ARTICLE

Evaluation of a health information exchange system for microcephaly case-finding — New York City, 2013—2015

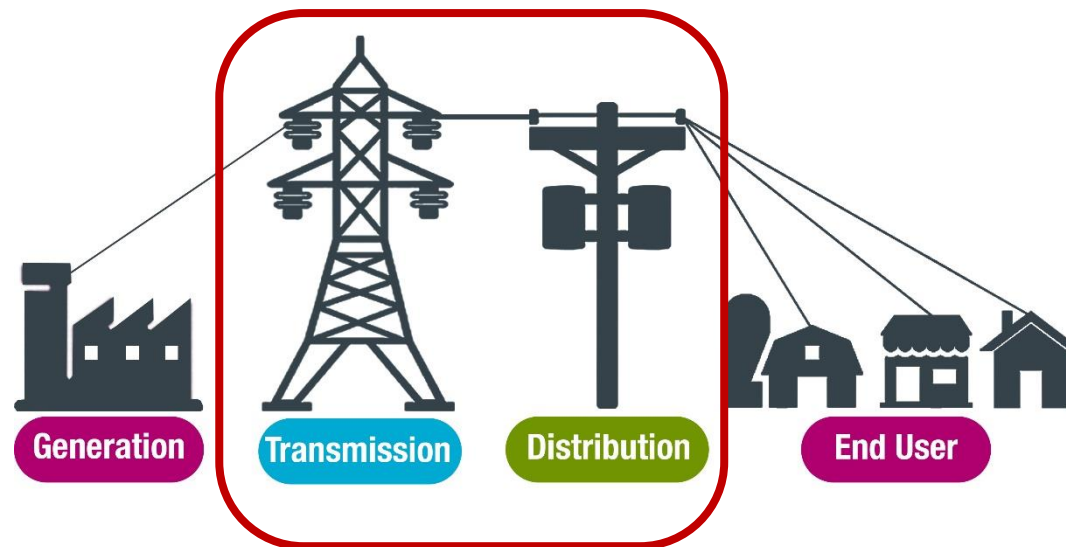
Eugenie Poirot^{1,2}, Carrie W. Mills², Andrew D. Fair^{2,3}, Krishika A. Graham², Emily Martinez², Lauren Schreiberstein³, Achala Talati², Katharine H. McVeigh^{2,*}

¹ Epidemic Intelligence Service, Division of Scientific Education and Professional Development, Centers for Disease Control and Prevention, Atlanta, Georgia, United States of America, ² New York City Department of Health and Mental Hygiene, New York, New York, United States of America, ³ Bronx RHIO, New York, New York, United States of America

* tmcveigh@health.nyc.gov

Health Data Utility

- Defined as entities which are ideally not-for-profit organizations with multistakeholder governance that combine, enhance, and exchange disparate electronic health data sets to provide comprehensive health data and analytics, supporting a specified geographic region.
- Typical functions of an HIE are a subset of HDU operations
- Add non-clinical, environmental, and other types of data that impact health








HIEs Evolving into HDUs

	HIE	HDU
Governance	Usually healthcare providers, mostly covered entities	Local and state governments, community organizations, healthcare providers, etc.
Data	Mainly clinical	Clinical, social, educational, crime, geographical, environmental, etc.
Use	Mainly in healthcare operations and reporting	Beyond healthcare for homelessness, food insecurity, housing, transportation, etc.
Stakeholders	Health systems, health plans, health departments	Broad group of state agencies, tribal governments, employers, policy-makers, correctional systems, schools, etc.
Regulatory environment	HIPAA and rules related to covered entities	HIPAA, FERPA, and rules & regulations applicable in other sectors
Major function	Mostly limited to interoperability and some reporting/analytics	Mostly around use cases like supporting managed care organizations, population health strategies, cross sector coordination, value-based care models, accountable communities, etc.

POLICY CORNER

The Role of Health Data Utilities in Supporting Health AI

Ahmad Alkasir , Dr.P.H., M.P.H.,¹ Gabriel Seidman , Dr.P.H.,¹ Jolie Ritzo , M.P.H.,² Lisa Bari , M.B.A., M.P.H.,² Anjum Khurshid , M.D., Ph.D.³

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Abstract

New developments in AI hold enormous promise for improving clinical delivery, health care administration, and public health, all of which contribute to better health outcomes. However, the ability to capture tangible improvements in health outcomes from the paradigm shift in AI capabilities will remain constrained unless health information systems, regulations, and governance structures are modernized for the AI era in a manner that enables effective development, rigorous validation, and ongoing monitoring of models for safety and efficacy (e.g., AI assurance). In this article, we summarize the role that health information exchanges (HIEs) have played in establishing the existing technical infrastructure and governance for collecting, sharing, and reusing health data, mostly for primary use cases (e.g., care coordination) and less so for secondary use cases (e.g., public health, research). We highlight the opportunity to modernize HIEs into health data utilities (HDUs) — statewide entities with diverse stakeholder governance structures that support the informatic needs of a variety of users in a state or region. Moreover, we regard health AI development as a secondary use of data and note how establishing state-designated HDUs would support AI advancements through their enhanced capabilities and authority as aggregators and stewards of validated, high-quality, multisource health data. Furthermore, while HIE networks are widely acknowledged as critical infrastructure for data exchange, we explain why and how these networks — as they transition to HDUs — could support AI assurance policy for a subset of health AI models by promoting AI regulatory guidance, standards, and best practices; enabling robust model evaluations and transparent reporting; and supporting prospective monitoring of deployed applications.

