Health Data Utility Framework —

A Guide to Implementation

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Networks for Health

MARYLAND
Health Care
Commission

Authors from Civitas Networks for Health

Lisa Bari, MBA, MPH, Chief Executive Officer

Kate Ricker, MS, State Health It Subject-Matter Expert

Heidi Penix, MPH, Program Manager

Jolie Ritzo, MPH, Senior Director

About Civitas Networks for Health

We're a mission-driven, member-centric national organization dedicated to using health information exchange, health data and multi-stakeholder, cross-sector approaches to improve health.

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Overview

Delivering high-quality, comprehensive care requires complete health data to enable whole-person care in ways that improve outcomes, reduce health disparities, and enable patient trust.[1] For more than a decade, federal, state, and private investments[2] in health data infrastructure have made concerted efforts at facilitating better communication and more coordinated care through health information exchange (HIE) platforms.[3] Most states have existing infrastructure in place for clinical data exchange through local, regional, or statewide HIEs with variation in governance, funding, policies, and technical capabilities.

States, HIEs, and community partners are expanding the availability of electronic health data to support broader clinical and public health purposes. Advancing exchange capabilities using combined clinical and non-clinical data sets is the evolution of HIE to function as a Health Data Utility (HDU). HDUs represent a new paradigm to support multi-stakeholder, cross-sector needs by serving as a data resource for use cases beyond clinical care delivery through multi-directional exchange. Information on this evolving landscape and drivers for emerging HDUs is included in the _Advancing Implementation of Health Data Utility Models Issue Brief_.

Civitas Networks for Health (Civitas) and the Maryland Health Care Commission (MHCC) hosted an HIE Roundtable Series (series) from January through April 2022. The series convened HIE representatives, state agencies, and regional health improvement collaboratives to discuss challenges and opportunities for advancing health data interoperability and infrastructure needs. Participants shared key considerations for health data exchange and collaborations that support HDU implementation. Discussion topics included governance, the role of states in overseeing HDU operations, evaluating use cases, and funding options to sustain such efforts. The series confirmed the need to develop a framework for defining and implementing an HDU.

The HDU Framework (Framework) is intended to guide states, regions, HIEs, and community partners in the design and implementation of an HDU that provides deeper integration of health-related data to support public health and care delivery. The Framework was developed by Civitas in collaboration with MHCC and the National HDU Advisory Council convened by Civitas from September through November 2022 (Appendix A).

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Defining Health Data Utility

HDUs are models with cooperative leadership, designated authority, and advanced technical capabilities to **combine, enhance, and exchange electronic health data across care and service settings for treatment, care coordination, quality improvement, and community and public health purposes.**

HDUs leverage existing infrastructure through collaboration with state and regional HIEs. In states that are larger in geography or population size, there is often increased complexity and need for coordination within and across regions as well as thoughtful attention to collaboration to meet local, regional, and state needs. Advanced technical services offered by HDUs support electronic exchange of clinical, non-clinical, administrative, and public health data to address data challenges and achieve greater value for state agencies, payers, providers, community partners, and the public. HDUs integrate data from health-related networks, state agencies, community collaboratives,[1] all-payer claims databases, and other relevant health data registries. The broadened role of HDUs enable complex use cases using clinical and non-clinical data while ensuring privacy and security of these data.

Key characteristics include:

Neutrality and flexibility in meeting stakeholders' goals – HDUs serve in a neutral capacity as a nonprofit, network, or independently governed state recognized entity. HDUs are flexible and nonpartisan with technical capabilities that support public health agencies and health care partners with comprehensive patient information to achieve health equity, better outcomes, and lower costs.

Broad geography – HDUs serve providers, payers, consumers, and health support organizations, among others, within specified geographies or public health jurisdictions.

HDUs represent a new paradigm to support multi-stakeholder, cross-sector needs by serving as a data resource for use cases beyond clinical care delivery through multi-directional exchange.

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Cooperative state and local leadership and broad governance – HDUs partner with state and local government, data authorities, and other decision-making bodies and are broadly governed by a mix of public and private sector stakeholders.

Leverage state and local authority – HDUs rely on policy levers to develop and expand health data interoperability, technical services, and infrastructure to support public and private health priorities.

Designated authority – HDUs are recognized and designated through a method of the state's choosing (e.g., legislation, executive order, rulemaking), which defines their roles and responsibilities.

Multi-stakeholder, cross-sector participation – HDUs seek and maintain various partnerships to inform and direct a data exchange and analytics model that incorporates clinical, social, community, behavioral, and public health perspectives.

Inclusive governance strategy – HDUs ensure transparent decision-making processes through advisory committees and other stakeholder workgroups, (e.g., finance, privacy, and security, reporting and analytics, consumers).

Sustainable financing – HDUs are expected to be sustainable through public and private revenue sources by delivering value-add services based on local, regional, and state needs.

Modular infrastructure and advanced technical services – HDUs have demonstrated capability to collect, aggregate, and analyze multiple data types (e.g., clinical, pharmacy, public health, administrative, quality, and operations data) for permitted purposes through integrated health-related networks.

Unlocking access to publicly available data and integrating non-clinical health-related data will lead to innovations that benefit all stakeholders.

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HDU design considerations and implementation approaches vary and may evolve as implementers progress to an ideal future state. The following table denotes aspects of HIEs and HDUs to guide planning, design, and implementation of an HDU model. An HIE may provide some but not all services described under HDU.

