

**Advancing
Implementation
of Health Data
Utility Models**

Issue Brief

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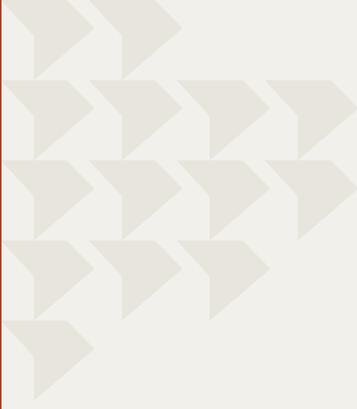


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Introduction

As demand for more complete health data and data interoperability accelerates, the landscape of health information exchange (HIE) and health improvement is rapidly evolving in the public and private sectors. Civitas Networks for Health (Civitas) and the Maryland Health Care Commission (MHCC) identified the need to differentiate key aspects of emerging Health Data Utility (HDU) models more clearly. HDUs utilize existing technical and relationship infrastructures within and across states to bring together personally identifiable health data as well as population and public health data more comprehensively. The approach relies on multistakeholder data governance, trust, and advanced technical services.

Fragmented and disparate data increases provider burden and impedes population health management, care coordination, quality improvement, patient safety, and value-based care. It thwarts the advancement of health equity and limits the utility of data in answering clinical and public health questions. Emerging HDU models are designed and implemented in alignment with states' policies and priorities to address the needs of a broader health care ecosystem. An HDU can be defined as one or more entities, guided by a diverse stakeholder governance structure, that combine, enhance, and exchange disparate electronic health data sets for treatment, care coordination, quality improvement, population health, public health emergencies, and other public and community health purposes, supporting a specified geographic region.

About this Issue Brief

This issue brief outlines the history, current state, and drivers for the emergence and advancement of HDUs. It is intended to inform and support multi-stakeholder collaborations that bring about more robust health data and use cases with the goal of improving population and public health and advancing health equity. This issue brief intends to solidify the HDU concept bringing increased clarity to the role and function of HDUs.



HISTORY

Health data infrastructure, in the form of electronic health records (EHRs) and interoperability services, has advanced in the past decade through federal and state investments, such as the Office of the National Coordinator for Health Information Technology (ONC) State Health Information Exchange (HIE) Cooperative Agreement¹ and Medicaid HITECH 90/10 Federal Financial Participation (FFP).² This funding supported the planning, development, and implementation of flexible interoperability technical and support services. Many states also advanced critical health data infrastructure and community technical assistance through participation in value-based payment model demonstrations and innovation models.³ Most states have existing infrastructure in place for clinical data exchange through regional and statewide HIEs.

EMERGENCE OF HEALTH DATA UTILITIES – CURRENT LANDSCAPE

Many states continue to develop and remodel state-level health data governance and exchange services to support broader community and key stakeholder needs. However, there is no standard state-level approach to health data and interoperability⁴. States have a wide range of approaches to advance health data availability and exchange for programs, populations, and health priorities. Increased recognition of the HDU concept and funding from federal agencies such as the Centers for Medicare & Medicaid Services (CMS) and COVID-19 relief funds has led several states to plan and implement legislation for strengthening HDUs.

As of 2022, advancing HDU has been dependent on the following (note, HIE organizations or states may overlap in multiple categories):

Policy levers (state-level policy, legislation, executive orders, contracting, financing incentives, and certification requirements used to advance interoperability)

- Advancing legislation or rules to expand HDU governance and funding authority for HIE services⁵ – 7 states
- Designated non-profit HIE organizations for technical or implementation services⁶ – 31 states
- HIE certification requirements for organizations providing HIE services (e.g., community, regional, enterprise, or vendor led networks)⁷ – 3 states

HIE leadership and organizational models (state agency, designated non-profit organizations, or market driven approaches to providing electronic health information technical and exchange services across the health care delivery and public health systems)

- State-agency HIE models – 9 state-run HIEs⁸
- Designated Entity – 30 states designated nonprofits for HIE technical services
- State-led orchestrator HIE models – 9 states⁹
- Organization-led orchestrator HIE models – 4 states¹⁰

