



Immunization Information Systems and Health Information Exchanges



An Environmental Scan of Factors Influencing Data Sharing and Opportunities to Advance Population Health

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Abbreviations

AIM	Association of Immunization Managers	IIS	Immunization Information System
AIRA	American Immunization Registry Association	IISAR	Immunization Information Systems Annual Report
ASTHO	Association of State and Territorial Health Officials	IZ Gateway	Immunization Gateway
CARES	Coronavirus Aid, Relief, and Economic Security Act	MMIS	Medicaid Management Information System
CDC	Centers for Disease Control and Prevention	O&M	Operations & Maintenance
Civitas	Civitas Networks for Health (formerly Strategic Health Information Exchange Collaborative, or SHIEC)	OAPDs	Operational Advanced Planning Documents
CMS	Centers for Medicare and Medicaid Services	ONC	Office of the National Coordinator for Health Information Technology
DDI	Design, Develop, and Implement	PCDH	Patient Centered Data Home™
DMI	Data Modernization Initiative	Section 317	Public Health Service Act Section 317
DOD	Department of Defense	SHIEC	Strategic Health Information Exchange Collaborative (now Civitas Networks for Health)
DSA	Data Sharing Agreement	SOAP	Simple Object Access Protocol
EHR	Electronic Health Record	Star HIE	Strengthening the Technical Advancement and Readiness of Health via Health Information Exchange Program
FFP	Federal Financial Participation	TEFCA	Trusted Exchange Framework and Common Agreement
FHIR®	Fast Healthcare Interoperability Resources	USCDI	U.S. Core Data for Interoperability
HDU	Health Data Utility	USCDI+	U.S. Core Data for Interoperability “Plus” Initiative
HIE	Health Information Exchange	VA	Veterans Affairs
HITECH	Health Information Technology for Economic and Clinical Health Act	VCI™	Verifiable Clinical Information
HL7®	Health Level 7 International	VFC	Vaccines For Children Program
IAPDs	Implementation Advanced Planning Documents	WSDL	Web Services Definition Language
IDEAS	COVID-19 Immunization Data Exchange, Advancement and Sharing Program		
IIP	Immunization Integration Program		

Executive Summary

The COVID-19 pandemic pushed the U.S. public health data infrastructure and information systems responsible for collecting, managing, and sharing critical public health data to their limits. Public health practitioners faced siloed and aging public health systems, unprecedented data volume and throughput, time-intensive and manual processes, and legal and policy challenges related to data sharing. The need to monitor and analyze COVID-19 immunization status across the country emerged as a top priority, placing public health immunization programs in state, territorial, and local public health agencies—and the immunization information systems (IISs) that collect and manage vaccination data—in the spotlight.

Public health practitioners explored solutions to address the increased demand placed on IISs, including strengthening and expanding partnerships with health information exchanges (HIEs). State-designated and community HIEs provide the technical infrastructure and services to facilitate the electronic exchange of health information within a community or jurisdiction. Bi-directional data exchange between IISs and HIEs can provide an array of public health and healthcare benefits including (1) enhanced public health reporting, (2) improved data quality and completeness for race and ethnicity information, (3) identification of populations with low vaccine coverage, and (4) consolidated patient records to improve care delivery and coordination.

To better understand the dynamics and factors influencing IIS and HIE vaccination data sharing status and opportunities, ASTHO conducted an environmental scan in 2021-2022. This report summarizes the background, methods, findings from the environmental scan, in addition to considerations for policymakers. The top findings are summarized below.

IIS and HIE Partnership Dynamics and History: There is a wide range of public health and HIE connectivity for immunization data sharing across the nation, and room for further advancement of data exchange. In 2020, approximately 15% (17,819/121,134) of provider sites connected to an IIS were mediated through an HIE, although levels of connectivity can vary significantly from one jurisdiction to another.¹

Governance and Legal Factors: IIS and HIE governance structures are often separate from one another. The legal authority and parameters to operate IISs and HIEs may differ, and usually derive from different statutes, regulations, and other policies. This context can lead to conflicting guidance or challenges interpreting guidance around IIS and HIE data exchange. Differences in consent requirements between IISs and HIEs—and lack of understanding around these policies—can also limit data submission and sharing across systems.

¹CDC. "2020 IIS Annual Report (IISAR)." Available at <https://www.cdc.gov/vaccines/programs/iis/annual-report-iisar/index.html>. Accessed September 1, 2022.



Funding: IISs and HIEs have been developed and maintained through separate funding mechanisms, resulting in different business models and incentives to pursue specific activities. COVID-19 funding offers opportunities for system modernization and integrations. Sustainable funding, however, remains a challenge impacting the ability to cover system operating costs, ensure continued advancement of technical solutions, and support long-term integration between IISs and HIEs.