COMPONENT	HIE	HDU
Scope of Technical Capabilities and Infrastructure	• Facilitates access to clinical data for treatment and care coordination across participating health care organizations. • May report clinical data for public health uses (e.g., vaccines, syndromic surveillance, notifiable conditions).	• Utilizes policy levers to advance data sharing and infrastructure for the aggregation and integration of multiple data sets (see examples in Appendix B) in ways that expand analytics, quality reporting, data visualization, and other services beyond traditional clinical data exchange. • Serves as a designated data source (e.g., public health registries, controlled and non-controlled medications, and social determinants of health data). • Expansive network connections directly or through other data networks to payers, providers, and community support services.
Relationship with State(s) and Authority Policy Levers	• May have a cooperative partnership with one or more states to align strategy, objectives, and funding. • May enter into a state or regional designation agreement, which outlines terms and conditions and is periodically reviewed and updated, as needed. • State participation in developing programs and services.	• Designated authority defines roles and responsibilities and is formalized via a method of the state's choosing (e.g., legislation, executive order, rulemaking). • Uses policy levers to increase efficient and appropriate data exchange and removes restrictions or barriers to electronic health data exchange. • Partners with state and local government to align public health goals and secure necessary funding.
Governance	• Multi-stakeholder structure for participating organizations and consumers. • May prioritize services internally or with a limited group of stakeholders, perhaps with a focus on sustainability.	• Establishes expansive multi-stakeholder, cross-sector governance model with state and community partners. • Prioritizes services through shared governance ensuring responsiveness to community health initiatives. • Ensures a neutral and transparent approach to decision-making.
Stakeholder Engagement and Community Partnerships	• Works in parallel with other health data networks. • May share data sets with community partners.	• Collaborates with data networks and community collaboratives to share and exchange data (e.g., emerging community care hubs,[4] community information exchanges, or All-Payer Claims Databases). • Houses or integrates with an existing community directory to offer information on community resources, locations, and services available for individuals, specific populations, or the community (e.g., food banks, homeless shelters, crisis intervention support, or behavioral health services).
Financing	• Time-limited funding for technical or implementation services; may receive Medicaid funding.	• Long-term, braided and blended funding strategy that encompasses local, state, federal, and private investments for value-add technical services, reusable infrastructure, and community engagement and support.
Privacy and Security	• May codify in statute, regulation, or other agreements required privacy and security policies above the minimum required in federal law.	• Continuous learning and implementation of cybersecurity and privacy frameworks and standards to ensure rigorous protections that provide appropriate assurances to federal, state, and regional authorities and build stakeholder confidence. • Includes frameworks and standards for health and relevant industries outside of health care.
Accountability and Measurement	• Reports information to assess performance, quality, and value of services to participating organizations.	• Increased accountability through oversight, performance measurement, and evaluation to monitor return on investment and guide strategy for clinical, community and public health purposes.

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HDU Value Proposition

HDUs effectuate use cases for clinical and public health purposes that combine data sets to enable more comprehensive approaches to care delivery, creating digital health infrastructure efficiencies and improving population health decision-making. Multi-stakeholder use cases support the broader health care ecosystem and aim to ensure data liquidity to improve quality, safety, equity, and cost of care. The following are core features and potential use cases associated with HDU planning and implementation.

Combining structured data from payers, providers, consumers, community support services, government agencies, or public health to create scalable data repositories:

- Accuracy in patient record matching to reduce duplicative records, eliminate errors, and enable greater use of patient data to improve measurement and evaluation.

- Patient records with information from community-based services, clinical services, screenings, referrals, outpatient services, hospital admissions, vaccinations, public health, and patient generated health data.

- Comprehensive health information and analysis to inform clinical decisions for treatment, care coordination, and transitions to community support services.

- Improve data utility for public health purposes (e.g., epidemiology, infectious disease, medical examinations).

Bolstering population health management to generate greater focus on key health problems and concerns and identify pathways to maximize resource allocation:

- A comprehensive view and analysis of care delivery to support whole-person care.

- Situational awareness of illness and disease trends, unmet needs, and emerging health threats including disaster response at the local, regional, and national level.

- Social needs screening data to determine select risks for targeted patient outreach.

- Consumer health education campaigns.

Expanding public health reporting to the state and other geographic regions:

- Lab test results for reportable conditions, as defined by a state or local public health authority.

- Case reports to public health agencies (e.g., sexually transmitted diseases, hospital/health care-acquired infections, etc.).

- Syndromic surveillance data on behalf of hospitals, urgent care centers, ambulatory practices, clinics, and long-term care settings, among others.

- Health data reporting for prevention, detection, and intervention programs (e.g., Injury and Violence Prevention Program, Early Hearing Detection and Intervention, blood lead registries).

- Admission, discharge, and transfer (ADT) notifications and clinical data for disease detection, outbreak surveillance, and monitoring.

- Advance directives and Medical Orders for Life-Sustaining Treatment (or "MOLST").

- Electronic vital statistics systems (e.g., newborn screenings, birth, death registries).

Enriching socio-demographic data reported to public health agencies:

- Enhanced vaccine dispensing information to include race, ethnicity, or language based on a matched patient from a hospital or primary care provider.

- Race and ethnicity data on reportable diseases (e.g., COVID) to improve equitable access to testing and services.

Enabling comprehensive event alerts that include broadened and customizable information in clinical notifications:

- Reports with patient specific immunization status in the state's immunization registry.

