

INNOVATING POPULATION HEALTH RESEARCH AND EPIDEMIOLOGY WITH HIE DATA: *RESULTS OF A WORKGROUP LEVERAGING A DISTRIBUTED NETWORK OF HIES*



Anjum Khurshid, MD, PhD
David Kendrick, MD, MPH
Tim Pletcher, DHA
Dan Porreca

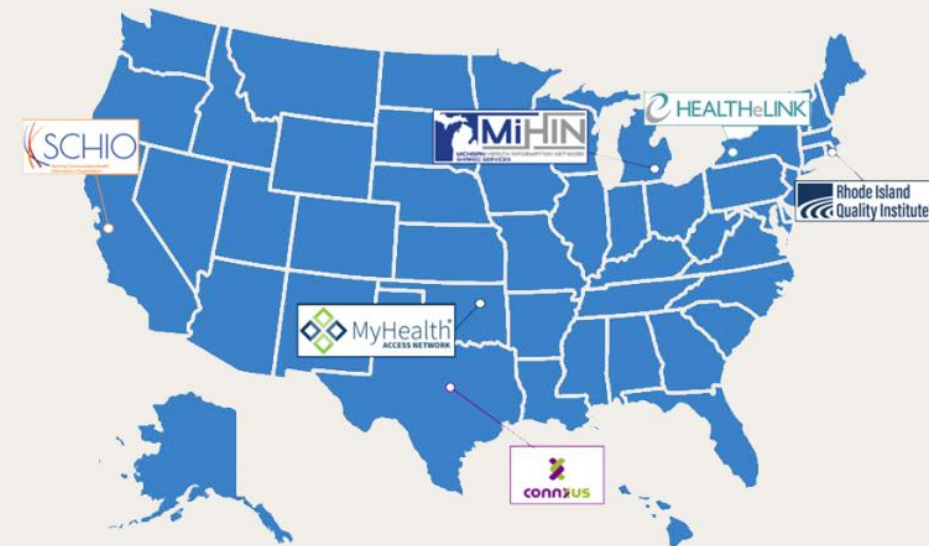
Tuesday, October 15, 2024





AGENDA

- Speaker and HIE Introductions
- Problem Statement and Our Approach
- “HIE Data Collaboration” Pilot
 - *Local Trust*
 - *Multiple Data Models*
 - *Decentralized and Comprehensive*
 - *“National Learning Health Systems”*
- Q&A



Anjum Khurshid, MD, PhD



- Harvard Medical School – Faculty
- Harvard Pilgrim Health Care Institute – Chief Data Scientist, Sentinel Operations Center
- Previous Co-Chief, Health Informatics, Data Science and Epidemiology Division, Department of Population Health at Dell Medical School, The University of Texas at Austin
- Previous board member of Connexus (Central TX HIE) and Greater New Orleans HIE (now PelX)

David Kendrick, MD, MPH



- CEO of MyHealth Access Network, Oklahoma State Designated Entity for HIE
- Board Member, CIVITAS Network for Health
- Chair, Department of Medical Informatics, University of Oklahoma's School of Community Medicine
- Member & Former Chair, National Committee for Quality Assurance (NCQA) Board of Directors
- Senior Counsel for Interoperability to National Coordinator DeSalvo

TIM PLETCHER, DHA



- Executive Director, Michigan Health Information Network Shared Services (MiHIN)
- Adjunct Research Investigator of Learning Health Sciences, University of Michigan Medical School
- Founding Director of the Institute for Health and Business Insight at Central Michigan University
- Chief Executive Officer for Velatura Public Benefit Corporation and the Interoperability Institute

DAN PORRECA



- President & CEO, HEALTHeLINK (Western NY HIE)
- Board Member, CIVITAS Network for Health
- Governing Board Member, Buffalo Translational Consortium (which oversees the Clinical and Translational Science Institutes)
- Former Board Member and Serving on New York eHealth Collaborative Business and Operations Council (SHIN-NY)

PROBLEM STATEMENT

- *Public health surveillance and population health research are severely limited by lack of authorized access to timely, comprehensive, high-quality data.*
- *Significant public funds are spent on supporting narrow, single use, incomplete, and duplicative data aggregation projects.*

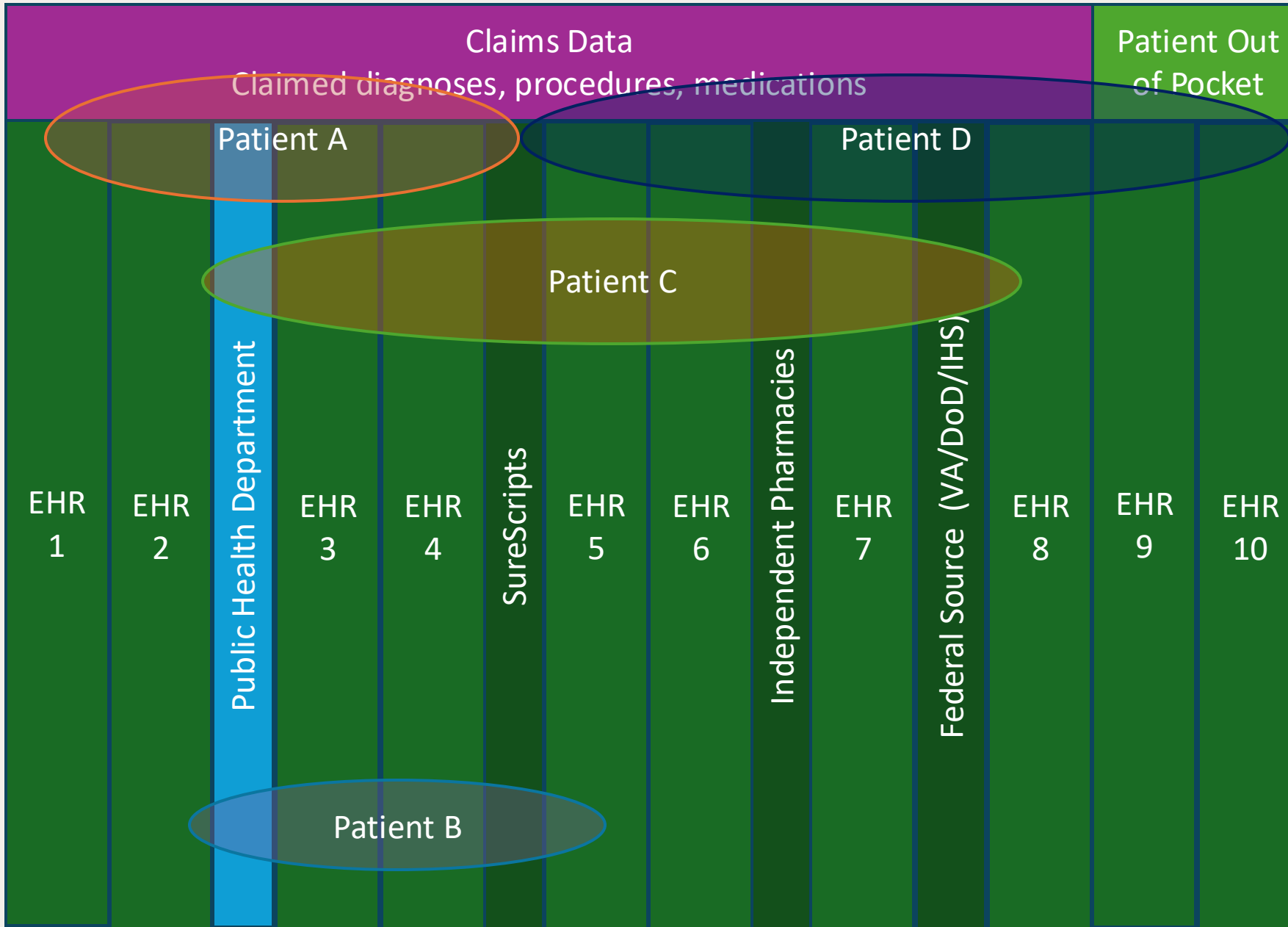


WHY IS THIS SO HARD TO SOLVE?

