CIVITAS
Networks for Health

3rd Annual USVI Digital Health Summit: HIE and the Emergence of Health Data Utilities

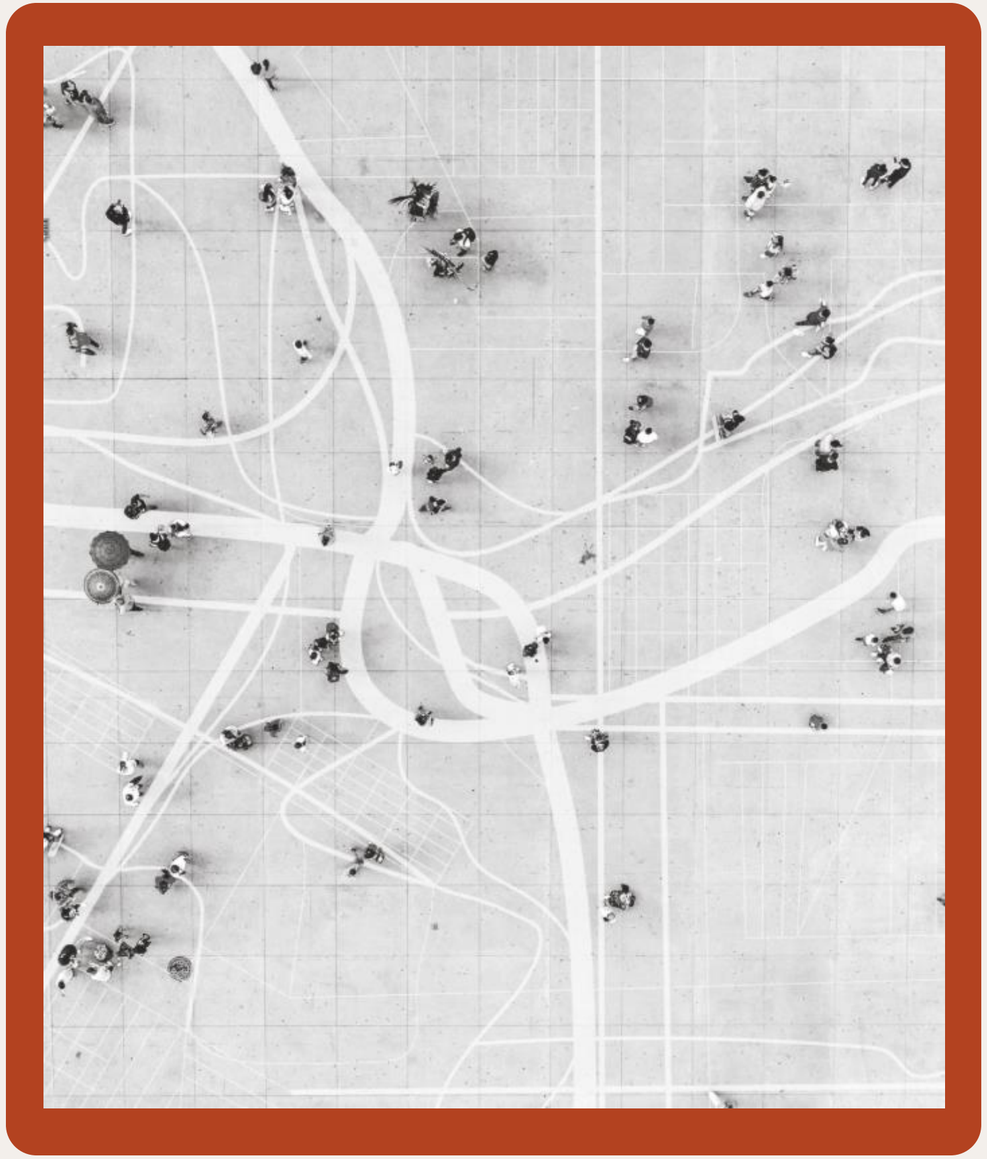
Lisa Bari
Civitas Networks for Health
November 18, 2024

WHAT IS CIVITAS NETWORKS FOR HEALTH?

