

Health Data Utilities: Enhancing and Exchanging Health Data for Health Equity and Health Improvement

Introduction

Five common public utilities in the United States are water, electricity, natural gas and sewage and sanitation. These utilities are designed for use by the public for the common good, and incorporate many different use cases and stakeholders, including individual people and families, government entities, and private businesses. In the United States, we have created and sustained the essential infrastructure to support access to many critical life-improving utilities. This was not without innovation, vision for a better way forward, and the will to create solutions and systems that would improve the lives of Americans.

Health data is increasingly beginning to fit the definition of a public-private utility, or critical shared infrastructure. As we envision thriving communities of tomorrow, ones that foster whole-person health and equitable outcomes, we must ensure the necessary infrastructure which will enable data-informed, multi-stakeholder and cross-sector approaches to making such advancements.

Creating a new utility

The emerging model for shared health data infrastructure is termed *Health Data Utilities* (HDU). In some states and regions throughout the country the concept has moved from theory into practice; this was precipitated by the urgency of the COVID-19 pandemic and disparate and siloed data systems. This promising model can be defined as statewide entities that combine, enhance, and exchange electronic health data across care and services settings for treatment, care coordination, quality improvement, and public and community health purposes. HDUs enable specific, defined use cases, with extra protections to ensure patient privacy and appropriate data use.

It is important to note that HDUs represent both the evolution of community health information exchange as well as a new paradigm—a multistakeholder, cross-sector data resource for multiple use cases and services. Whole-person and public health today is reflected in clinical and non-clinical data across multiple settings and sources. What makes HDUs different? HDUs emphasize multistakeholder organizational and use case-specific data governance with an emphasis on public health. Most organizations at the center of an HDU will be designated non-profit organizations or independent state agencies. In all cases, state and multistakeholder governance, oversight, and accountability is paramount. HDUs are flexible and uniquely capable of meeting state-specific health data needs.

Other necessary conditions

The first HDUs and proto-HDUs have generally exhibited the following conditions:

- State policy levers including incentives and/or mandates
- Broad stakeholder participation, connectivity, exchange, and community-level engagement
- Mature use cases in place for Medicaid and public health
- Multistakeholder, transparent corporate and data/network governance

- High standards for data privacy and security going beyond the baseline of state and federal laws

Building on already existing infrastructure

Throughout the United States, many states have existing infrastructure in place for clinical data exchange, including regional and statewide HIEs. However, this existing technical and relationship infrastructure needs to be strengthened and developed further. In states where such services and organization are not capable of meeting HDU requirements, there needs to be a pathway and a funding stream to support both the planning and development needed to build capacity. It is also important to call attention to lack of infrastructure in many states to support interoperability of social care data. To this end, states should be eligible to apply for funding to include social care data infrastructure and multi-sector data aggregation.

HDU use cases

HDU use cases must provide value to their communities. However, there are some baseline use cases that should be present in all HDUs across the country. This non-exhaustive list will evolve as the HDU concept matures:

- Access: query health records based on permitted purposes, including relevant public health data
- Social care: referral management, resource directories, social determinants of health referrals
- Consumer engagement: Patient education, individual access, patient-generated data
- Care delivery: alert discharge and transfer (ADT)/event notification, alerting, lab results, prescription drug monitoring, imaging, overdose alerts
- Public health: enhancing immunization and other disease registries, facilitating reporting and notifiable conditions, heat maps, situational awareness
- Quality: reporting, analytics, benchmarks, provider dashboards

In summary: what can HDUs do?

HDUs break down data silos; they combine data to enhance data. They deliver data back to clinicians and other providers in the field, engaged in care delivery, care coordination, and public health activities. They create comprehensive data sets that can enable communities to prepare, respond and make critical improvements in health, health care, public and community health. HDUs foster whole-person care and reduce provider burden of additional reporting requirements. And they leverage existing infrastructure, displaying the critical application and responsible use of federal funds.

Furthering the concept and building a maturity model

[Civitas Networks for Health](#), a mission- and member-driven organization dedicated to using health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health is well positioned to advance a HDU maturity model. Civitas Networks for Health represents more than one hundred regional and statewide health information exchanges (HIEs), regional health improvement collaboratives (RHICs), quality improvement organizations (QIOs), and all-payer claims databases (APCDs) as well as more than 50 affiliated organizations as members and reaches approximately 95 percent of the United States population. With this

extensive geographic footprint and network of implementers, co-creating a roadmap for HDUs is possible.

Civitas has expertise in convening and designing communities of practice where learning and problem-solving across regions and states is a reality. We have work to realize the full potential of HDUs and propose launching such an effort as an important next step to having a newly recognized utility in our country which not only will assist in essential health improvement efforts but also expand collective efforts to advance health equity.