- School absentee data to a student's treating pediatrician.

- Infectious disease diagnosis for individuals recently served by emergency medical services (EMS) personnel.

- Information on noncontrolled prescription drugs dispensed to patients for treating providers.

- Patients' prior diagnosis of drug resistant infections to emergency department providers.

Strengthening public health analysis, forecasting, evaluation, and education:

- Integrating immunization schedule of care gaps for vulnerable populations, including enrollees of the Children's Health Insurance Program.

- Infectious disease surveillance analysis matching chronic conditions to reported cases and vaccination status.

- Evaluation of program and community interventions based on priority measures, benchmarks, and targets.

- Developing science-based policies to guide public health practice.

- Modeling and forecasting potential health impacts of environmental disasters (e.g., floods, fires) and climate change on vulnerable communities.[5]

- Improving chronic disease prevention by calculating changes in rates of preventative health care services delivered during public health emergencies.

- Targeting public health education campaigns.

Advancing value-based payment models to promote transformation in care delivery and the determination of provider incentive payments by utilizing data to support:

- Predictive modeling of data related to health status, quality, and cost goals.

- Program evaluation by collecting and integrating clinical and administrative data.

- Population-based health analytics using data to monitor social determinants of health, disease control, interventions, preparedness, and equity.

- Comparative performance measures to guide quality initiatives and payment models.

- Performance measurement reporting analytics (e.g., quality, process, outcomes) and dashboards.

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HDU Adoption Phases

States, HIEs, and community organizations are at different readiness levels to implement an HDU. The following are progressive phases of HDU adoption and questions to guide states, regions, HIEs, and community organizations. The following phases are described linearly; however, HDUs grow incrementally with ongoing planning and continuous improvement.

1

Assessment

Conduct an environmental scan that analyzes current conditions for achieving and maintaining HDU status and policy levers and opportunities to support planning and implementation; identify strengths and weaknesses of the current environment and needs to support ongoing innovation. Periodic assessments should be conducted at some frequency after the initial assessment.

2

Planning

Organize activities by convening key stakeholders, establishing an oversight committee, and developing pragmatic action plans with specific and measurable goals and objectives; timelines should consider potential risks and how to mitigate risks.

3

Implementation

Coordinate and combine resources with stakeholders to maximize efficiency, turn data exchange and analysis plans into action, and conduct ongoing assessments of progress, performance, and quality.

4

Sustainability

Secure diverse and comprehensive funding and incorporate continuous quality improvement strategies that consist of system-wide reviews, ongoing training, expanded data sources, and technical assistance that increase participants' effective use of the data and extend technical capabilities to broader stakeholder groups. Sustainability planning is ongoing and should be considered concurrently during each phase.

Assessment

<div style="text-align:right">1</div>

Readiness

ACTIVITIES	QUESTIONS
Complete a strengths, weakness, opportunities, and threats (SWOT) analysis of current health data infrastructure and services.	• How would an HDU support state and local government and other stakeholder health priorities? • How does the HDU align with and support national data modernization efforts (e.g., Centers for Disease Control and Prevent (CDC) Data Modernization Initiative (DMI)?[6] • What are the leading or perceived barriers to implementing an HDU? • How can an HDU alleviate unmet multi-stakeholder needs? • What are HDU successes and lessons learned from other states and regions? • What financial barriers to entry exist for stakeholders to engage with and comply with HDU requirements and standards?
Assess the data needs of providers, payers, public health, and health support organizations.	• Is there an existing statewide and/or regional health data strategy, governance model, or health IT roadmap? • What processes exist to convene stakeholders and formulate statewide and/or regional health data strategies?
Determine interest among state and local government for cross-agency data sharing.	• What state or local government department(s) or agency(ies) are appropriate to coordinate development and oversight of HDU activities? • How will the HDU be designated? • How will HIEs or other health data organizations achieve HDU status?
Identify other stakeholders' interest in data sharing.	• What are the stakeholder data needs and opportunities to expand data sources? • What efforts, currently underway or planned, seek to address multi-stakeholder data needs that would benefit from an HDU?

Multi-Stakeholder Governance

ACTIVITIES	QUESTIONS
Identify essential stakeholders to provide oversight and guidance on HDU policy development, operations, technology, and sustainability.	• What integrated data governance structures are in place today (e.g., Medicaid, public health, cross-agency)? • What modifications are needed to ensure the governance structure can progressively achieve HDU goals? • Are there any nonprofit stakeholders that can provide select support services (e.g., operations, technical services, end users support)?

Stakeholder Engagement and Community Partnerships

ACTIVITIES	QUESTIONS
Consider stakeholder relationships needed to support HDU implementation; examples include: • Federal government (where applicable); • State and local government; • Legislature; • Employers; • Payers; • Providers; • Consumers; • School-based health centers; • Academic/medical institutions; • Health care associations; and • Community service organizations.	• Who are the relevant data contributors and data users that are deemed essential to make HDUs successful? • What stakeholder relationships are key to achieving shared HDU goals? • What stakeholder relationships exist? • Which ones need to be strengthened? • How is trust established and maintained? • What are stakeholder value propositions for engagement and technical services?

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Policy Levers

ACTIVITIES	QUESTIONS
Identify policies that may need to be developed, modified, or could potentially impede HDU implementation and identify solutions to address potential policy barriers.	• Are there legislation, executive orders, policies, or programs that could impede or advance electronic health data exchange? If yes, assess impact on an HDU. • What is the process for making changes to legislation, executive orders, policies, or programs?