DATA

DOING

CIVITAS
Networks for Health

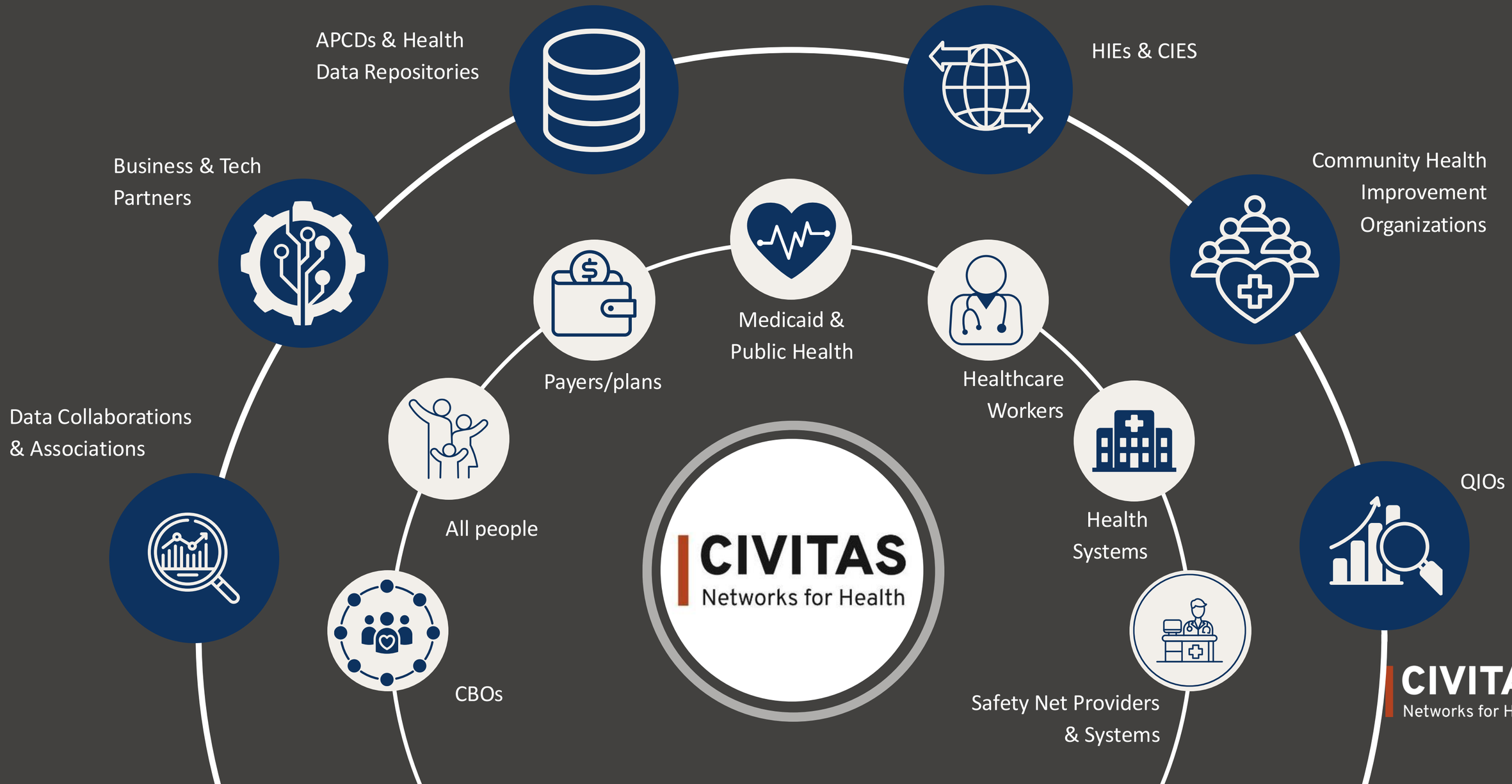


Regional innovation, national impact.

Our vision: Communities are thriving and healthy, realizing the full potential of data-driven, multi-stakeholder, and cross-sector approaches to health information exchange and health improvement.