Role in Health AI

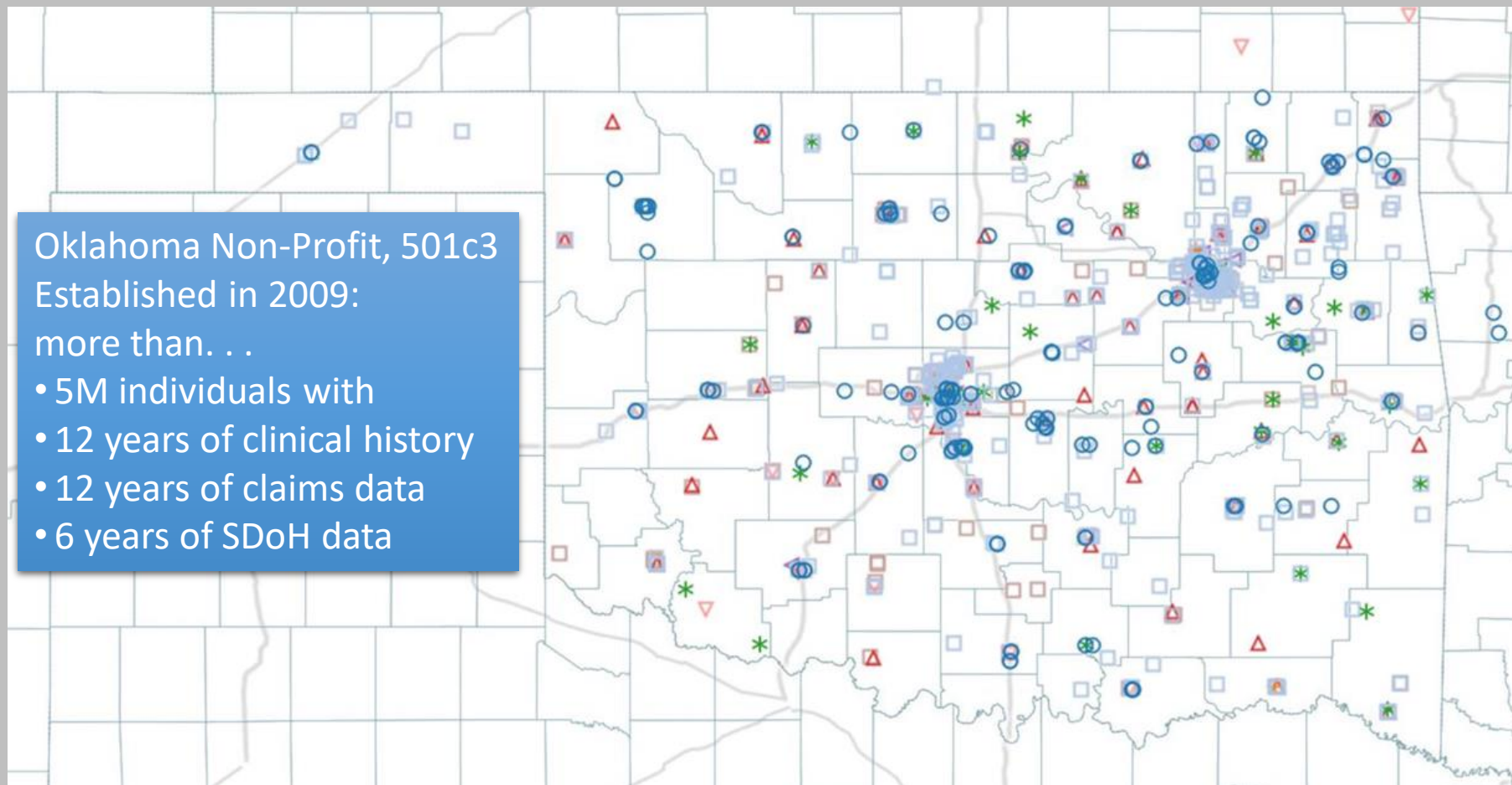


MyHealth Access Network



Oklahoma Non-Profit, 501c3
Established in 2009:
more than . . .