HIE Networks (state-run HIEs, multiple HIE organizations, one primary organization, or no statewide HIE services)

- One primary network (state-run or state designated entity) – 31 states¹¹
- State-run HIEs with multiple HIE organizations – 2 states¹²
- Multiple HIE organizations – 15 states¹³
- Market driven with one primary HIE organization – 2 states¹⁴
- Market driven with multiple HIE organizations¹⁵ – 2 states
- No statewide HIE services or transitioning models¹⁶ – 5 states¹⁹
- Interstate/regional HIE technical services¹⁷ – 3

Enhancements to public health data sharing (does not equate to number of states and public health jurisdictions):

- 20 HIEs are connected to immunization information systems (IIS) reporting, querying, or disseminating immunization data¹⁸
- 40 HIEs are reporting data to public health jurisdictions¹⁹
- 38 HIEs allow access by public health employees for case investigation or medical examinations²⁰
- 23 HIEs are enhancing clinical data for public health by combing data sets, linking patients, or enhancing data to improve data quality and accuracy²¹
- 36 HIEs are disseminating public health data to the health delivery system assisting providers at the point of care²²

WHAT DISTINGUISHES A HEALTH INFORMATION EXCHANGE FROM A HEALTH DATA UTILITY?

Many states and HIEs are well-positioned to evolve into an HDU model. HDUs have more advanced technical infrastructures, greater interoperability, and provide public health with valuable information obtained from multiple sources and policy support.

HDUs are statewide models or entities with the advanced technical capabilities to **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 privacy and security that exceeds federal minimum standards established by HIPAA and as amended by HITECH to ensure patient privacy and appropriate data use.

HIEs are commonly defined as **delivering the electronic transmission of health care-related data among health care facilities**. HIEs have traditionally facilitated access to and **retrieval of clinical data** to provide safer and more timely, efficient, effective, and equitable patient-centered care.²³

DRIVERS

The existing technical and relationship infrastructure for health data exchange needs strengthening; states and HIEs are building on more than a decade of health IT investments and learnings to expand the role of health data to improve care delivery and support public health priorities.²⁴ The following drivers contribute to the greater need for common health data infrastructure and governance models.

1. **Multistakeholder data needs**
Health care, public health, and community health data are often siloed, managed by different entities, and have different data sharing policies that can be restrictive and create challenges in matching or combining data to further shared interests and goals. A data-centered collaborative approach to enhancing health data collection, sharing, and analysis are critical to advancing the health of communities.²⁵
2. **Statewide health data interoperability infrastructure**
Disparate information systems often serve as a barrier to patients/individuals/families/caregivers and delivery system providers (e.g., hospitals, care providers, community organizations) as well as coordination with data organizations, community partners, and state agencies. Ubiquitous data sharing and use across all geographies, serving all settings, providers, and populations is crucial in addressing health priorities.²⁶
3. **Social data needs**
Many states also lack infrastructure to support standardized social data capture, interoperability of data across sectors, and integrated data aggregation and advanced analytics. Social data and community-level coordination are critical in addressing individuals' social needs and health inequities. Emerging Community Care Hubs, community-centered entities that organize and support networks of community-based organizations (CBOs) through centralized administrative and operational infrastructure, and social health platform vendors should be considered.²⁷
4. **Data-informed public health preparedness, readiness, response, and recovery**
Public health jurisdictions have broad data and technology needs to analyze determinants of health and health indicators and track disease burden and equity considerations.²⁸ Integrating data sources and leveraging data and infrastructure modernization investments improve data availability and insights among the health care, social, and public health sectors.²⁹
5. **Standards for data privacy and security**
Federal and state privacy rules vary. Ensuring alignment of data privacy and security controls that keep pace with a rapidly evolving health-data and technology landscape addresses gaps and ambiguities in consent, protection, and access.