Technical Capabilities

ACTIVITIES	QUESTIONS
Identify existing HIE(s) service(s) to determine service area gaps or overlaps.	• To what extent do state, local governments and/or public health jurisdictions leverage HIEs with analytic capabilities? • Is there an existing designated entity, orchestrating entity, or lead entity for health data exchange? • Do multiple organizations serve one or more specific roles? How are these roles coordinated and managed?
Ascertain existing HIE(s) technical capabilities to determine what HDU services could be supported by the existing technical infrastructure.	• Does the network provide services across the state's geography, care settings, and populations? • Is the network inclusive or specific to Medicaid only? • Does the network have data use agreements (DUAs) in place and send data to public health agencies? • To what extent does the network have advanced data aggregation, integration, and analytics capabilities?
Identify limitations in the existing HIE technical infrastructure that impedes interoperability.	• Do state or local governments offer statewide data sharing services? If yes, what providers, settings, sectors, and populations are not currently served? • Is data available from multiple organizations? If yes, what is the pathway to accessing data? • Is there an existing analytic infrastructure? If so, how could it be improved by an HDU?

Funding

ACTIVITIES	QUESTIONS
Identify core HDU services and stakeholder-specific support required to achieve HDU recognition. Assess stakeholder desirability to advance incremental development of use cases. Explore opportunities to engage self-insured employers in funding the HDU using a workforce wellness analysis approach.	• How are existing data sharing initiatives funded? • Are funds diversified? • How can technical components of existing infrastructure be repurposed to support deeper integration of data from multiple sources? • What administrative functions, project management, or data governance can be reconfigured to maximize resources (e.g., human, financial, and technical)? • What data will stakeholders need to inform HDU funding decisions? • Who are the recognized political and business leaders to champion HDU value? • What organizations can support a multi-stakeholder messaging approach? • What is the long-term funding strategy, including flexibility to adapt the strategy and investments across the HDU ecosystem?

CONSIDERATIONS

1. Multi-stakeholder interoperability projects require buy-in from all stakeholders working collaboratively. A multi-stakeholder approach identifies priorities and informs development of an HDU roadmap:

   - Identify HDU champions.

   - Engage public and private sector stakeholders to obtain input on HDU services and capabilities.

   - Strengthen awareness and inclusiveness through stakeholder specific messaging and engagement.

   - Include federal, state and local government in HDU design, development, and implementation.

2. HDU services need to support multiple stakeholders, such as providers, private payers, Medicaid, public health infectious disease programs, and community-based organizations:

   - Work with local governments and statewide legislatures to advocate for HDU designation and codify HDU language into statute, regulation, or agreements, aligning language to federal models where appropriate. Ensure a flexible governance is established to gain recognition as an HDU.

3. State and local government autonomy for designating a data authority for specific federated services can differ. Options may vary regarding federal networks and building technical solutions (e.g., state-based health insurance exchanges) or designating entities to build out services (e.g., state-designated entities for health information exchange):

   - Consider specific technical needs that can leverage existing infrastructure and necessary requirements to serve as the HDU.

4. Public health agencies typically have multi-level relationships with national, regional, state, and local public health services and data networks. Additionally, local and state public health agencies may have specific data authorities and requirements specified in federal statute for program funding (e.g., immunization information systems (IIS)). States may also have a decentralized public services model with local health departments providing services and data systems:

   - Identify the public health jurisdictions and data systems available and supporting the delivery of public health services.

   - Become familiar with the current data sharing models used in the public health sector and analyze where an HDU can complement or improve data for public health purposes and build on existing strategies, such as the CDC Data Modernization Initiative (DMI),[7] a joint effort between CDC and the Office of the National Coordinator (ONC), to create a public health infrastructure for jurisdictions to share information with each other and the CDC.

   - Collaborate with public health to determine the unique level of services provided at the local and regional levels.

   - Determine if an HDU can support and complement specific public health authority data needs. Federal authorities do not currently recognize HDUs. This could impact potential funding streams for reusable technology and data implementation requirements.

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Planning

2

Aligned Strategy

ACTIVITIES	QUESTIONS
Create shared HDU vision, principles, and objectives. Determine what is in scope initially and potentially in the future (i.e., agencies, programs, providers, populations, and data sets).	• What is the scope of the collaborative governance model? • Who provides funding (state and/or local government general funds, agency budgets, federal grants and programs, private sector investment)? • What are data-sharing/privacy challenges? • What is the role of the consumer in data sharing? • Is data sharing collaboration feasible given the existing capacity? • What are potential HDU use cases and key activities based on needs identified from the assessment?
Develop a strategic plan based on select use cases that provides the greatest benefit to multiple stakeholders.	• What is the availability of resources, data, activities that are already underway, to support and fund identified use cases? • What resources are needed for implementation? • What is the timeline for developing use cases, putting in place DUAs, and obtaining funding? • What are long-term and short-term goals based on the shared vision and principles?