- 5M individuals with
- 12 years of clinical history
- 12 years of claims data
- 6 years of SDoH data



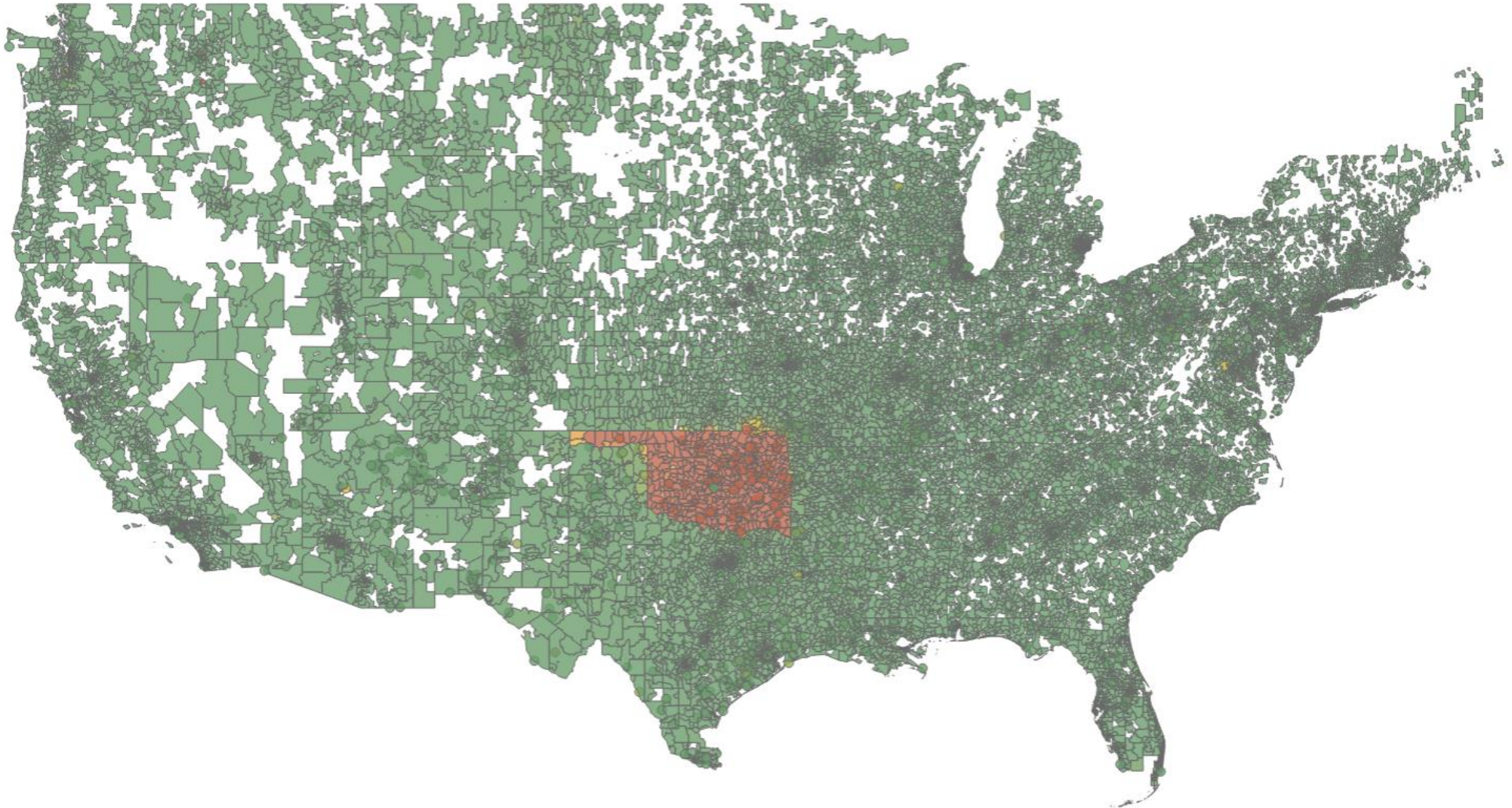
Facility Type

- | | | | |
|----------------------|--------------------|---------------------|----------------------|
| Null | Emergency Services | Lab | Pharmacy |
| Behavioral Health... | FQHC | Long Term Care ... | Public Health |
| Clinic | Hospice | Ophthalmology/Op... | Urgent Care Facility |
| Community/Social... | Hospital | Payer | |