- *Harmonizing health and social services data for analysis **requires expertise in content, technology, data governance, and standards** related to health information*
- *Research and surveillance require more than access to raw data but need quality data, with defined sources, valid information, and complete coverage of the topic under study*
- *Sources of data are health systems, health plans, and patients, who do not directly conduct research or surveillance, and their IT systems are not designed for this role*

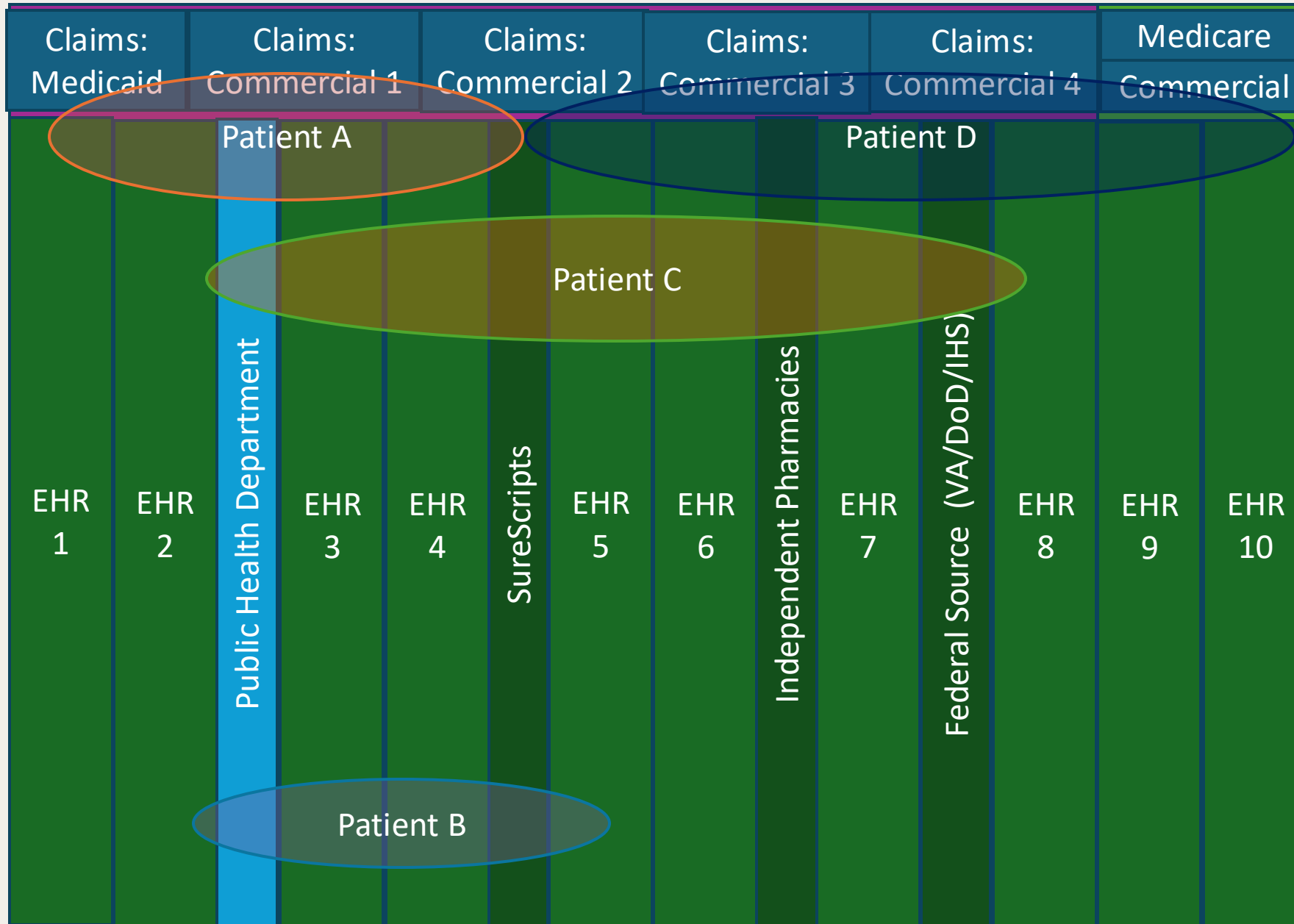


HEALTH DATA FRAGMENTATION



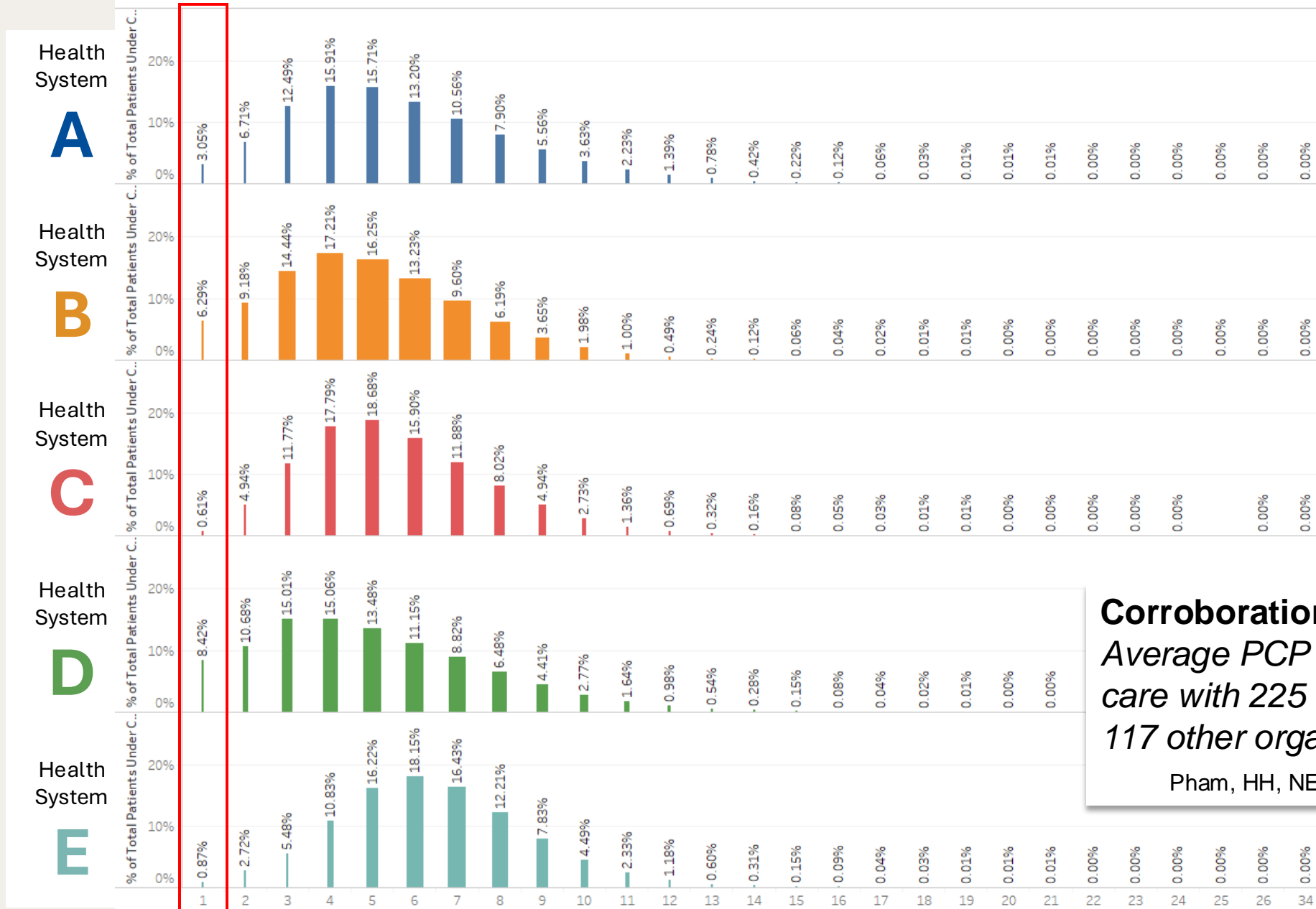
#Civitas2024

HEALTH DATA FRAGMENTATION



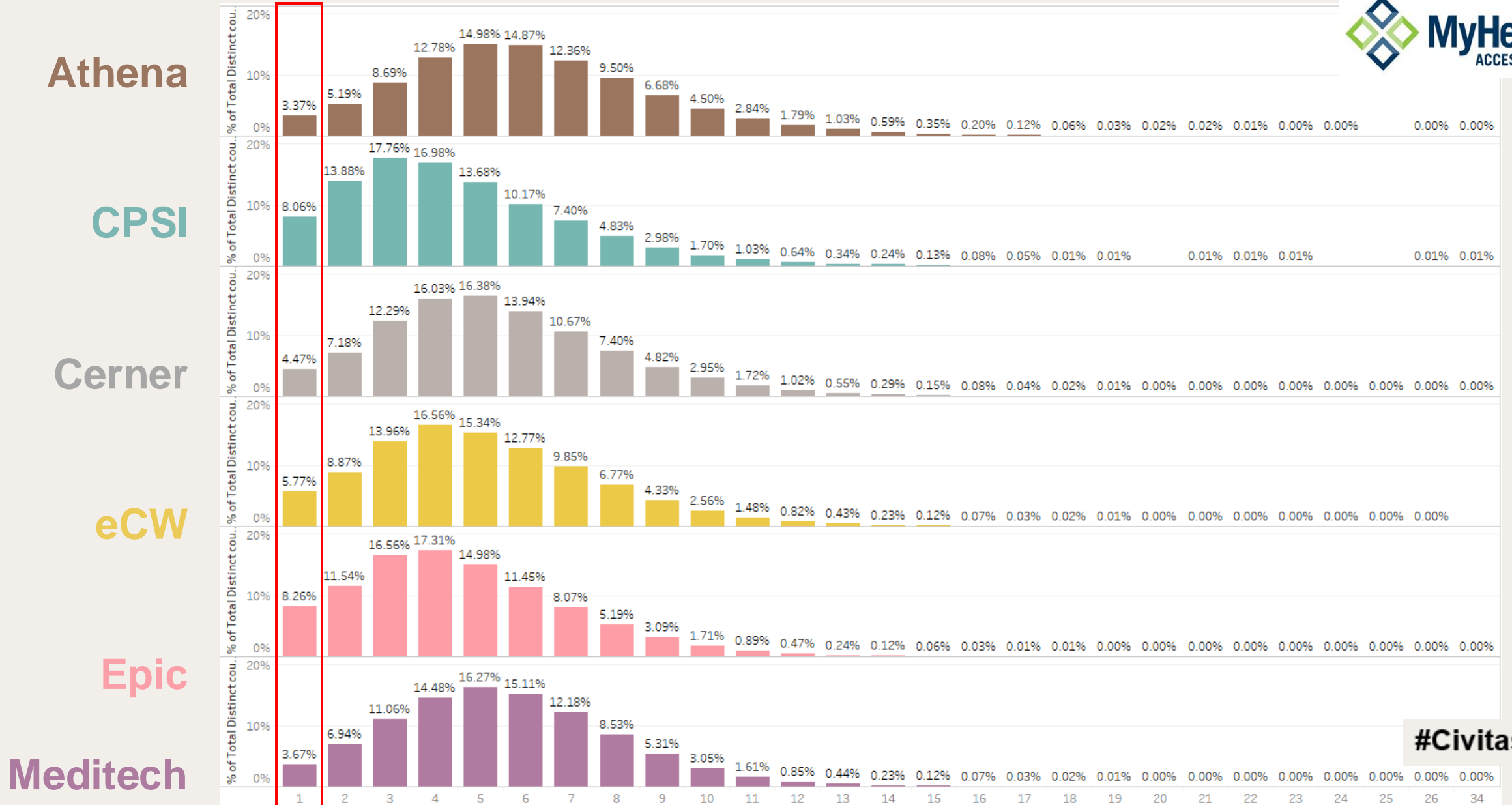
#Civitas2024

FRAGMENTATION BY HEALTH SYSTEM



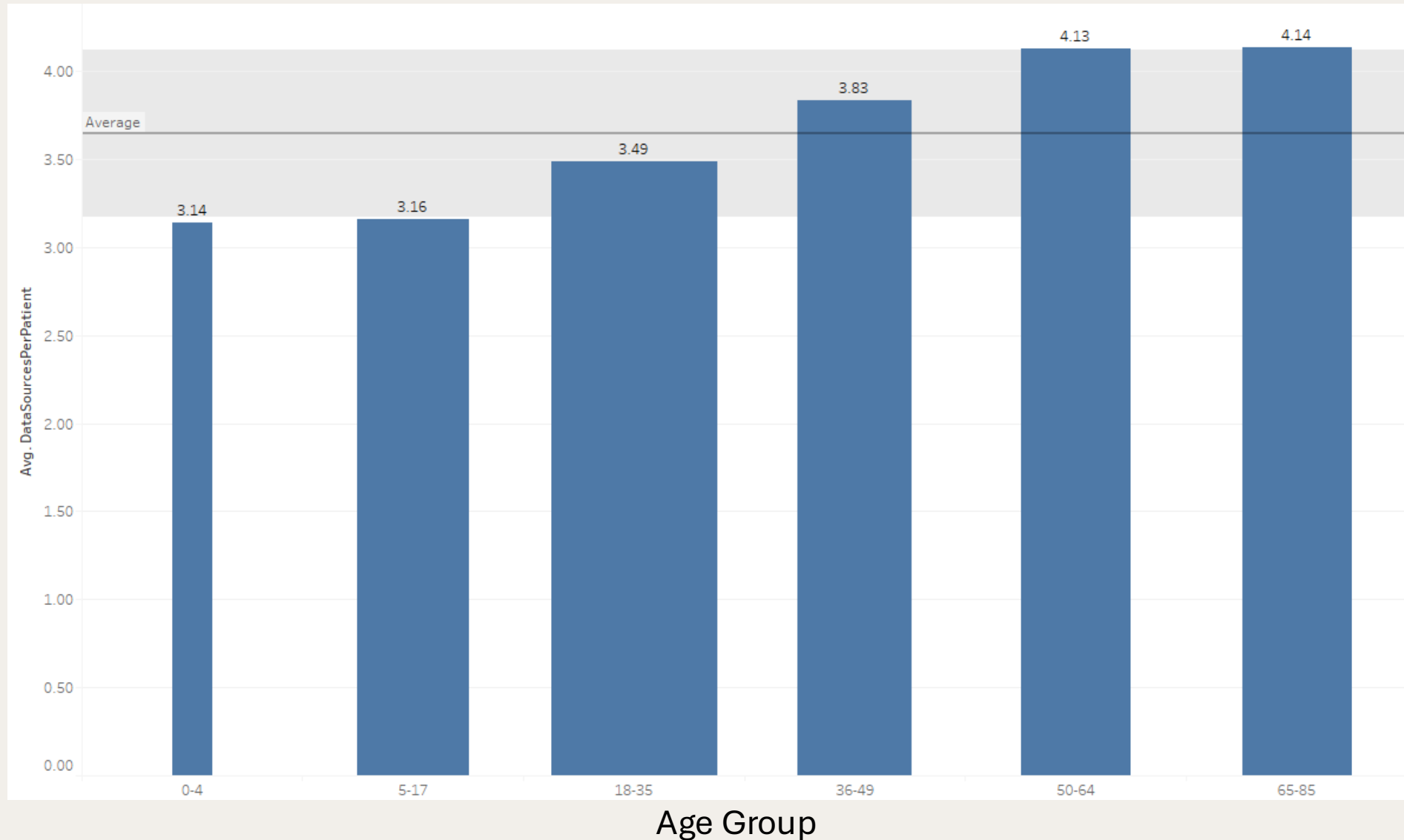
Corroboration:
Average PCP must coordinate care with 225 other providers in 117 other organizations
 Pham, HH, NEJM 2007; 356: 1130-1139