Meeting Stakeholder Needs

Health data, technical infrastructure, and interoperability are integral parts of the health care system. They are components of health equity infrastructure and create links to better care.³⁰ Delivery of high-quality comprehensive care requires complete and timely health data to enable whole-person care and to address drivers of poor health outcomes.³¹ Whole-person care focuses on restoring health, promoting resilience, and preventing disease across a lifespan;³² and effective delivery of whole-person care includes leveraging community-level data across multiple coordinated services regularly outside the realm of health care delivery.³³ However, data is often siloed and disconnected. Restricted access and use of critical data limits the value of health information exchange platforms and erodes confidence in data completeness.

Disconnected data not only limits the potential for the health care sector to effectively partner with public health and other community health stakeholders but impedes public health and community partners from accessing needed data sources.³⁴ Public health and community partners utilize a variety of data sources to plan, implement, and evaluate data driven prevention, surveillance, intervention, and evaluation initiatives aimed to improve public health. Public health and community partners, such as state and local departments of health and local and regional nonprofits, often lack access to timely, needed clinical data sources, whether identifiable or in aggregate, or the means to quickly analyze and apply data findings. Public health and community health partners access to health data is particularly important in the identification and monitoring of infectious disease outbreaks and vaccination efforts.³⁵

There is growing need to effectively share and integrate data from multiple sources as the health care ecosystem continues to shift towards value-based care where providers are financially rewarded or penalized on the basis of health outcomes and quality of care. Expanded data integration requires quality measurement and reporting, measuring and tracking social determinants of health, and improving care coordination within and outside the formal health care system.³⁶



Delivery of high-quality comprehensive care requires complete and timely health data to enable whole-person care and to address drivers of poor health outcomes.

The COVID-19 pandemic demonstrated the need to build more robust HIE capabilities and greater interconnectivity across states. HIE-to-public health connections vary across states. The Promoting Interoperability Program (formerly referred to as the Meaningful Use Incentive Program) supports additional HIE-to-public health connections; however, inconsistencies exist across jurisdictions. Providers manage different public health reporting requirements for reportable conditions, case investigations, immunization reporting, and syndromic surveillance through point-to-point connections.³⁷ Public health data systems and data sets generally remain disconnected.

In recent years, public health officials expanded health data needs in response to the COVID-19 public health emergency. The need for additional data continues in areas such as broader provider and payer engagement, laboratory information systems, vaccine data and social supports from vulnerable populations and underserved communities. These data will enable increased chronic disease surveillance, automated data feeds augmenting manual data processes, and supply and hospital bed capacity reporting.³⁸ A broader set of health data reporting to public health during the pandemic from long-term care and skilled nursing facilities, correctional facilities, and pharmacies, and mass testing and vaccination sites proved to be beneficial in managing population health. Many state policies were revised to allow access to the HIE for public health employees for case investigation and public health surveillance by epidemiologists, contact tracers, case investigators, coroners, and medical examiners.

State Medicaid agencies have historically funded health information networks supporting Medicaid programs, providers, and clients. Integrating datasets with Medicaid's modular enterprise systems can support population health analytics and inform program development, evaluation, and business analytics. Additionally, many state Medicaid agencies administer enhanced behavioral health, care management, and wrap around services for vulnerable populations through managed care organizations and community-based organizations. These expanded services need health and social care data interoperability to collect, share, and analyze social care information for population health improvements. However, data and technical services may be developed within program and funding silos and lack integration with clinical data exchange networks. Medicaid agencies benefit from integrated data services to inform gaps in care among vulnerable populations, such as the Children's Health Insurance Program.³⁹

Interoperable electronic health data and advanced technical services support data-informed decision making, enhanced surveillance, and program and intervention evaluation. Building critical, reusable health data infrastructure through HDU implementation benefits multiple stakeholders' data needs.

State health IT governance – Enabling statewide data exchange services across geography, sectors, and settings supporting administration health priorities and multiple agency data needs for data-informed policy, program, and interventions.

Medicaid – Supporting state Medicaid agency waivers and programs supporting whole-person care; enhanced care management and community services for vulnerable populations, such as people experiencing homelessness, incarcerated populations returning to the community, and home-and community-based services.