Multi-Stakeholder Governance

ACTIVITIES	QUESTIONS
Determine key elements of an HDU governance structure, keeping the structure flexible to support expansion of services and coordination with other data governance bodies. Invite stakeholders to participate in the HDU governance structure.	• Based on findings from the assessment, what are the value proposition(s) for stakeholder participation? • How can an HDU leverage or coordinate with parallel, data sharing governance models? • What will be the roles and responsibilities of individuals within the governance structure?
Formalize the governance structure.	• Will the governance structure be government-led, designated organization-led, or collaborative? • What business, privacy, and security policies need to be established or amended to recognize and potentially codify the HDU governance model? • Will there be a governing board with additional advisory committees?
Put in place a leadership structure that provides stakeholders with meaningful guidance on planning and operations, focusing on how data is contributed, accessed, and used to support priority use cases.	• How is leadership identified? • Who should advise/provide input? • How are business decisions made and by whom? • What is the accountability structure? • What is the data reciprocity policy? • What are the critical business processes to support HDU implementation? • Who are the data users? • Who are the data contributors?
Define the HDU organization decision-making structure and processes.	• How will subcommittees, workgroups, and advisory councils inform decision-making? • What mechanisms are in place to express dissenting views and resolve challenges?

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Policy Levers

ACTIVITIES	QUESTIONS
Codify HDU scope and authority into statute, regulation, or other agreements.	• Will HDU authority be designated to one or more organizations? Will a single HDU coordinate multiple organizations such as HIEs? • What policies and programs in the community, region, and state need to be aligned for collective impact and improved outcomes? • Will the state designated authority need to convene a Policy Board to inform the drafting of select policies/regulations?
Identify and develop policies and programs to increase the data availability and use of the HDU.	• What policies or regulations need to be aligned or updated to facilitate data sharing with the HDU and use of HDU services? • What policy, contracting, or financing options, such as mandates or incentives might encourage broader participation?
Designate HDU authority, roles, and responsibilities.	• Is there a policy process to identify data and technology needs? • How can needs identified during the assessment be used to support the policy process?
Align data sharing and consumer consent policies.	• What activities need to occur to identify and develop policies? • What are current consent policies for sharing and using clinical health information, sensitive health information, and public health information? • Are there existing processes for data use agreements and/or contracts for cross-agency data sharing and between state and non-state entities? • What policies need to be aligned across stakeholders?
Identify, develop, and align privacy and security policies with key federal, state, and local government requirements.	• What are the existing privacy, security, and data use policies and procedures (e.g., clinical, administrative, claims, social determinants of health)? • What alignment and consolidation might be needed to enable an HDU to use administrative, clinical, and public health data for care delivery and population health purposes?

Funding Strategy

ACTIVITIES	QUESTIONS
Calculate the estimated fiscal impact of adding future use cases. Engage state and local governments to support the inclusion of HDU funding in operations budgets. Establish a funding and fiscal oversight model with blended and braided funding strategies. Identify procurement requirements and funding to acquire, build, or contract for technical services.	• Identify a financial distribution path to secure public and private funding. • Develop a coordinated funding plan with stakeholders, including state or local government agencies. • Identify opportunities to reuse federal funding participation to maximize health technology funding opportunities.

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Stakeholder Engagement & Communication

ACTIVITIES	QUESTIONS
Establish a stakeholder communication plan that considers the unique needs of different stakeholder groups.	• What are the key elements to consider in a communications plan? • Who should be informed, consulted, and included in communications?

Operations

ACTIVITIES	QUESTIONS
Establish a critical path and appropriate timeline to launch an HDU that includes achievable tasks and milestones.	• What are the leadership and staffing needs? • How are staff roles defined?

CONSIDERATIONS

1. **Building and maintaining stakeholder trust is necessary to achieve HDU status and to evolve services:**

   - Align activities and use cases with stakeholder data needs.

   - Build credibility with demonstration projects; include a transparent evaluation process that incorporates stakeholder feedback and a pathway for scaling the demonstrations.

   - Engage stakeholders in the development and prioritization of demonstration projects.

2. **Develop a strategy to achieve broad stakeholder participation and maximize HDU value:**

   - Define how the HDU will support, coordinate, and serve as critical infrastructure for clinical and public health purposes.

   - Implement a stakeholder engagement process to modify and prioritize HDU data strategies based on stakeholder data needs.

3. **HDU planning efforts must balance existing funding resources with expanding personnel needs:**

   - Assess human resource sharing across select stakeholders.

   - Prioritize services that can be met with available human resources and the technical infrastructure.

4. **Explore opportunities to support public health services and multi-year cooperative grant programs in partnership with public health entities:**

   - Identify existing public health cooperative agreements and determine if the HDU can support the program objectives.

   - Evaluate the possibility of securing additional public funds to enable select HDU components and services.

5. **State and local governments often have varying levels of reusable technical capabilities:**

   - Engage a third-party to identify data gaps and technical capabilities and opportunities to reuse technical investments.

6. **Private sector data, technology, and interoperability needs may not coincide with public sector data strategies:**

   - Continuously engage stakeholders in the design, development, and implementation efforts of an HDU to create a shared technology roadmap that includes public and private sector perspectives and addresses key data stakeholder needs.

   - Determine potential alignment of existing data sources, build on shared goals and objectives by assessing existing and potential data sources with data contributors to address misaligned data.

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Implementation

Multi-Stakeholder Governance

ACTIVITIES	QUESTIONS
Establish core operations workgroups, committees, and advisory councils to make recommendations on technology, funding, use case development, and privacy and security requirements inclusive of all stakeholders.	• What approaches are needed to establish and facilitate workgroups, committees, and advisory councils? How should the governance bodies be managed? • How are stakeholders engaged in identifying opportunities for using enhanced and integrated data sets?