FRAGMENTATION BY EHR VENDOR



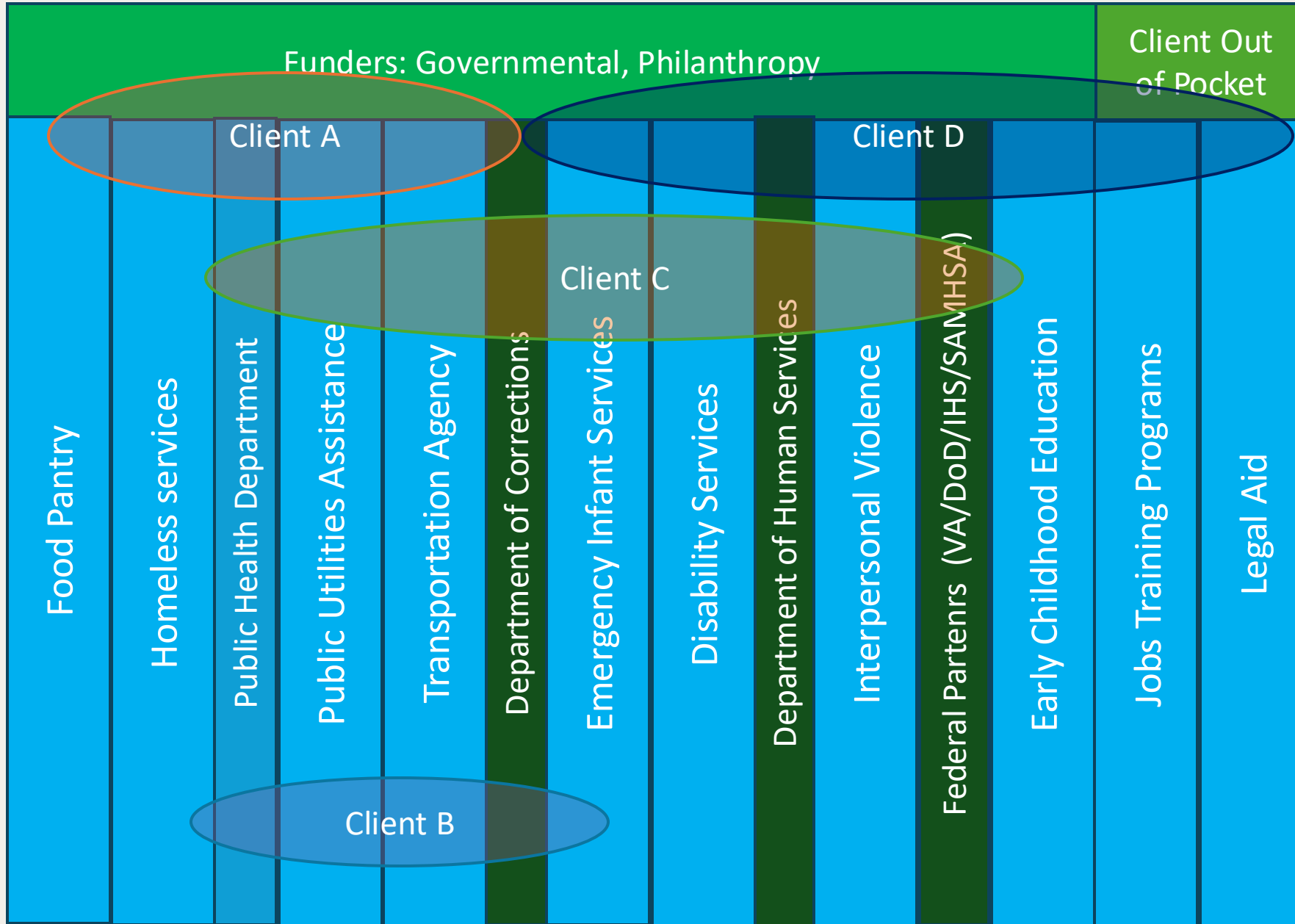
#Civitas2024

OF DATA SOURCES BY AGE GROUP

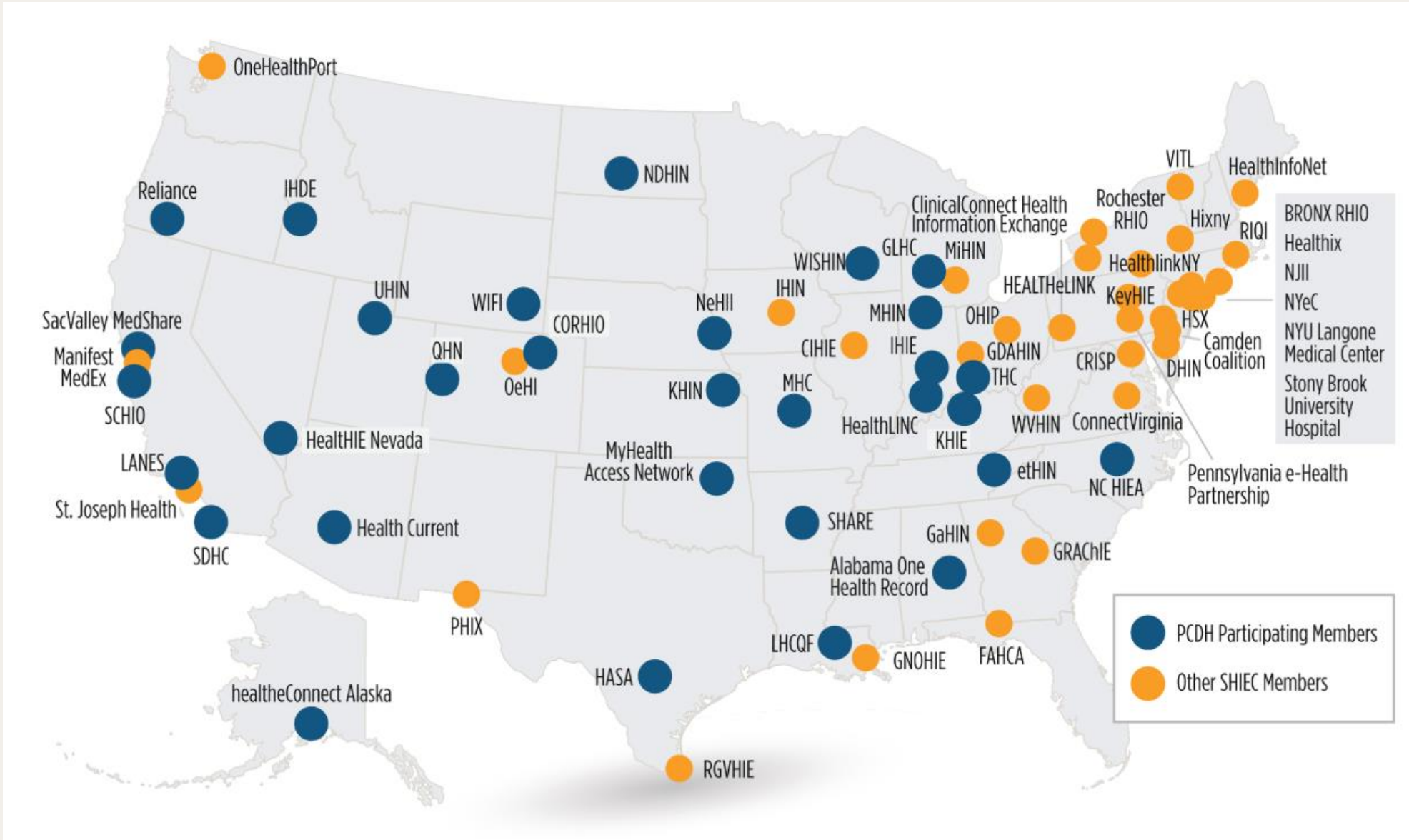


#Civitas2024

SOCIAL DETERMINANTS OF HEALTH DATA

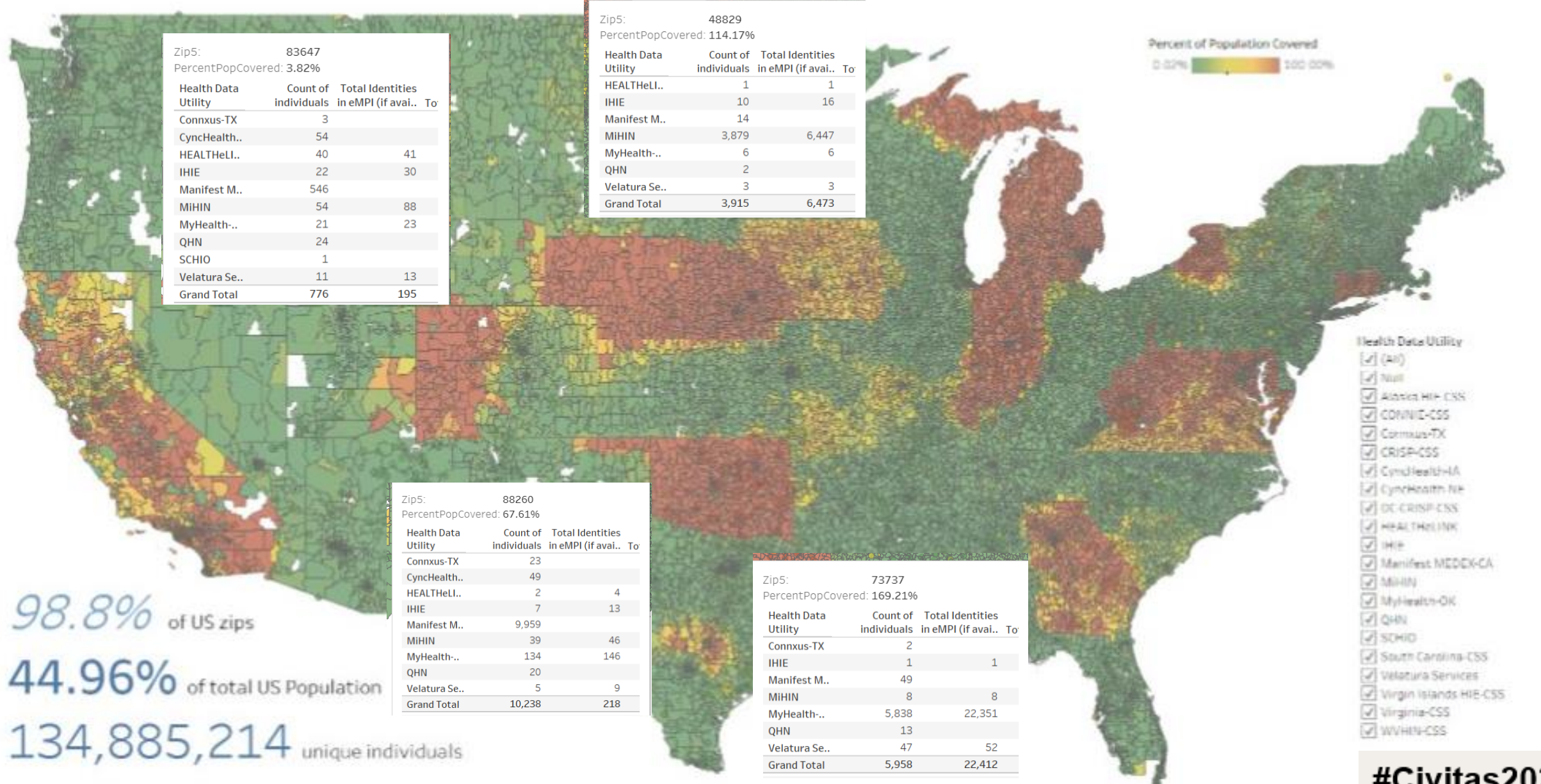


MASSIVE POTENTIAL FOR HIE IMPACT



#Civitas2024

AREAS/POPULATIONS COVERED BY HDUs



Zip5: 83647
PercentPopCovered: 3.82%

Health Data Utility	Count of individuals	Total Identities in eMPI (if avail.. To
Connxus-TX	3	
CyncHealth..	54	
HEALTHeLI..	40	41
IHIE	22	30
Manifest M..	546	
MIHIN	54	88
MyHealth..	21	23
QHN	24	
SCHIO	1	
Velatura Se..	11	13
Grand Total	776	195

Zip5: 48829
PercentPopCovered: 114.17%

Health Data Utility	Count of individuals	Total Identities in eMPI (if avail.. To
HEALTHeLI..	1	1
IHIE	10	16
Manifest M..	14	
MIHIN	3,879	6,447
MyHealth..	6	6
QHN	2	
Velatura Se..	3	3
Grand Total	3,915	6,473

Zip5: 88260
PercentPopCovered: 67.61%

Health Data Utility	Count of individuals	Total Identities in eMPI (if avail.. To