Public health – Accessing real-time comprehensive data sets that inform planning, resource allocation, preparedness, response, and at times swift action.

Payers – Enabling quality measurement and care coordination services and supporting value-based payment models.

Providers and hospitals – Reducing provider burden and duplicative reporting for public health, quality measurement, and other compliance requirements. Integrating data into the workflow and EHRs while compiling longitudinal patient records across health and community organizations. Supporting broader connectivity to community services enabling closed-loop referrals and population health analysis.

Community-based organizations and social support agencies – Supporting standardized data capture, cross-organizational data exchange, and integrated data for population health analytics.

Community partners – Building a foundation of trust among community partners to encourage growth and collaboration.

Federal partners – Aligning local, state, and national data exchange efforts and advocating for federal authorities to modernize and advance health data consistently.



Civitas Networks for Health and MHCC gathered information to develop an HDU framework. The list below identifies key takeaways from the multistakeholder Health Data Utility roundtable convenings:



Multistakeholder, cross-sector governance, and strategy



Securing funding and demonstrating value



State and federal actions



Policy levers



Technical services and infrastructure



Foundational, new, and expanded use cases

HEALTH DATA UTILITY ROUNDTABLES – KEY TAKEAWAYS

In early 2022, a four-part roundtable series convened HIE organizations, Regional Health Improvement Collaboratives (RHICs), and state health leaders to learn, share, and advise on key considerations for health data exchange and collaborations that support HDU implementation and adoption. Through the convenings, Civitas and MHCC gathered preliminary information to develop an HDU framework. Participants engaged in shared learning and discussed health data governance, the role of states in overseeing operations, evaluating use cases, and funding to sustain such efforts. The list below identifies key takeaways from the series:

Multistakeholder, cross-sector governance, and strategy are foundational for stakeholder trust and buy-in and should represent public-private partnerships. This includes state and federal agencies, health care system representatives, consumers, community service organizations, and others depending on implemented use cases. Strategic community and stakeholder engagement in governance informs priorities and increases transparency and accountability. Trust is strengthened with cross-sector input.

Securing funding and demonstrating value are important for balancing funding across federal, state, fees, subscriptions, and other sources. Funding services and capabilities must provide value and align with strategic priorities. Address variability in interoperability pricing, offered services, business models, and funding strategies by identifying best practices for funding the HDU model.

State and federal actions (e.g., legislation and funding) influence health data interoperability evolution at the state level. Align HDU development to state health policy goals, while managing shifting national priorities, such as Centers for Disease Control and Prevention (CDC) Data Modernization Initiative strategy. Positioning the state as an advocate for HDU with federal agencies may better align priorities and policies and gain buy-in from federal partners. Defining the state's role for policy levers, oversight, and funding is important.

Policy levers need to be defined and distributed widely. Legacy laws may need updating to reflect the evolving needs for health data and technology. Policies around oversight, authority, data governance, service priority, and other factors need to reflect state-level partnerships and data infrastructure.

Technical services and infrastructure can streamline statewide resources and support interoperability goals. This can include broadening interoperability use cases while balancing privacy through the HDU infrastructure. States have different approaches to health technology architecture ranging from centralized, decentralized, and networked infrastructures. An incremental approach should be taken to expanding infrastructure, starting with strengthening existing systems and creating incentives to grow the technical capabilities of partner organizations.

Foundational, new, and expanded use cases create opportunities to broaden participation and funding, but expansion relies on demonstrated value. Legacy systems and current infrastructure may not be adequate, and gaps should be addressed to implement use cases.

Health Data Utility Implementation

Most states' existing technical and relationship infrastructure needs to be strengthened and developed further as data exchange is insufficient in the context of public health data modernization and in meeting broad stakeholder needs. HDU requirements must include pathways and funding streams to support planning and capacity building.