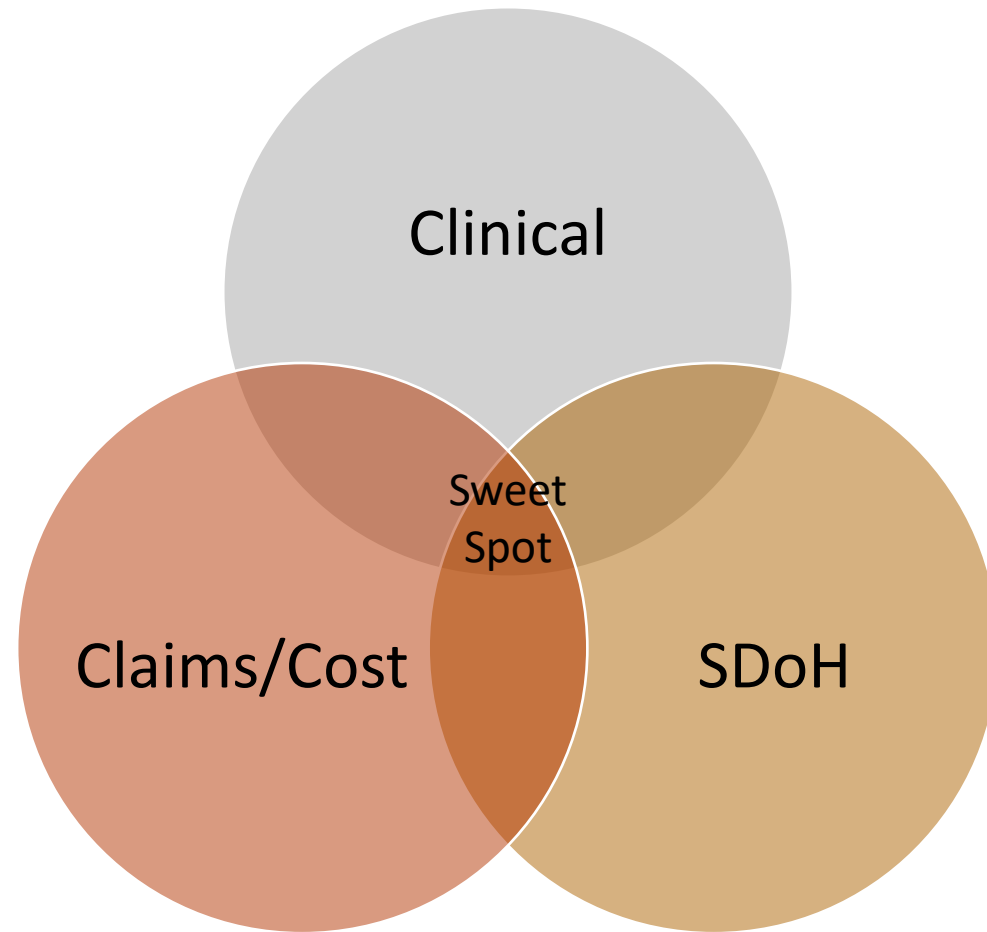
Facility Type

- | | | | |
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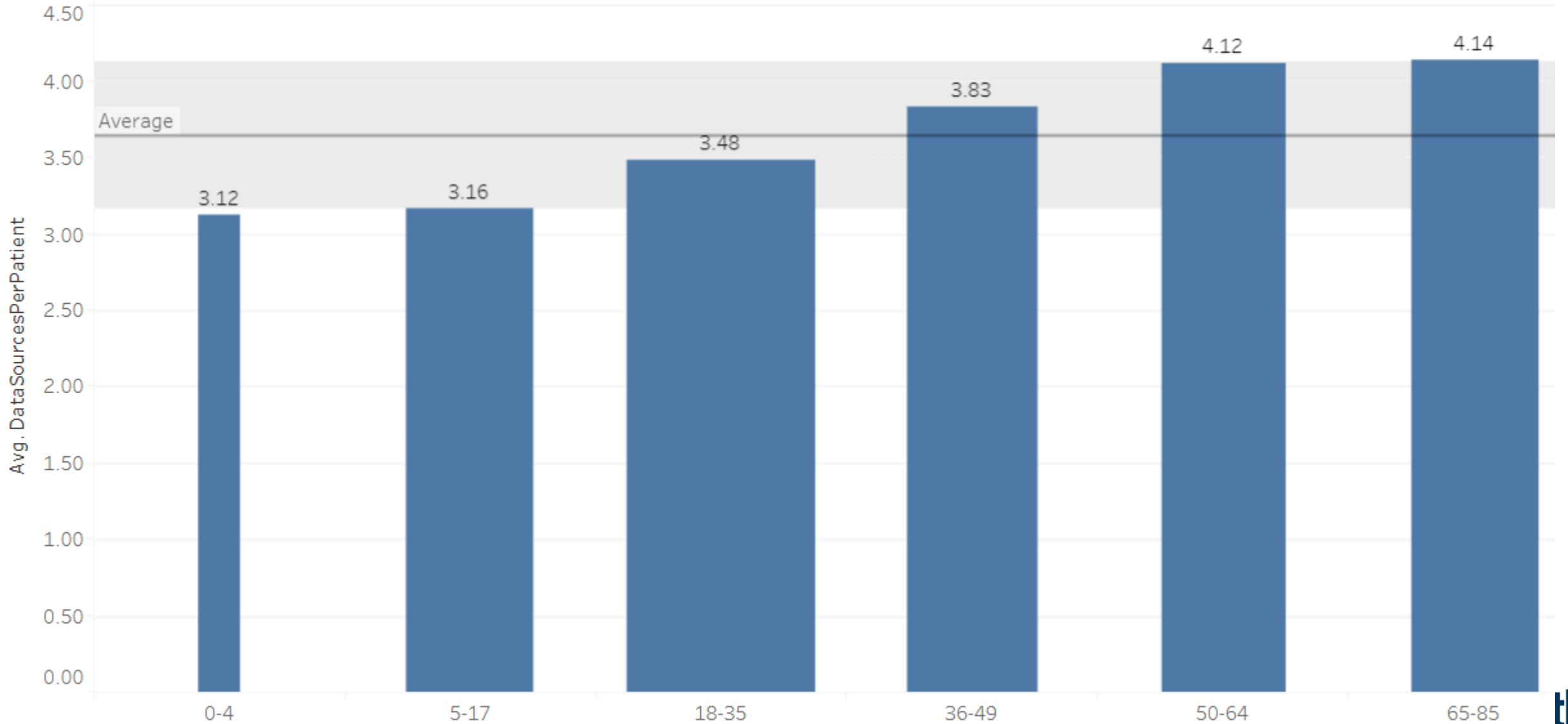
Patients often get care far from home