Connxus-TX	23	
CyncHealth..	49	
HEALTHeLI..	2	4
IHIE	7	13
Manifest M..	9,959	
MIHIN	39	46
MyHealth..	134	146
QHN	20	
Velatura Se..	5	9
Grand Total	10,238	218

Zip5: 73737
PercentPopCovered: 169.21%

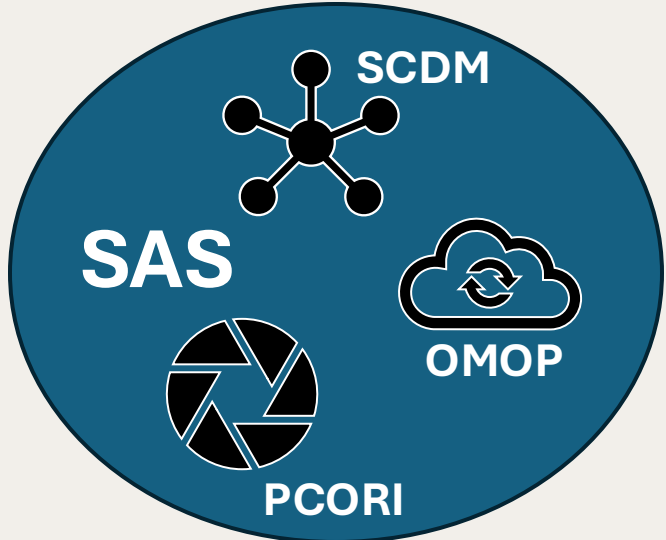
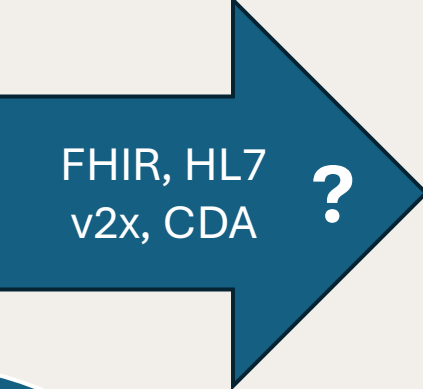
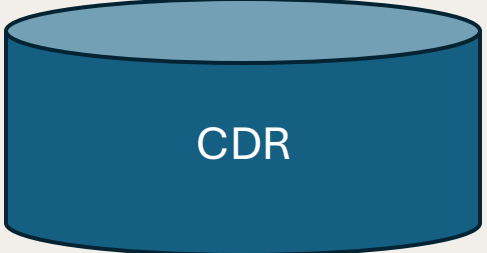
Health Data Utility	Count of individuals	Total Identities in eMPI (if avail.. To
Connxus-TX	2	
IHIE	1	1
Manifest M..	49	
MIHIN	8	8
MyHealth..	5,838	22,351
QHN	13	
Velatura Se..	47	52
Grand Total	5,958	22,412

98.8% of US zips
44.96% of total US Population
134,885,214 unique individuals

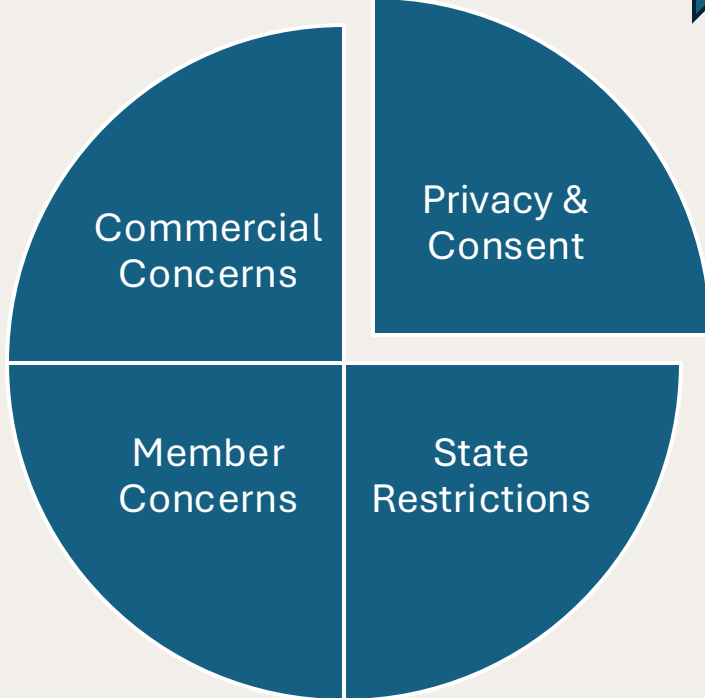
- Health Data Utility
- (All)
 - Null
 - Alonix HIE-CSS
 - CONNIE-CSS
 - Connxus-TX
 - CRISP-CSS
 - CyncHealth-IA
 - CyncHealth-NE
 - DC-CRISP-CSS
 - HEALTHeLINK
 - IHIE
 - Manifest MEDIX-CA
 - MIHIN
 - MyHealth-OK
 - QHN
 - SCHIO
 - South Carolina-CSS
 - Velatura Services
 - Virgin Islands HIE-CSS
 - Virginia-CSS
 - WVHIN-CSS