CURRENT CHALLENGES FOR SOME AND OPPORTUNITIES FOR OTHERS

1. Community readiness and stewardship – Implementing an HDU is resource intensive, and stakeholders may be hesitant to support expanded data sharing due to an uncertain value proposition and privacy and security concerns in how the data will be managed and analyzed. Understand market forces in the geographic areas and populations of focus, assess needs, capacity, and willingness of communities to participate, and develop stakeholders' shared rights and responsibilities through codesign, evaluation, and decision-making.⁴⁰

2. Trust – Public trust in health data ecosystems is pivotal for effective and efficient functioning.⁴¹ Low levels of trust can be a barrier to partnerships and willingness to share data. Clear and meaningful use cases help clarify the value proposition and must be inclusive of community perspectives. Maintaining trust across stakeholders creates a foundation for collective action and sustainable, flexible models that can scale future use cases.

3. Unreliable, disconnected funding streams – Funding streams for strategic investments, governance, and support services have historically been from time-limited federal grants, state funding, philanthropic funds, and network partner contributions. Public sector funds are segregated across federal agency funders and programs and distributed to different state-level agencies and/or designated organizations. Inconsistent financing models for health data infrastructure across states and data networks and disconnected funding creates challenges in sustaining health technology investments and supporting increasing data needs and new use cases.⁴²

4. Political will – There is significant variation across states when it comes to legislative support for health data exchange and infrastructure. Similarly, Medicaid expansion or investment in public health funding varies.

HDU Implementation Challenges

1

Community Readiness & Stewardship

Implementing an HDU is resource intensive, and stakeholders may be hesitant to support expanded data sharing



2

Trust

Low levels of trust can be a barrier to partnerships and willingness to share data



3

Unreliable, disconnected funding streams

Inconsistent financing models creates challenge in sustaining health technology investments



4

Political Will

There is significant variation across states when it comes to legislative support for health data exchange and infrastructure



HEALTH DATA UTILITIES ARE EVOLVING AND ADAPTABLE

HDUs represent both the evolution of community, as well as a new paradigm – a multistakeholder, cross-sector data resource for multiple use cases and services supporting not only clinical care delivery but public health and community health initiatives.

HDUs are flexible models in their ability to be used in many facets of the health care ecosystem and meet state-specific health data needs serving multiple care settings, community partners, and public health with various health data sources. Most organizations with a designation are nonprofit organizations or independent state agencies. In all cases, state and multistakeholder governance, oversight, coupled with robust privacy and security laws or policies are paramount.

Components of a Health Data Utility Implementation Framework

Foundational structural elements are necessary for the HDU to operate with integrity and transparency. These components consist of the following:

HDU Components	Summary
Governance	A statewide, multistakeholder governing body with transparent decision-making processes, defined network roles and responsibilities, oversight, and accountability.
Stakeholders and Community Partners	Convening diverse stakeholders to support participation, connectivity, exchange, and community-level engagement.
Policy Levers	Leveraging federal, state, and local policy opportunities to advance the ability to collect, share, and use standardized health data to support health priorities, which may include incentives, penalties, or mandates to effectuate adoption and change. ⁴³ <ul style="list-style-type: none"> • Align and coordinate policies and programs in the community, region, and state for collective impact and improved outcomes. • Designate authority and roles and responsibilities. • Enable funding and procurement processes.
Privacy and Security Policy	Ensuring robust standards for data privacy and security that go beyond federal baseline protections and create alignment with cross-sector privacy policies .
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.
Financing	Leveraging local, state, federal, and private financial investments for value-add technical services, reusable infrastructure, and community engagement and support.
Technical Services	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. ⁴⁴
Technical Infrastructure	Align hardware, software, data, processes, and standards to enable scalable and interoperable data and technical systems to exchange information through predefined data formats and structures that support centralized or decentralized network data exchange. ⁴⁵
Measurement and Evaluation	Monitoring and evaluating performance metrics on the implementation of an HDU including returns on investments, individual and population outcomes, program effectiveness, and data quality management and improvement with standardized metrics.
User Support and Learning Network	User support and learning network activities, including assessment of community challenges and needs, education, communication, training, technical assistance, peer-to-peer learning, and identification of promising practices and lessons learned.