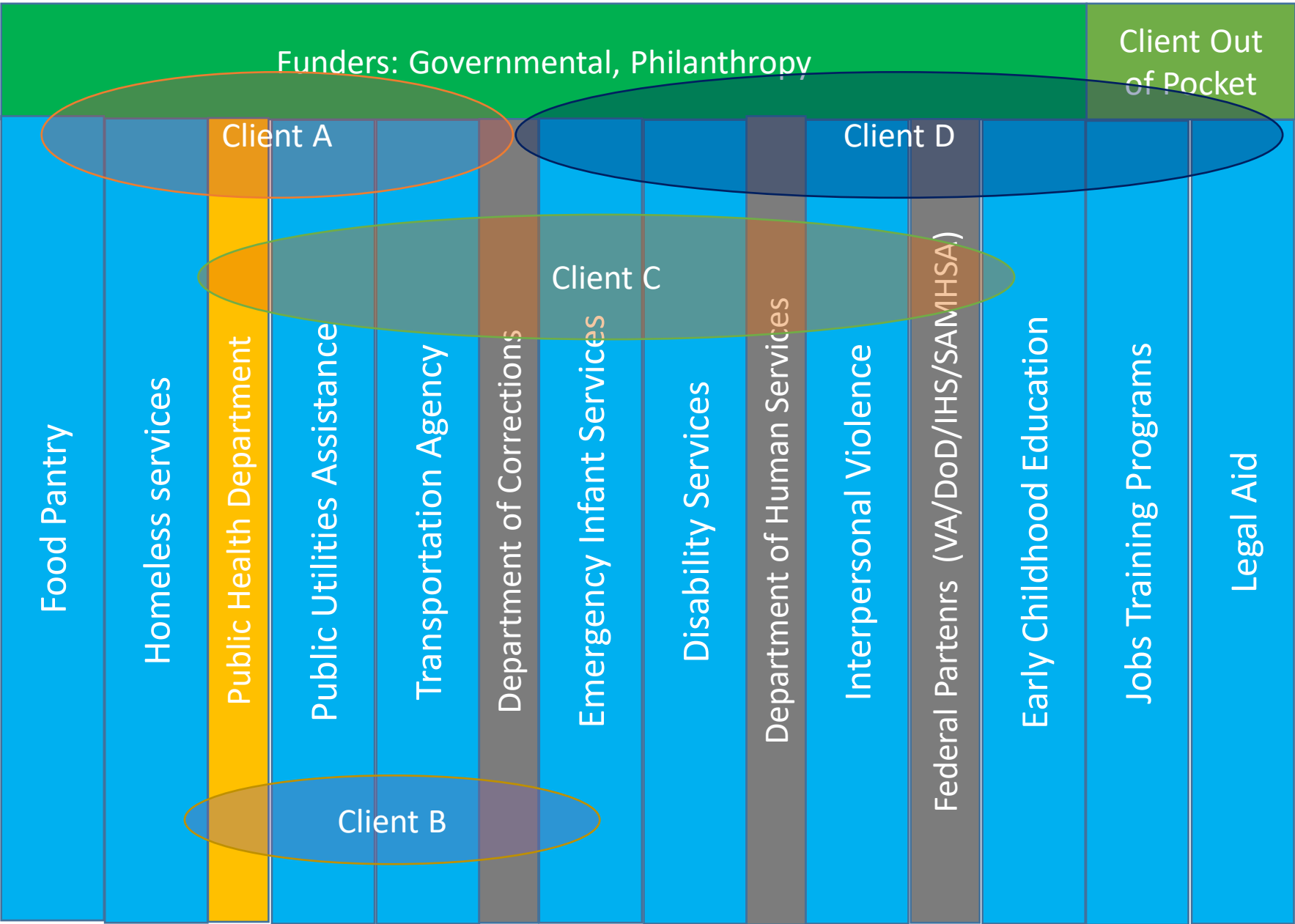
Putting it All Together



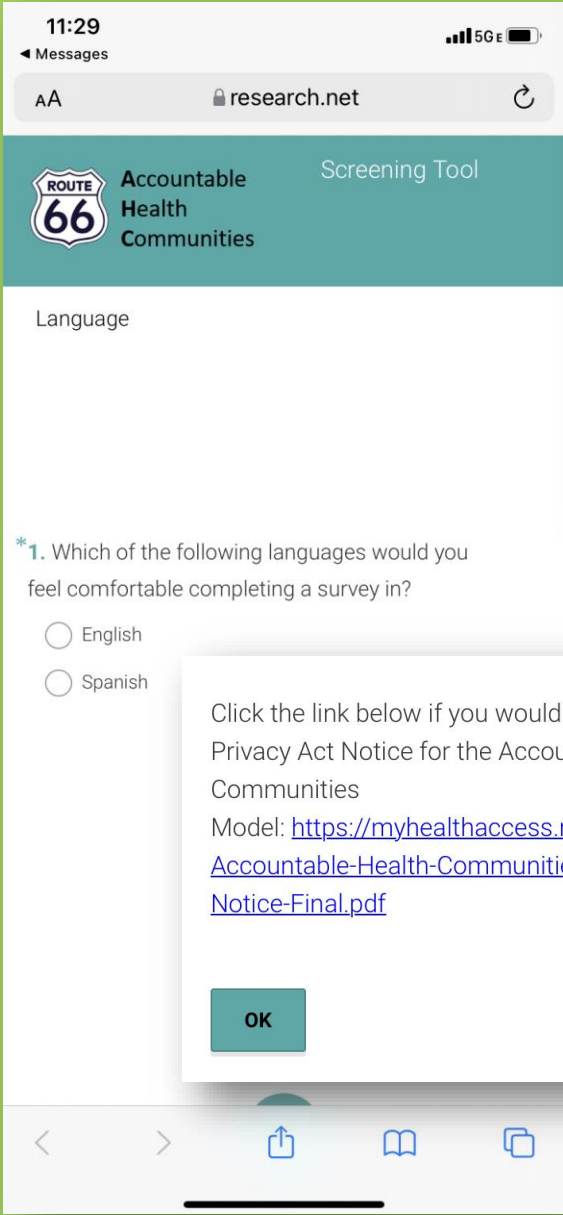
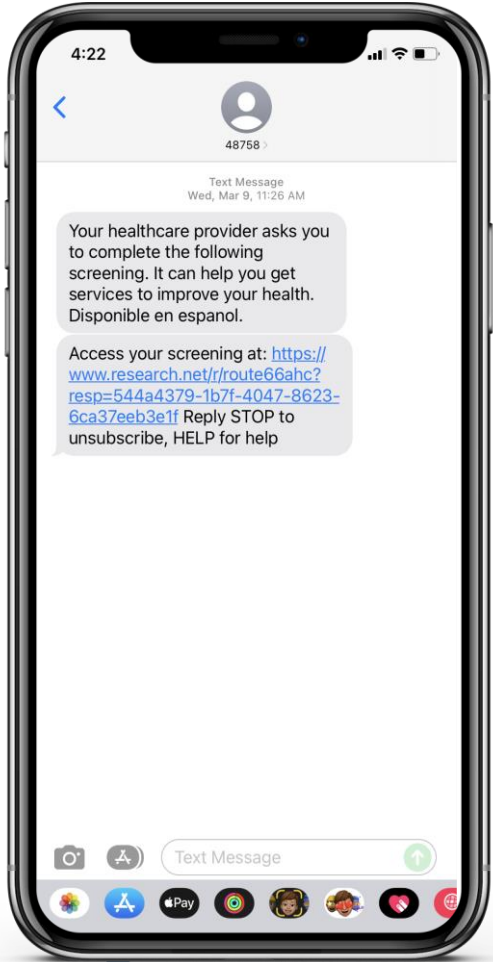
Fragmentation of Data Sources by Age



Fragmentation of Social Determinants of Health



SDOH Mobile Screening