Legal Framework

ACTIVITIES	QUESTIONS
Develop data use and business associate agreements that represent robust privacy and security protections aligned with stakeholder interests.	• What public health programs require HDU integration? Where could they be defined to help prioritize efforts for public health partnerships? • What existing requirements, processes, and policies are in place to share data sets within and across agencies and private sector partners? Do these need to be aligned? Updated?

Technical/Data Implementation

ACTIVITIES	QUESTIONS
Identify data, tools, and technology to be supported by the HDU and interoperability goals. Build functional, business, and technical requirements for the HDU service. Ensure the technical infrastructure consists of technology that can support a broad array of use cases.	• What existing services are available through a shared infrastructure? • Are there legacy systems available for reuse? How are these legacy systems assessed? • What decision-making process should be used to determine if the technical infrastructure or other processes can support the HDU?
Establish a data reciprocity and validation process.	• What are the data standards and requirements? What entities are involved in establishing the standards? • Are data standards aligned? Does the data need to be normalized/transformed? • What are the data redisclosure policies for different data sets? • How will data be validated to ensure it is interpreted correctly and aligns with use case requirements?

Stakeholder Engagement & Community Partnerships

ACTIVITIES	QUESTIONS
Implement a broad and inclusive stakeholder engagement and communication strategy.	• What additional stakeholders need to be engaged? • What role should the state or local governments assume in stakeholder engagement? • Is there a communication or dissemination plan that includes public and private stakeholders? • What resources do public and private sector stakeholders need to facilitate their engagement? • What non-health care sector learning groups can support stakeholder engagement?
Develop a comprehensive education and awareness program for stakeholders participating in the HDU.	• Is the education and awareness program responsive to varying levels of knowledge? • What resources are needed to build out user awareness initiatives? What are the best delivery methods?

Operations

ACTIVITIES	QUESTIONS
Provide stakeholder guidance for updating policies and procedures, such as: • Bylaws; • Privacy and security policies; • Cybersecurity policies; • Breach notification policies; and • Audit requirements. **Identify and report on infrastructure activities.**	• What policies and procedures need to be updated? • What level of support is needed to analyze and develop guidance? What stakeholder support is needed? • What infrastructure was developed and/or enhanced? What challenges were encountered? • What are the technical capabilities and infrastructure improvements planned? • What actions steps are prioritized to reach the infrastructure objectives?

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CONSIDERATIONS

1. The HDU vision should be tailored to address the specific needs of the geography served:

   - Modify services and supports to ensure resources, best practices, and processes are aligned with the geography served.

   - Balance services with available resources and stakeholder needs.

   - Engage stakeholders in activities to address the needs of the service area.

2. Continuous stakeholder communication reduces confusion, allows for timely mitigation of issues, and can bolster HDU support:

   - Identify communication channels and develop processes to collect and communicate information on HDU activity.

   - Develop processes to collect and communicate information on phases of HDU activity.

   - Plan appropriately for staff time required to engage with and respond to stakeholder concerns.

3. Leadership is essential to transform systems, create change, and sustain outcomes:

   - Identify stakeholder champions who can assume leadership roles with critical use cases.

4. Establish iterative monitoring of HDU activities. The ability to make timely modifications is critical:

   - Identify key implementation and process metrics.

   - Provide continuous progress monitoring and stakeholder communication.

5. State and local government partnership and/or participation should include specific requirements related to governance, oversight, and funding:

   - Collaborate with stakeholders to establish transparent oversight and accountability processes, goals, and measures of success.

   - Include oversight and accountability metrics into HDU governance decision-making and administration processes.

Sustainability

4

Stakeholder Engagement

ACTIVITIES	QUESTIONS
Continuously engage existing and potential stakeholders to assess interest and define priorities. **Align planning with strategic goals and objectives.** **Develop robust stakeholder communication plans.**	• What approaches need to be considered to ensure that stakeholders are engaged? • Why would new stakeholders want to engage and utilize the HDU?

Funding

ACTIVITIES	QUESTIONS
Create a balanced stakeholder funding model with short-term and long-term funding options. A graduated funding strategy should be considered.	• What funding or policy incentives or mandates should be implemented to advance the HDU? Does the funding matrix reflect stakeholder category contributions? • Could Medicaid Enterprise Systems funding with the enhanced federal match at 75-25 be leveraged? System certification is required, and costs must be allocated for Medicaid's fair share.[8]

Technical Capabilities

ACTIVITIES	QUESTIONS
Create an evaluation process for determining stakeholder use case investment and scalability.	• How is HDU diffusion and expansion measured and monitored? • What gaps or needs does a use case need to meet for broad deployment? • What community partners can support scaling and expanding HDU?

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CONSIDERATIONS

1. **Stakeholder participation may vary over time; trust-building needs to continuously occur throughout the HDU adoption phases:**

   - Engage legislatures in conversations regarding HDU services that support improving health care quality, access, and cost.

   - Collaborate with health care associations to identify targeted value messages.

   - Work with consumer advocates to address any concerns and foster engagement.

   - Identify and engage champions to establish and maintain relationships with stakeholders.

2. **A long-term funding strategy is needed to ensure sustainability:**

   - Identify funding strategies in collaboration with stakeholders to support current and future use cases; include financial fair share models by stakeholder category based, in part, on perceived value.