CIVITAS
Networks for Health

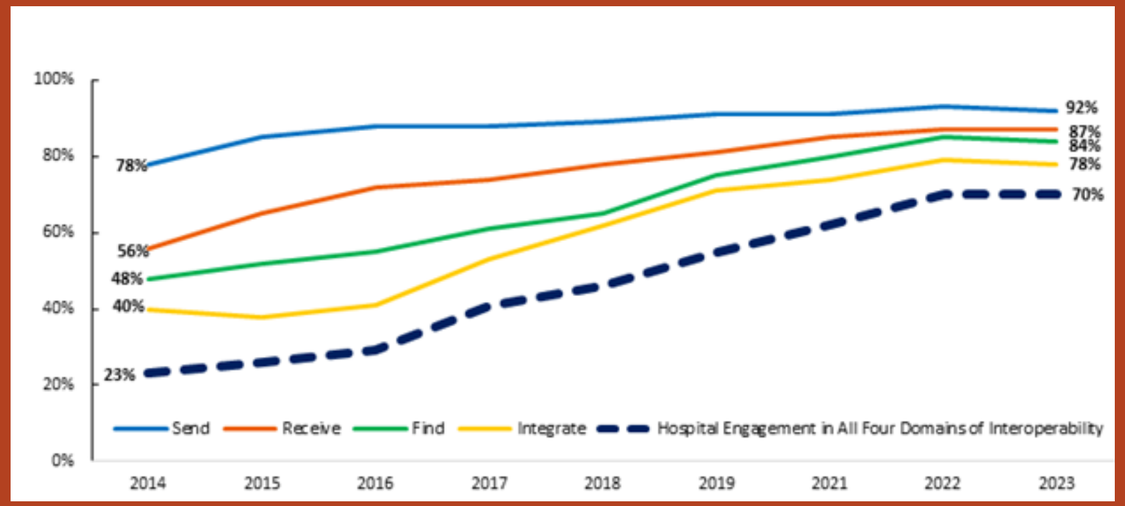
WHO CIVITAS SERVES

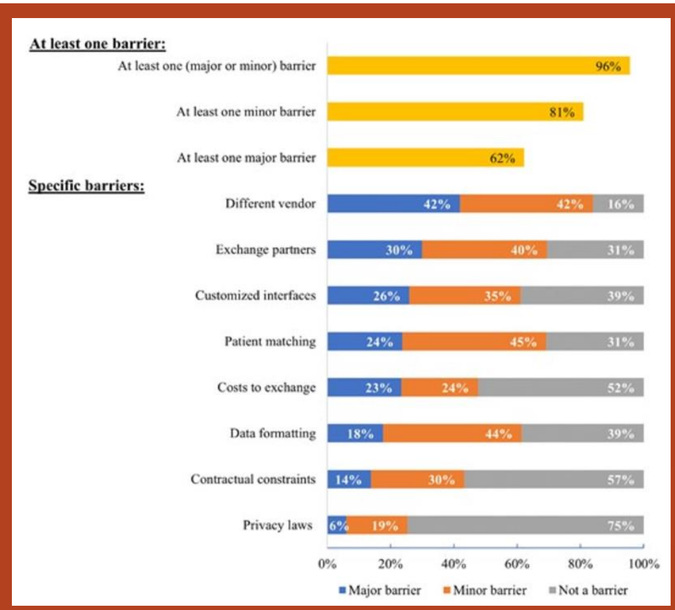


20 YEARS OF HEALTH IT AND HIE POLICY AND REGULATION

- HITECH Act
- Health IT Certification
- Billions of $$ for Meaningful Use
- MACRA/QPP
- Medicaid Enterprise Systems
- 21st Century Cures
- Health-Related Social Needs Data
- Community Information Exchange
- TEFCA
- Data Privacy?
- Health AI Assurance

True Interoperability Still Elusive





https://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/interoperability-electronic-health-and-medical-records/raising-the-bar-on-interoperability-a-decade-of-data-show-that-sometimes-isnt-good-enough
https://academic.oup.com/jamia/advance-article/doi/10.1093/jamia/ocae263/7821240