HIE RESEARCH SUPPORT CHALLENGES

**TECHNICAL &
DATA
PURPOSE
ISSUES**



GOVERNANCE



Sentinel Common Data Model (SCDM)

#Civitas2024

Administrative Data							Mother-Infant Linkage Data	Auxiliary Data		Feature Engineering Data
Enrollment	Demographic	Dispensing	Encounter	Diagnosis	Procedure	Prescribing	Mother-Infant Linkage	Facility	Provider	Feature Engineering
Patient ID	Patient ID	Patient ID	Patient ID	Patient ID	Patient ID	Patient ID	Mother ID	Facility ID	Provider ID	Patient ID
Enrollment Start & End Dates	Birth Date	Provider ID	Encounter ID & Type	Encounter ID & Type	Encounter ID & Type	Encounter ID	Mother Birth Date	Facility Location	Provider Specialty & Specialty Code Type	Encounter ID
Medical Coverage	Sex	Dispensing Date	Service Date(s)	Provider ID	Provider ID	Provider ID	Encounter ID & Type			Feature ID
Drug Coverage	Postal Code	Rx	Facility ID	Service Date(s)	Service Date(s)	Order Date	Mother Admission & Discharge Date			Feature
Medical Record Availability	Race	Rx Code Type	Etc.	Diagnosis Code & Type	Procedure Code & Type	Rx	Child ID			FE Code Type
	Etc.	Days Supply		Principal Discharge Diagnosis	Etc.	Days Supply	Childbirth Date			Etc.
		Amount Dispensed				Rx Route of Delivery	Mother-Infant Match Method			
						Etc.	Etc.			

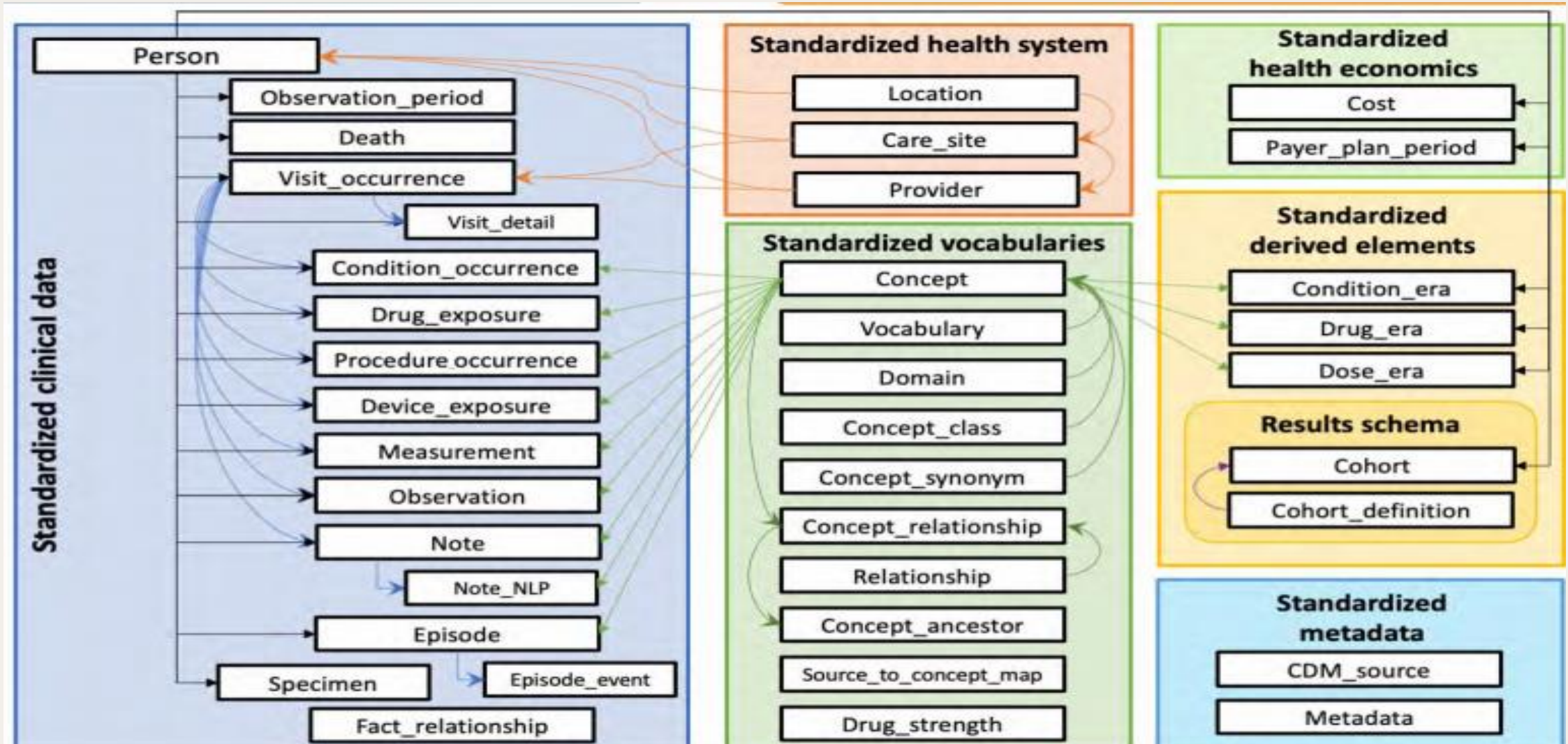
Registry Data		
Death	Cause of Death	State Vaccine*
Patient ID	Patient ID	Patient ID
Death Date	Cause of Death	Vaccination Date
Date Imputed Flag	Source	Admission Date
Source	Confidence	Vaccine Code & Type
Confidence	Etc.	Provider
Etc.		Etc.

Inpatient Data	
Inpatient Pharmacy	Inpatient Transfusion
Patient ID	Patient ID
Encounter ID	Encounter ID
Rx Administration Date & Time	Transfusion Administration ID
National Drug Code (NDC)	Administration Start & End Date & Time
Rx ID	Transfusion Product Code
Route	Blood Type
Dose	Etc.
Etc.	