   - Involve stakeholders in transparent modeling of funding approaches and seek public comment on proposed plans.

   - Continually assess core services where state funding mandates are appropriate to consider.

3. **Communities within an HDU service area have diverse needs that must be considered to achieve community-wide participation:**

   - Routinely engage stakeholders to assess the evolving landscape, and establish a dynamic responsiveness culture within the HDU.

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Conclusion

Connecting data silos and meaningfully integrating data to achieve actionable insights is within reach and necessary to advance health equity and whole-person care.

Civitas appreciates stakeholders' guidance in developing the Framework, which creates a vision and strategy to achieve and optimize HDU value. Greater availability and use of accurate, timely, and actionable data is crucial to inform policy development and improve population health. HDUs build upon prior investments in a digital health care system and are well-suited to adopt protections that respect consumer choice. Unlocking access to publicly available data and integrating non-clinical health-related data will lead to innovations that benefit everyone.

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Appendix A: National Health Data Utility Advisory Council

NAME	ORGANIZATION
Beth Anderson, President & CEO	Vermont Information Technology Leaders
Angie Bass, Executive Vice President and Chief Strategy Officer	MIHIN/Velatura HIE Corp
Phil Beckett, CEO	C3HIE
Craig Behm, President & CEO	CRISP
Jaime Bland, President & CEO	CyncHealth
Martin Ciccocioppo, Director	Pennsylvania eHealth Partnership Program
Erica Galvez, CEO	Manifest MedEx
George Gooch, CEO	Texas Health Services Authority
Morgan Honea, Executive Vice President and CEO	Contexture and the Consortium for State and Regional Interoperability
David Horrocks, CEO	New York eHealth Collaborative
John Kansky, President & CEO	Indiana Health Information Exchange
Dan Paoletti, CEO	Ohio Health Information Partnership (CliniSync)
Anne Santifer, Executive Director	SHARE Arkansas
Norman Thurston, Executive Director	National Association of Health Data Organizations

Appendix B: Data Sources

HDUs combine, aggregate, and integrate multiple data sources for clinical and public health analytic insights. Data from multiple sources is transformed into a common format that provides valuable insights to support comprehensive care delivery, social supports, research, evaluation, public health, and policy analysis.

Examples of data types and sources HDUs may leverage include:

DATA TYPE	SUMMARY	EXAMPLE DATA SOURCES
Demographic	Information about an individual's age, gender, race/ethnicity/language/sexual orientation, address, contact information, medical record number, guarantor number, and other person-specific details.	Multiple sources with individual patient-level data, such as electronic health records (EHRs), registries, claims, and/or administrative data.
Claims	Information collected from health insurers related to clinical care provided and paid for by the health plan.	Claims data systems
Clinical	Information collected about a patient's health-related information associated with treatment and care coordination. Data may include a patient's demographics, medical history, progress notes, symptoms, diagnoses, medications, treatment plans, immunization dates, allergies, test results, and radiology images.	Multiple sources, such as EHRs, clinical data registries, remote monitoring devices, image systems.
Administrative	Health care administrative data collected by health care organizations for administrative purposes, such as billing and payment, compliance with regulations, and managing health care services. Administrative data is typically used to support the administrative and operational functions of health care organizations.	EHRs, claims clearing houses, membership files, eligibility, and enrollment data systems.
Community and Service Resources	Information on community resources, locations, and services available for individuals, specific populations, or the community (e.g., food banks, homeless shelters, crisis intervention support, behavioral health services and availability).	Dial 211, local government websites, licensing systems, Medicaid provider credentialing systems, CMS, National Plan and Provider Enumeration System (NPPES), payer contracted provider directories.
All-Payer Claims Database	Claims data registry data base across all Medicaid, Medicare and commercial payers in a state or region.	Commercial health plans, Medicaid, Medicare.
Prescription Drug Monitoring Programs (PDMP)	Dispensed controlled substance and non-controlled substance prescriptions data are collected and tracked in a state electronic database, known as a PDMP, and is used by health care providers and pharmacists for informed decision-making about prescribing and dispensing controlled substances. Data may include information on dispensed medications (e.g., drug name, dosage, quantity, date, refills), patients receiving medications, providers prescribing medications, and dispensers dispensing medications.	EHRs and Prescription Information Management Systems.
Social Risk and Needs Data	Information collected, managed, and used by organizations that provide services to individuals, families, and communities. This type of data may include demographic, social needs and risk factors, economic, and health-related information about the individuals and families who receive services, and information about the services provided and their outcomes.	State and county human service systems, community-based organizations, and state licensed human services organizations.
Public Health	Information collected and used to support public health services at the state and local levels in disease prevention, infectious disease surveillance, and interventions protecting and promoting health. Data sets may be available from national data sources, such as survey systems (e.g., Behavior Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS), Children's Health Assessment Survey (CHAS)).	IIS, disease registries, surveillance systems from clinical data sources (e.g., syndromic surveillance, case investigation, notifiable conditions (National Electronic Disease Surveillance System), Electronic Lab Reporting from commercial labs, state labs, or hospital labs). Specialized registries (e.g., birth defect registry, trauma registry, environmental health hazard surveillance, and electronic vital statistics systems).