CIVITAS
Networks for Health

SOME QUESTIONS…

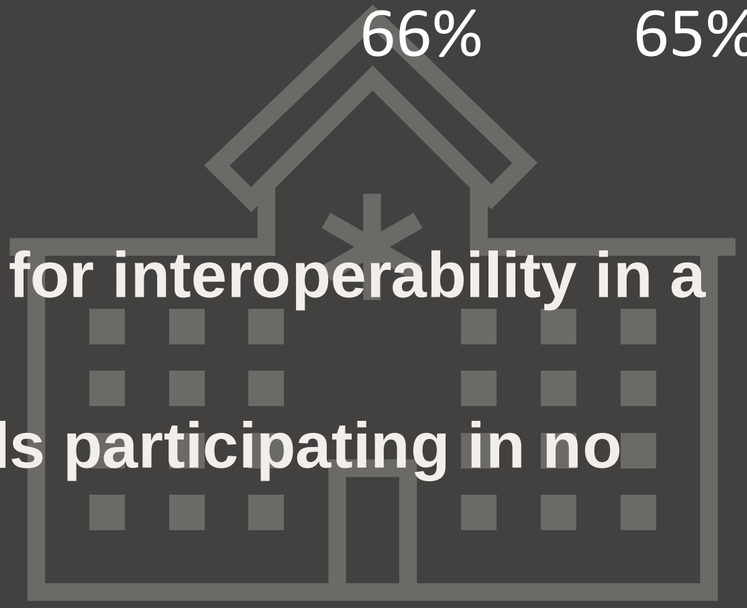
- What about the nationwide networks, private networks and national interoperability frameworks?
- Will data exchange issues be solved at the federal or nationwide level?
- Why do states, HIEs, local data collaboratives, and emerging HDUs matter?

TEFCA℠ carequality eHealth Exchange™ commonwell® HEALTH ALLIANCE

CIVITAS Networks for Health

HEALTH CARE SYSTEM ADOPTION OF HIE

	2021	2023
% of acute care hospitals using state, regional HIEs	79%	78%
% of acute care hospitals using national networks	66%	65%



- **57% are using both--there is no single solution for interoperability in a complex health care landscape.**
- **Further progress is stalled with 14% of hospitals participating in no HIE/interoperability networks.**

Source: 2023 AHA Annual Survey Information Technology Supplement

CIVITAS
Networks for Health

WHY COMMUNITY GOVERNANCE?

Nationwide Interoperability Networks & Frameworks

Community Governed HIE Organizations

Progress over the last two decades points to nationwide centralization, consolidation, and an EHR-centric view of interoperability and data exchange...

BUT

Data governance must happen at the community level with local stakeholders, in line with state, tribal, local, and territorial laws and needs. These organizations can co-exist with nationwide exchanges and frameworks.

CIVITAS
Networks for Health

THE EMERGENCE OF HEALTH DATA UTILITIES

HDUs are regional, statewide, territorial, or tribal entities that combine, enhance, and exchange electronic health data across care and service settings for treatment, care coordination, quality improvement, and public and community health purposes.

They enable specific, defined, cross-sector use cases with extra safeguards to ensure patient privacy and protection.

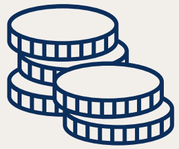
They build on existing technical, organizational, and trust infrastructure.

CIVITAS
Networks for Health

EMERGING HDU CHARACTERISTICS

Neutrality and flexibility in meeting stakeholders' goals

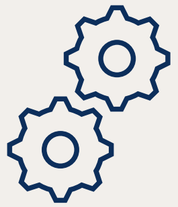
Designated Authority for specific services