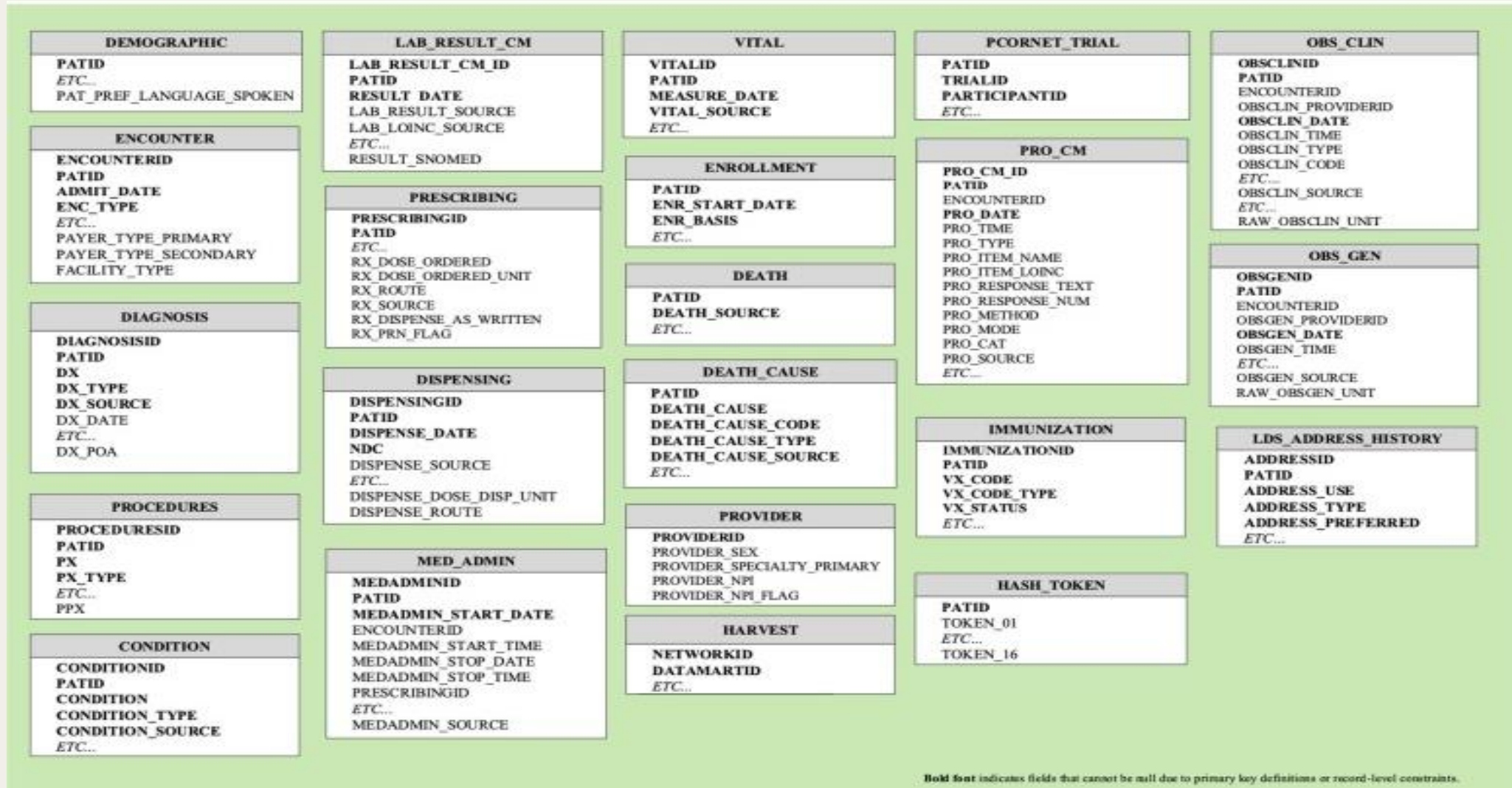
Clinical Data	
Lab Result	Vital Signs
Patient ID	Patient ID
Result & Specimen Collection Dates	Measurement Date & Time
Test Type, Immediacy & Location	Height & Weight
Logical Observation Identifiers Names and Codes (LOINC®)	Diastolic & Systolic BP
Etc.	Tobacco Use & Type
	Etc.

Patient-Reported Measures (PRM) Data	
PRM Survey	PRM Survey Response
Measure ID	Patient ID
Survey ID	Encounter ID
Question ID	Measure ID
Etc.	Survey ID
	Question ID
	Response Text
	Etc.

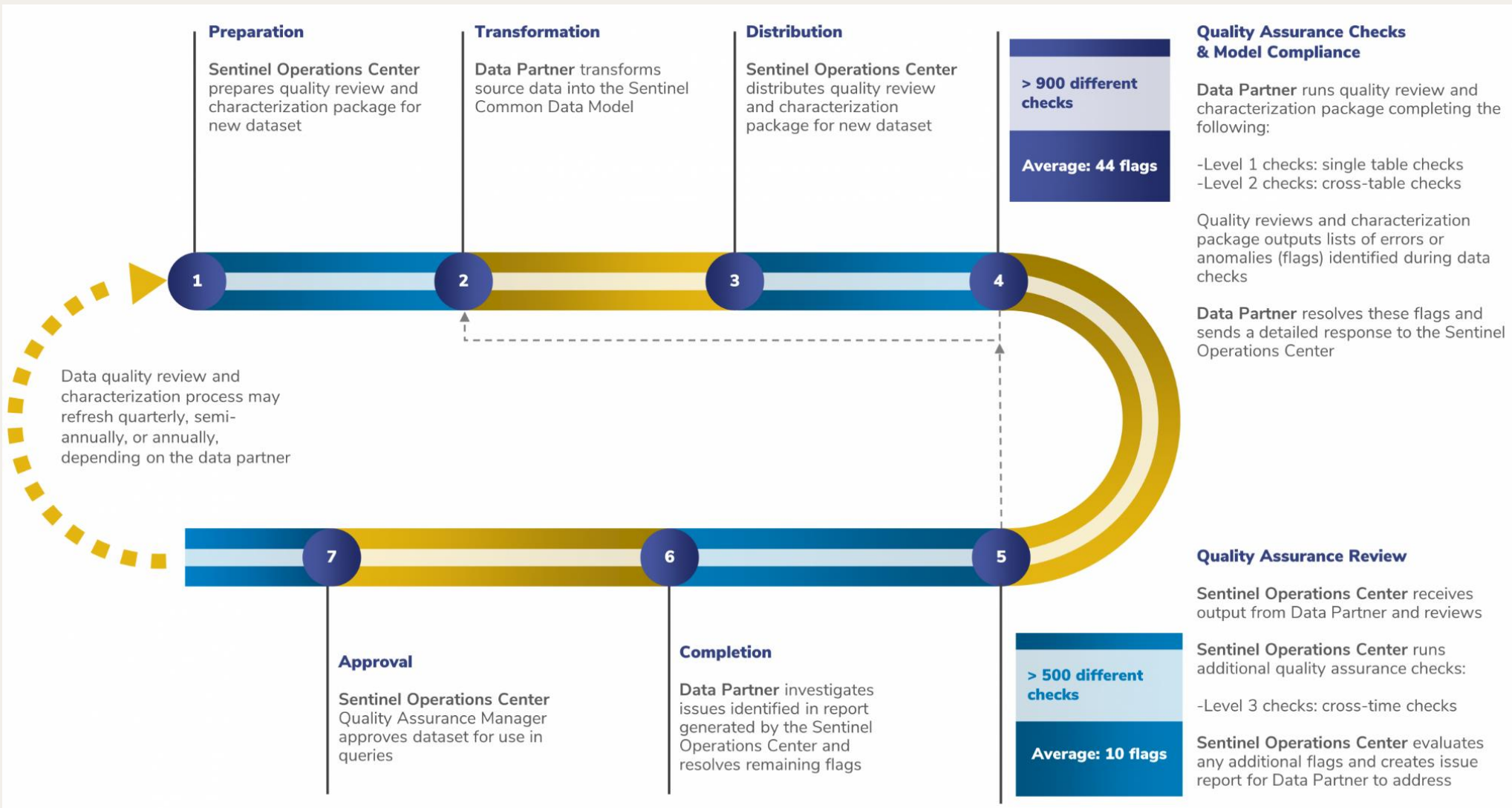
Observational Medical Outcomes Partnership (OMOP)



PCORnet Common Data Model (PCORnet CDM)