7. Within the past 12 months, you worried that your food would run out before you got money to buy more.

Often true

Sometimes true

Never true

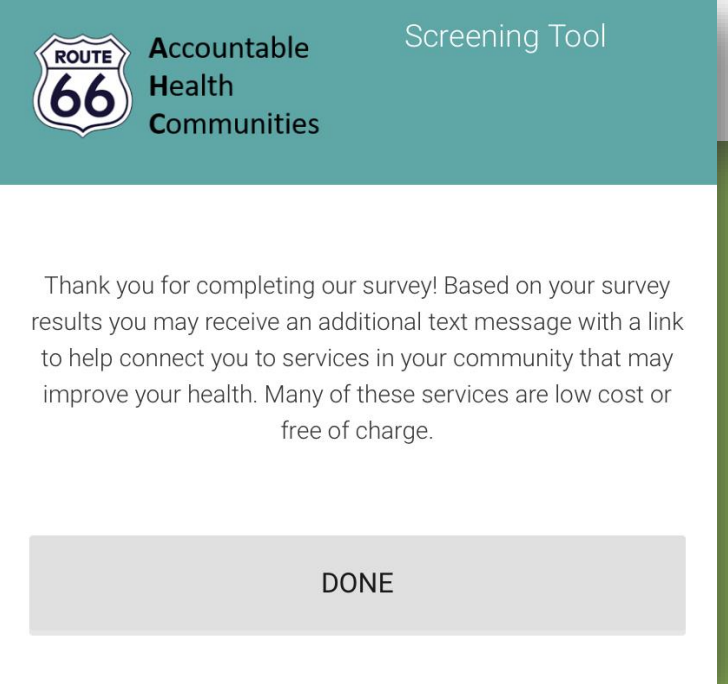
9. In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting to things needed for daily living?