Sustainable financing

Connected geography

Multi-stakeholder, cross-sector participation



Modular infrastructure and advanced technical services

Public-private partnerships

Inclusive governance strategy

Leverage state, territorial, tribal, and local program and data authority

CIVITAS
Networks for Health

THE RIGHT EQUATION FOR HIE AND HDU INFRASTRUCTURE

Robust HDUs covering every jurisdiction in the nation

+

High adoption of nationwide networks and frameworks

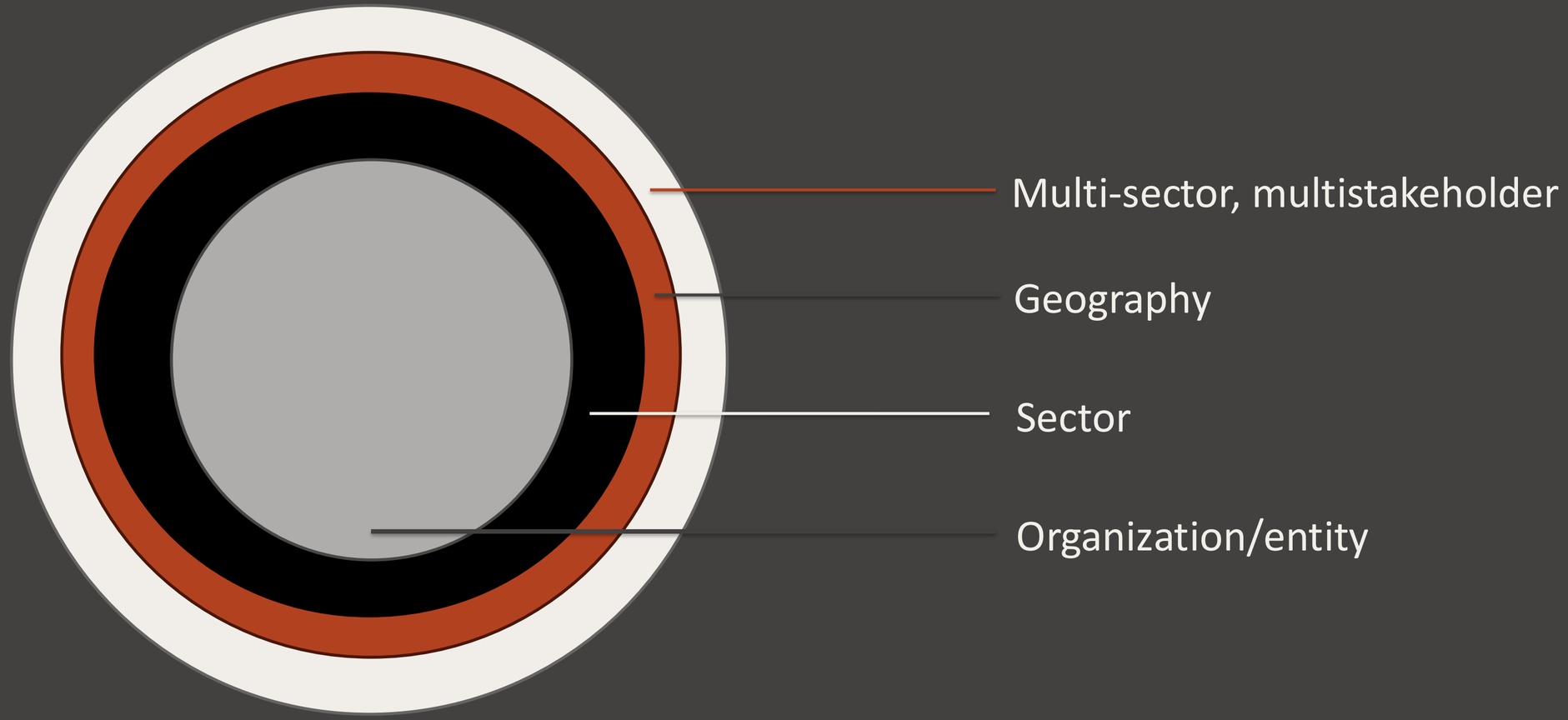
=

Meeting health, quality, equity, and interoperability needs

CIVITAS
Networks for Health

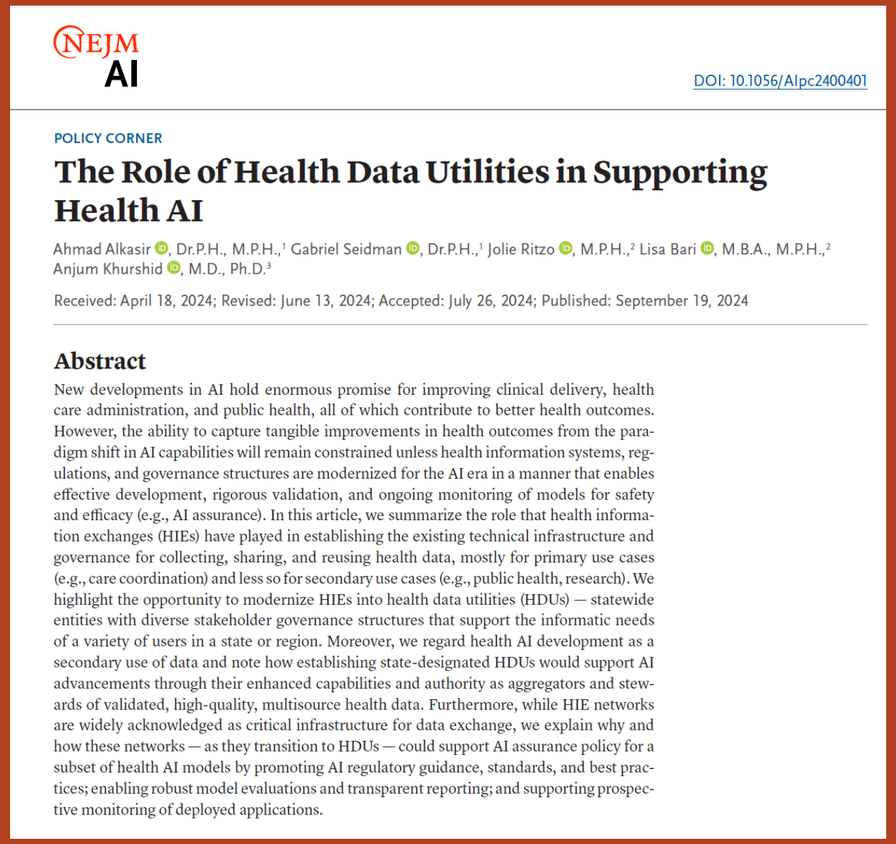
HDU COMMUNITY GOVERNANCE

Collaborative, flexible community governance to support expanding use cases across geographies and settings.



CIVITAS
Networks for Health

HDUS CAN SUPPORT HEALTH AI GOVERNANCE



NEJM AI

DOI: 10.1056/AIpc2400401

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]

Received: April 18, 2024; Revised: June 13, 2024; Accepted: July 26, 2024; Published: September 19, 2024

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.

- Even back-office applications of health AI are risky, and need inclusive, agile governance.
- Training AI models for safer use requires robust, connected, representative data.
- **Health Data Utilities** are governing bodies for cross-sector healthcare, public health, and social care data in specific regions or jurisdictions, and **are uniquely positioned to support these AI governance needs**.

CIVITAS
Networks for Health

A PATH FORWARD WITH HDU FOR THE U.S. VIRGIN ISLANDS

- Choose a great partner…
- Define baseline use cases – Medicaid, public health, health related social needs.
- **Develop inclusive governance and oversight.**
- **Build once and deliver valuable services and data to many**.
- Share your learnings, advance the HDU model, and be a leader in the community!