Appendix C: State-level, Public Private Partnership HDU Components (Overview)

GOVERNANCE	POLICY	TECHNICAL	OPERATIONS
Decision-Making Structure Established statewide public-private, multi-stakeholder, multi-agency relationship and data governance structure with transparent decision-making and advisory processes at the executive, program, and technical operations levels. Decision making and governance is needed at the network, organizational, and data levels.	**Policy Levers & Responsibilities** Leveraging federal, state, and local policy levers to advance the ability to collect, share, and use standardized health data supporting health priorities. Policy levers may include incentives, penalties, participation and data submission mandates to advance adoption and use of the HDU network and services. Designate authorities for fiscal, operational, or administering network infrastructure.	**Tools and Technology** Implementing, maintaining, and growing technical services that enable the exchange of health information across organizations, systems, and sectors building the technical capacity and capabilities to support mature use cases for Medicaid, public health data needs, community, and delivery system needs.	**Legal Framework** Establishing the framework of processes and operations, along with rights and obligations, to support data use and sharing and compliance with Federal, state, local and tribal laws. Legal agreements can authorize, submit, access, or disclose health information.
Roles and Responsibilities Defined network roles and responsibilities for management of data through data networks. Identify data sources, intermediaries, stewards, and users. Determine oversight, accountability, and enforcement, and whether entities will have designated authorities.	**Designated Authorities** Establish or designate state agency, non-profit organizations, and health information network partners to operate, administer network and/or technical services for a statewide health information network. Designating funding distribution for technical services or supporting cooperative agreements, programs, and grants.	**Reusable Architecture** Align hardware, software, data, processes, and standards to enable scalable and interoperable data and technical systems to exchange information through predefined data formats and structure. Supporting health data exchange network and HDU designated services (e.g., Master Patient Index (MPI), Prescription Drug Monitoring Program (PDMP), clinical or integrated data repository).	**Equitable and Sustainable Financing** Leveraging local, state, federal, and private financial investments for value-add technical services, reusable infrastructure, and community engagement and support. Financing needs include planning and investment, ongoing maintenance of technical services, and sustainable funding for extending and scaling the health information network and services.
Stakeholder Engagement and Transparent Communications Ongoing stakeholder engagement and communication plan to participate in HDU network, decision-making processes, advising and feedback loops, and roles and responsibilities. Enable data-informed public health communications processes.	**Privacy and Security** Ensuring data privacy and security policies meet and exceed the baseline of state and federal laws, and align across sector privacy policies and consent models, and cyber security measures.	**Permitted Data Use, Data Quality, and Security** Ensure technical systems are designed and implemented to ensure and monitor data quality, security, and availability of data for defined, permitted data uses. Reusing data for multiple purposes with transparent processes with data sources and documented allowable redisclosure uses.	**Oversight, Performance Measurement and Evaluation** Ensure technical systems, network infrastructure, and data storage is monitored for reliability, availability, usability, cost effectiveness. Establish remediation strategies for technology performance improvement and accountability.
User Support/Learning Action Network User support and learning network activities include assessment of community challenges and needs, education, communication, training, technical assistance, peer-to-peer learning, and identification of best practices and lessons learned.	**Policy and Program Compliance** Establish transparent and flexible processes for stakeholder compliance managing and monitoring federal, state, and local data policy and program compliance.	**Standards** Establish collaborative and transparent processes for the ongoing use and implementation of standards (e.g., semantic standards, interoperability standards, taxonomies, business rules) and policies (e.g., privacy and security policies, redisclosure of data).	**Processes and Standard Operating Procedures (SOPs)** Documented process for disaster recovery plans, cyber security plans, reporting requirements.

References

[1] Medical Economics, *Whole-person health is the key to reducing disparities and driving patient trust,* September 2022. Available at: www.medicaleconomics.com/view/whole-person-health-is-the-key-to-reducing-disparities-and-driving-patient-trust.

[2] States have used policy levers, such as legislation, executive orders, and contracts to designate authority, define operational models, and distribute funding to community partners to develop this critical infrastructure.

[3] The American Recovery & Reinvestment Act of 2009 (ARRA) established the Health Information Technology for Economic Clinical Health Act (HITECH Act) and provided the Department of Health and Human Services (HHS) the authority to develop programs to improve health care quality, safety, and efficiency through the promotion of health IT, including electronic health records and private and secure electronic health information exchange. More information is available at: https://www.healthit.gov/topic/laws-regulation-and-policy/health-it-legislation.

[4] ACL Administration for Community Living, *ACL Announces Selected Participants of the Community Care Hub National Learning Community,* November 2022. Available at: https://acl.gov/news-and-events/announcements/acl-announces-selected-participants-community-care-hub-national.

[5] The White House, *Executive Order on Protecting Public Health and the Environment and Restoring Science to Tackle the Climate Crisis*, January 2021. Available at: https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-protecting-public-health-and-environment-and-restoring-science-to-tackle-climate-crisis/.

[6] https://www.cdc.gov/surveillance/data-modernization/index.html

[7] ONC is assisting CDC and the public health community with infrastructure approaches to ease burden and increase efficacy of public health data systems and applications. This effort is referred to the North Star Architecture, a cloud-based service model that integrates shared data repositories and applications, hosted STLT infrastructure and collaborative governance. More information is available at: https://www.cdc.gov/surveillance/data-modernization/technologies/north-star-architecture.html.

[8] Tsai, Daniel, CMS. [Letter from Tsai Daniel to State Medicaid Director, Baltimore, MD] (April 14, 2022). Available at: https://www.medicaid.gov/federal-policy-guidance/downloads/smd22001.pdf.