MARYLAND HEALTH CARE COMMISSION AND CIVITAS NETWORKS FOR HEALTH COLLABORATION

The MHCC partnered with Civitas to host the four-part HDU roundtables series in early 2022 and develop an HDU Framework implementation guide. The HDU Framework will be released in early 2023 and will serve as a guide to assist Maryland and other states, HIEs, and community partners in developing and implementing an HDU.

The State of Maryland and MHCC are leaders in multistakeholder-governed health data exchange and technical resources benefiting Maryland residents, public health agencies, health care providers, payers, purchasers, and community organizations.⁴⁶ In 2022, Maryland passed legislation, HB 1127 - Public Health – State Designated Exchange – Health Data Utility, requiring the state designated exchange (CRISP) to operate as a health data utility for specific purposes and serves as a model for other states and entities that are moving towards HDU implementation.

Civitas Networks for Health (known as Civitas Networks for Health, Corp. in the State of Maryland) is a mission- and member-driven organization dedicated to using health information exchange, health data, and multistakeholder, cross-sector approaches to improve health and is well positioned to advance a HDU maturity model. Civitas represents more than one hundred regional and statewide HIEs, regional health improvement collaboratives (RHICs), quality improvement organizations (QIOs), and all-payer claims databases (APCDs) as well as more than 80 affiliated organizations as members and reaches approximately 95% of the United States population through its member base. Civitas was previously known as the Strategic Health Information Exchange Collaborative and the Network for Regional Healthcare Improvement. The two organizations joined forces to create Civitas in October 2021. Civitas Networks for Health is a 501(c)(3) organization. Civitas leads and participates in a variety of regional and national programs – technical assistance, training, and educational programming activities are delivered through virtual and in-person meetings as well as at larger events.

LIMITATIONS

This issue brief reflects the current HDU landscape. It does not detail specifics of various evolving HDU models or coordination with national-level and Qualified Health Information Networks and the Trusted Exchange Framework and Common Agreement.



100+ Civitas represents more than 100 regional and statewide HIEs

80+ More than 80 affiliated organizations

95% Civitas reaches 95% the US population through its member base

Appendix: 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
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

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.



- ¹ ONC State HIE Cooperative Agreement Program funded 56 state, territory, and district efforts “to rapidly build capacity for exchanging health information across the health care systems” to develop state-level directories and enable HIE technical services, remove HIE barriers, create HIE enablers to ensure the trust of and support for a statewide approach to HIE, coordinate an integrated approach with Medicaid and public health, and develop or update HIE policy and security requirements. The State HIE Program directed states to designate the funding recipients and HIE leadership, policy, and technical services and operations model from option 1) state-led, 2) Medicaid-led, or 3) designated 501c3 non-profit organization. *The Evolution of the State HIE Cooperative Agreement*. (ONC, 2011) and *State Health Information Exchange* (ONC 2019).
- ² Centers for Medicare & Medicaid Services (CMS) and State Medicaid Agencies support electronic health data collection, exchange, and data use through State Plan Amendments, 1115 Demonstrations, and 1915 waivers for Home and Community-Based Services (HCBS). The HITECH Act authorized 90% matching funding with a state’s 10% financial contribution to plan, develop, and implement interoperability among healthcare organizations, public health agencies, and other community-level assistance programs. *Federal Financial Participation for HIT and HIE Related Resources, HITECH Administrative Funding* (CMS, 2020).
- ³ The Center for Medicare & Medicaid Innovation (CMMI) tests payment and service delivery models aimed at improving quality of care, better health, and lower costs. The CMMI models have data and technology needs, data sharing requirements, and technical assistance to support community capacity building. Examples include the Merit-based Incentive Payment System (MIPS), State Innovation Model, alternative payment models (APMs) (e.g., Maternal Opioid Model, Integrated Children and Kids Model, Primary Care First), or all payer models (e.g., Vermont All-Payer ACO Model, Maryland All-Payer and Total Cost of Care Model). *CMS Innovation Center Strategy Refresh* (CMS, 2021).
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