HEALTH DATA UTILITY

CIVITAS Networks for Health

CIVITAS HDU RESOURCES

What are Health Data Utilities?

Health Data Utilities represent a new paradigm to support community-centric health data exchange. They serve as a resource to multiple stakeholders within a defined region with expanded purposes beyond clinical data exchange such as public health, social determinants of health, quality improvement, and value-based care.

Explore resources for Health Data Utilities.

Defining Health Data Utilities

Health Data Utilities (HDUs) are regional or statewide entities that combine, enhance, and exchange electronic health data across care and service settings for treatment, care coordination, quality improvement, health equity, and public and community health purposes. They serve as health equity infrastructure and enable specific, defined use cases with extra protections to ensure patient privacy and protection. HDUs should build on existing technical, organizational, and trust infrastructure in states and regions.

Key Characteristics of Health Data Utilities

Health Data Utilities, despite their diverse implementations, share several key characteristics:

- Neutrality and flexibility in meeting stakeholders' goals
- Designated authority
- Sustainable financing
- Connected region or state geography
- Multi-stakeholder, cross-sector participation
- Modular infrastructure and advanced technical services
- Public-private partnerships
- Inclusive governance strategy
- Leverage state and local authority

CIVITAS
Networks for Health

SAVE THE DATE FOR #CIVITAS2025

Civitas Networks for Health's 2025 "Bridging Data and Doing" Annual Conference in Partnership with 211 San Diego/CIE will take place in Anaheim, CA from September 28-30, 2025.

Learn more via the Civitas website and sign up for our personalized newsletter at www.civitasforhealth.org.