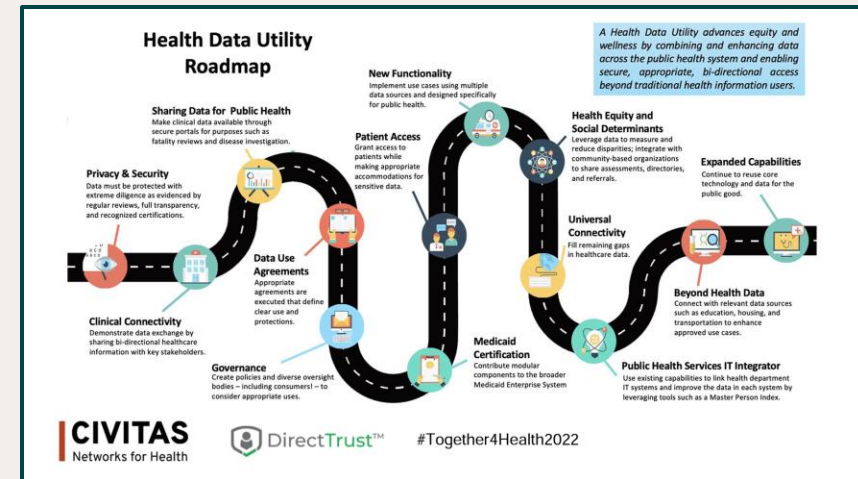
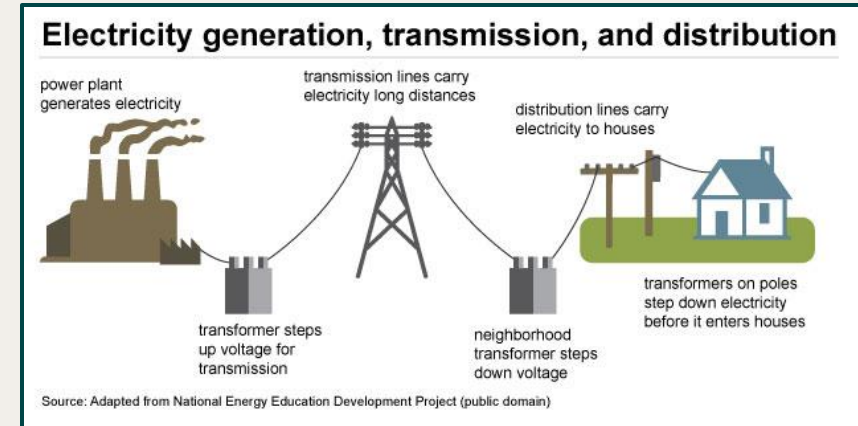
SENTINEL QUALITY ASSURANCE (QA) PROCESS



#Civitas2024

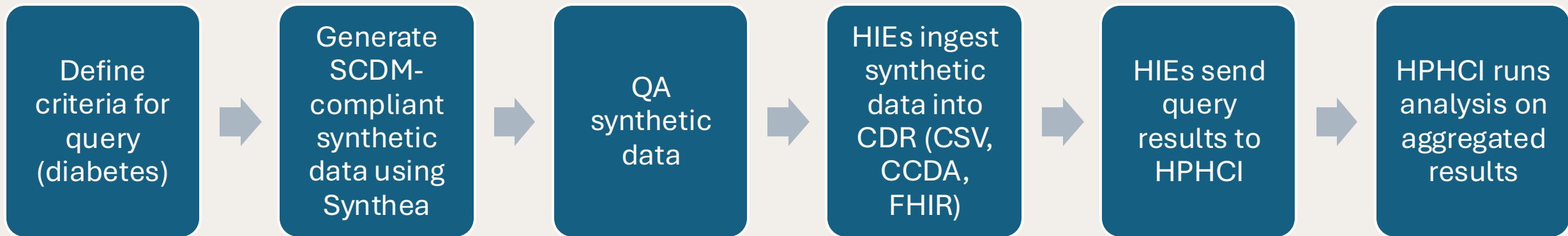
PROPOSED SOLUTION

- *Health data utilities (HDU) that source, integrate, refine, and exchange health-related information:*
 - *from multiple sources*
 - *under local trust and governance*
 - *for multiple approved uses*
 - *for the public benefit*
- *Test the ability of a distributed group of HIEs/HDUs to answer a common question using a shared set of operational principles, data quality assurance (QA) processes, and common data model (CDM).*

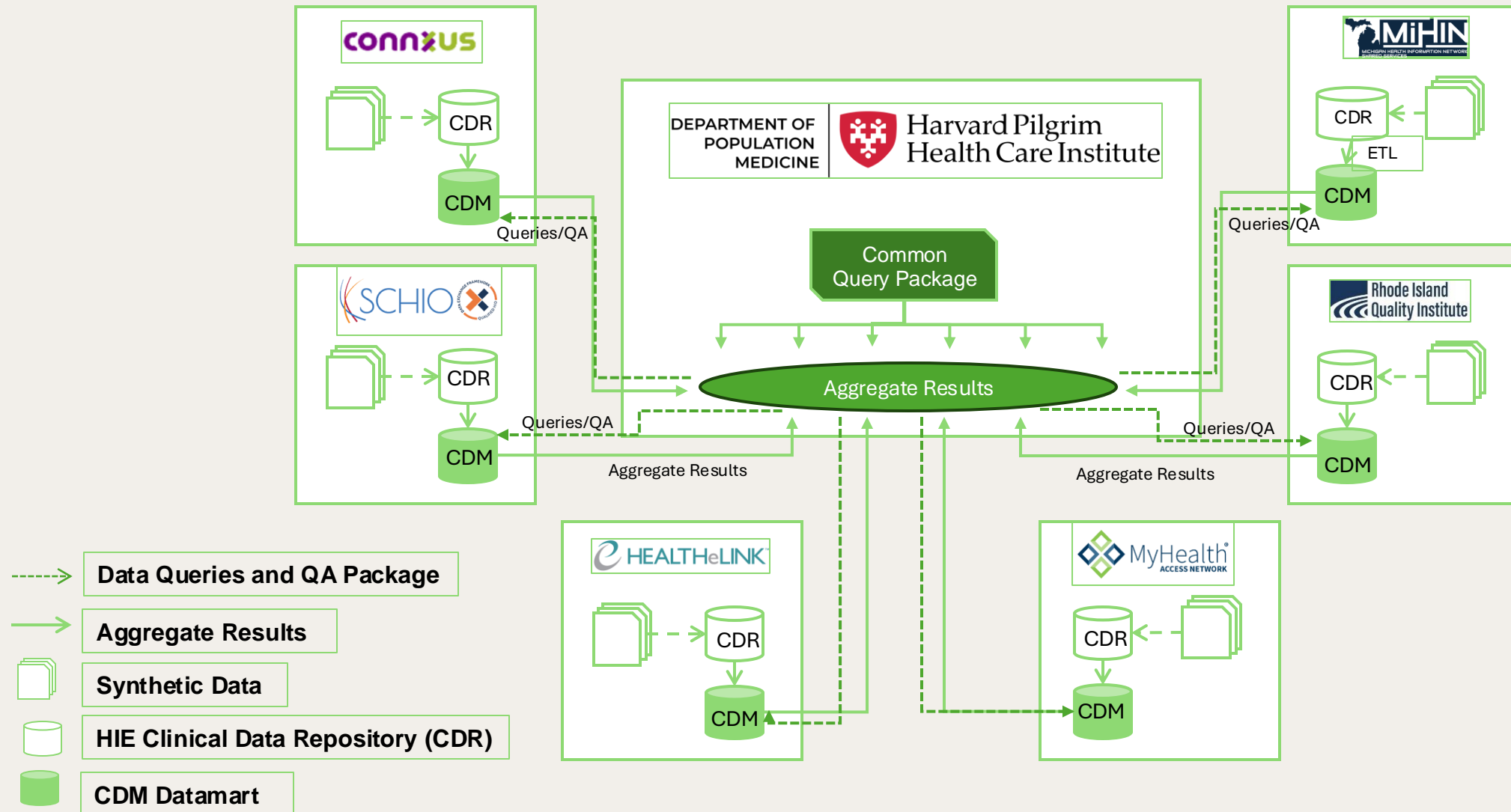


SYNTHETIC DATA PILOT STUDY

Data for each participating organization remains within the control of that organization.



ARCHITECTURE OF PILOT STUDY



FRAMEWORK FOR HIE/HDU COLLABORATION

Decentralized &
Comprehensive

Common Tools

Local Trust

Impactful
Knowledge
Creation

Cross-Sector
Data Integration

National
Standards

Multiple
Data Models

“Learning Health
Systems”
Approach

Privacy

Sustainability

BENEFITS OF NATIONAL, HIE APPROACH

- Enhanced clinical insights: longitudinal, multidimensional (imaging, labs, pharmacy)
- SDoH data for studying health equity
- Streamlined access to patient-level charts (as needed)
- Unstructured data from notes
- Cost efficiency in sustaining and operating the network
- Public health use



Q&A



#Civitas2024