Yes

No

Click the link below if you would like to view the Privacy Act Notice for the Accountable Health Communities

Model: <https://myhealthaccess.net/MyHealth-Accountable-Health-Communities-Screening-Privacy-Notice-Final.pdf>



SDoH Program Metrics

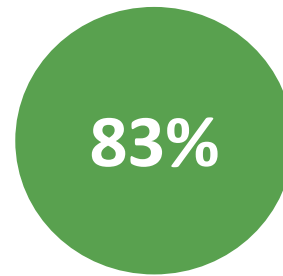
August 2018– May 30, 2024



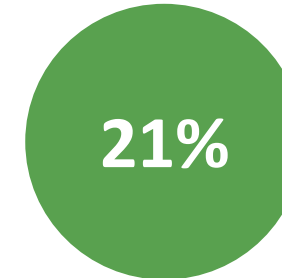
By the numbers:

- ✓ **4.6+** million offers to screen
- ✓ **900,000+** responses
- ✓ **300,000+** responses with needs
- ✓ **400,000+** individual needs reported & addressed

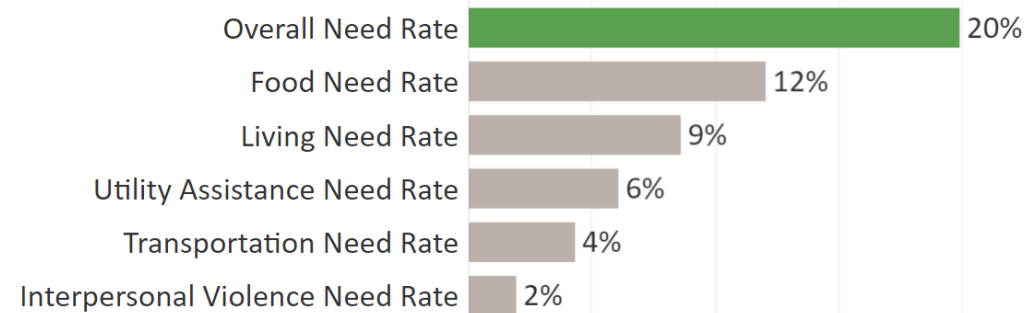
Screening Delivery Rate



Screening Response Rate



Need Rates for 5 Core Needs Screened for through MyHealth's SDoH Screening



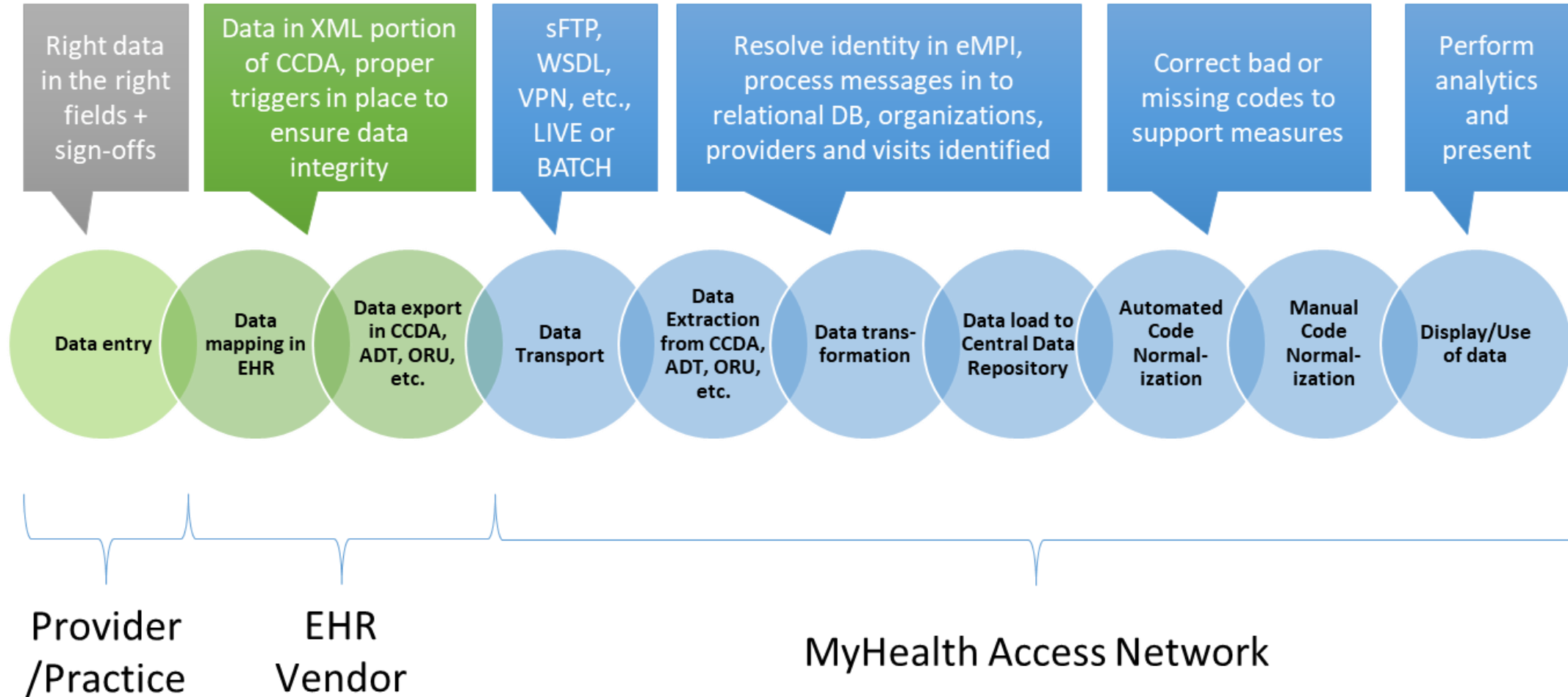
24% of responses report 2+ needs

average of **1.7** needs are reported per need positive screening

85% of responses with a living need is due to living conditions* rather than having a place to stay