CIVITAS
Networks for Health

THANK YOU! PLEASE KEEP IN TOUCH

SCAN

CIVITAS
Networks for Health

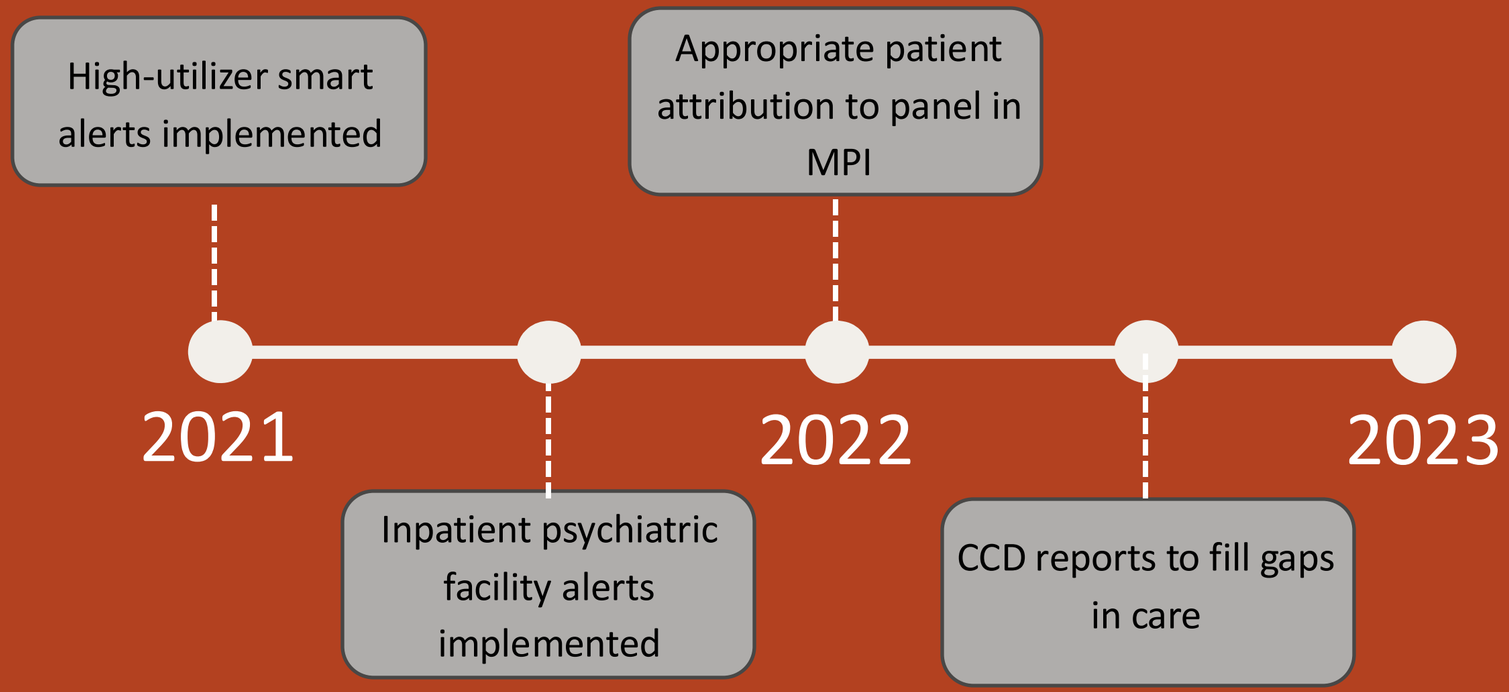
WHAT CAN HDUs DO FOR THEIR COMMUNITIES?

- Enable value-based care and quality improvement
- Data sharing for health-related social needs
- Public health data modernization
- Advancement of health equity

CIVITAS
Networks for Health

VALUE-BASED CARE ENABLEMENT

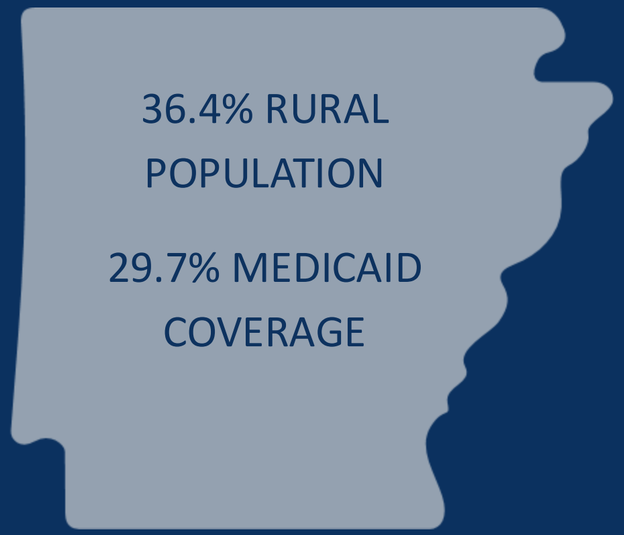
In Arizona, the public health and Medicaid systems are utilizing Contexture to improve value-based care delivery. This enables providers to take on risk arrangements for their patient populations because they have more comprehensive quality data that supports whole person care.



CIVITAS
Networks for Health

VALUE-BASED CARE ENABLEMENT

In Arkansas, through its partnership with HCP-LAN's State Transformation Collaboratives (STC) and the State Health Alliance for Records Exchange (SHARE), different alignment strategies have enabled providers to have a comprehensive view of patient care encounters and patterns. Payers receive comprehensive performance data more quickly rather than having to reconcile data from different practices, helping the state achieve progress toward its national value-based care arrangement.

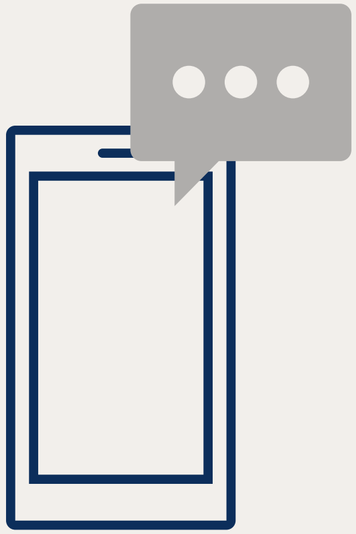


In 2023, the Arkansas STC will build on CPC+ and Primary Care First Model alignment efforts to form an aligned quality measure set. Their immediate focus is to increase payer representation in quality measure discussions.

CIVITAS
Networks for Health

HEALTH-RELATED SOCIAL NEEDS DATA

In Oklahoma, MyHealthAccess Network, a Gravity Project pilot site, utilized its existing HIE infrastructure to enable HDU for health-related social needs data sharing in a number of settings statewide. The organization did so by implementing an easy-to-use patient survey delivered via text message prior to every appointment with a provider.



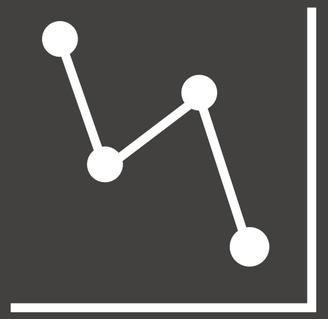
This work helped to reduce healthcare professional burden while still collecting vital data to improve care coordination and delivery. The Gravity Project has supported the rollout by providing technical assistance for the past eight months.

CIVITAS
Networks for Health

PUBLIC HEALTH DATA MODERNIZATION

The California Department of Public Health needed a better way to collect, organize, track, and report lab result registry data. They expanded the original Electronic Lab Reporting data to create SaPHIRE in 2020. By 2022, with mass amounts of data coming in from COVID-19, SaPHIRE's success required further data modernization efforts. To make this a reality and migrate participating labs to the upgraded system, the state partnered with Manifest MedEx and J2 Interactive.

The two organizations mobilized a team of solution architects, Rhapsody engineers, and HIE subject matter experts to build the necessary interoperability framework to enable secure inbound and outbound data feeds for over 350 participants.



CIVITAS
Networks for Health

PUBLIC HEALTH DATA MODERNIZATION

To improve hypertension rates statewide, Bronx RHIO partnered with the New York State Department of Health to enhance data intake, tracking, and reporting. By modernizing the systems, they were able to Increase the identification of patients with undiagnosed hypertension using electronic health data and explore and test innovative ways to engage non-physician team members.

This enabled them to generate zip-code, county or regional data reports for a measure to support the community health assessment process and development of Community Health Improvement Plans.

CIVITAS
Networks for Health

HEALTH EQUITY DATA

In Nebraska and Iowa, CyncHealth is using its HIE/HDU designation to help health care teams identify at-risk mothers and infants to enable improved and informed care coordination before, during, and after delivery. The data is used to address gaps in care, ensure mothers are receiving the appropriate referrals at every step, and advance health equity among BIPOC populations.

This work is focused on supporting Black, African American, American Indian, and Alaska Native parents with high-risk conditions who participate in Medicaid/CHIP

CIVITAS
Networks for Health