*Living condition issues include lack of heating, lead paint or pipes, mold, oven or stove not working, pests, missing or not working smoke detectors, and water leaks

Data Quality: Chain of Evidence



CCDA – Consolidated Care Document Architecture
eMPI – electronic Master Patient Index

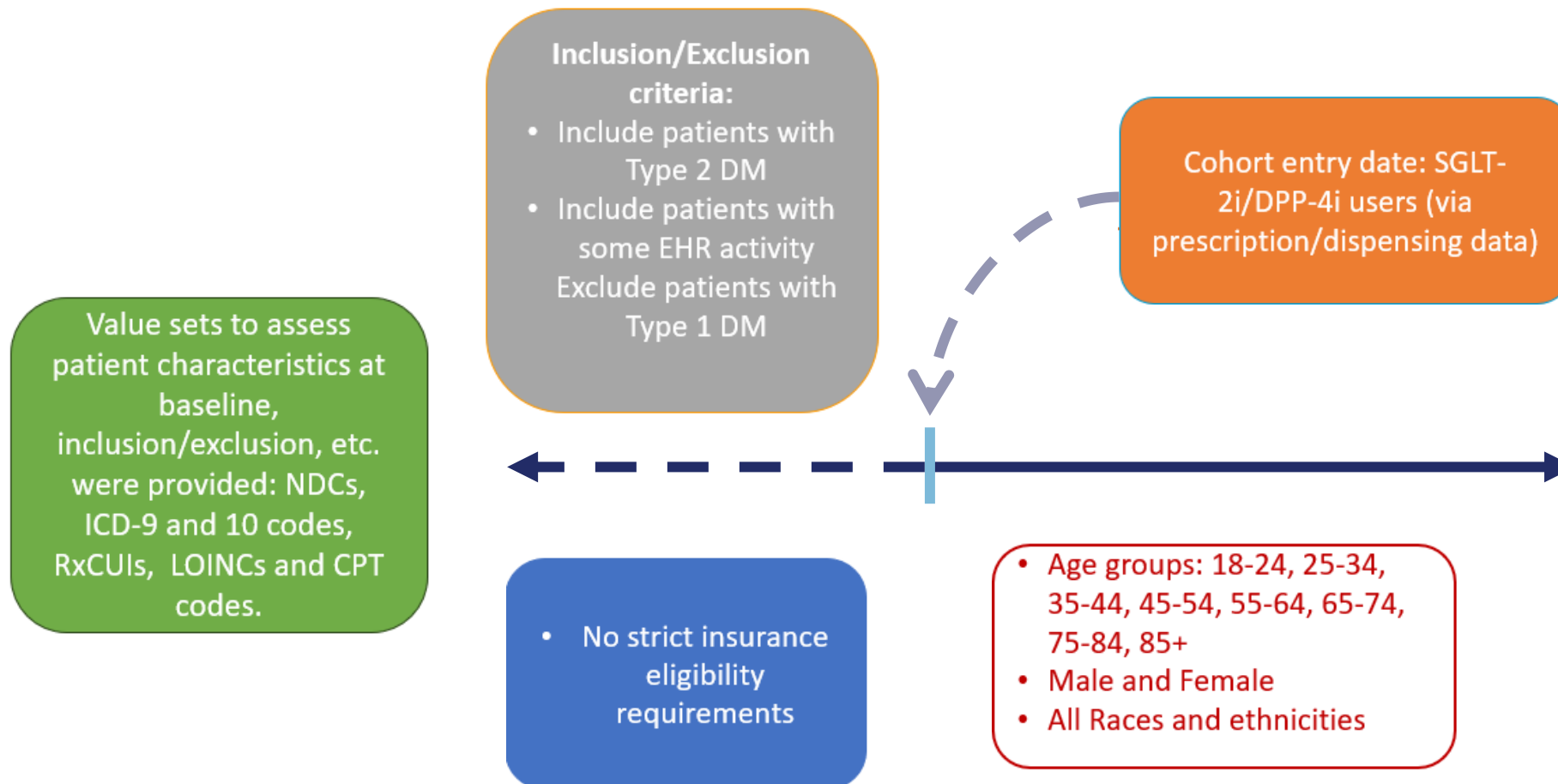
ADT – Admission, Discharge, Transfer
WSDL – Web Services Description Language



Data Characterization Exercise with Sentinel Innovation Center*

Visual Summary of the Study Design

HDU Governance approvals





Thank You

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