Participants: A variety of participants report and retrieve data from IISs and/or HIEs. An understanding of how IIS and HIE participants overlap or diverge can help decision-makers better characterize the benefits of data exchange between these two systems. While both IISs and HIEs interface largely with similar types of participants, there are differences in the healthcare provider groups contributing data to each system, and variation in payer and consumer access/use of IIS and HIE data.

Technical Factors: Different drivers impact the technical capabilities and services offered by IISs and HIEs. IISs and HIEs have the best chance to benefit from each other if they (1) use the same vocabularies and coding systems among themselves and with data exchange partners, (2) maintain high quality data that is deduplicated and complete—particularly for data needed for record matching, and (3) use a standard messaging format and transmission method for data exchange.

Intra- and Inter-Jurisdictional Factors: Variations in jurisdictional exchange add a layer of complexity to IIS and HIE data exchange efforts. Multiple HIEs (and sometimes more than one IIS) within state boundaries lead to incomplete state-level data within individual systems. More than 40% (25/61) of jurisdictions engaged in IIS-to-IIS data exchange in 2022.ⁱⁱ A 2019 HIE survey found that 53% of community and state HIEs were connected to HIEs in other states.ⁱⁱⁱ National initiatives led by federal partners may advance data exchange efforts within and across borders.

COVID-19-Specific Factors: During the COVID-19 pandemic, IISs and HIEs have leveraged routine functions to support data needs associated with the pandemic. IISs also strived to accommodate new demands, while HIEs augmented services and partnership efforts with public health. The demonstrated value of successful partnerships during the pandemic may pave the way for ongoing collaborative efforts in the future.

This report also includes considerations for health, data, and technology leaders interested in advancing IIS and HIE connectivity. Considerations touch on funding, legal and regulatory, data utility, planning, and implementation topics.

ⁱⁱ Information provided by AIRA. [unpublished].

ⁱⁱⁱ Adler-Milstein J, Garg A, Zhao W, Patel, V. "A Survey Of Health Information Exchange Organizations In Advance Of A Nationwide Connectivity Framework." Health Affairs. 2021. 40:5, 736-744. <https://doi.org/10.1377/hlthaff.2020.01497>



Introduction

The COVID-19 pandemic placed a significant burden on the U.S. public health system—including the surveillance and data infrastructure that drives it. To meet the immediate and ongoing demands of the pandemic, public health practitioners increased efforts and developed short-term solutions to adapt to the data challenges and limitations exposed by the pandemic. There is an opportunity to explore long-term solutions to ensure that the United States is ready for the next pandemic. Multiple federal procurements aim to improve the nation’s public health data infrastructure. In addition to new funding opportunities, there is newfound awareness of the need to maintain and connect information systems to address public health challenges. In 2020, CDC launched the Data Modernization Initiative (DMI), which aims to (1) develop a response-ready public health data infrastructure, (2) accelerate the transformation of data into action, (3) develop a workforce to build and maintain modern systems, (4) expand partnerships, and (5) support innovation and change. Amplifying the need for a robust, data-driven response to COVID-19 and future public health threats, the President signed an executive order in January 2021 that, among other things, directs the HHS Secretary to:

“...review the effectiveness, interoperability, and connectivity of public health data systems supporting the detection of and response to high-consequence public health threats, such as the COVID-19 pandemic...[and issue] recommendations for addressing areas for improvement...”¹

The executive order also provided for other efforts, including enhancing data collection capabilities and driving innovation in the area of public health data and analytics.

Building on this momentum, HHS’s Office of the National Coordinator for Health Information Technology (ONC) and CDC partnered to leverage advancements in the healthcare system to benefit public health. Initiatives around the U.S. Core Data for Interoperability “Plus” Initiative (USCDI+) for Public Health Domain, Helios Fast Healthcare Interoperability Resources (FHIR®) Accelerator, Trusted Exchange Framework and Common Agreement (TEFCA), and North Star Architecture aim to align and standardize public health data, transform data sharing, aggregate and make public health information accessible in bulk, and generate a flexible, shared data infrastructure for public health.

Modernizing the Immunization Data Infrastructure

The COVID-19 pandemic placed a spotlight on the systems involved in collecting, managing, and sharing immunization data. Immunization information systems (IISs) experienced an estimated 10-fold increase in data submissions and queries, threatening to overwhelm the capabilities of some systems.² Public health and healthcare partners called for a modernized immunization data infrastructure, noting the need for enhanced IIS technical capacity, improved data quality, standardization, and system interoperability, and facilitation of cross-jurisdictional data sharing.³ DMI efforts have expanded to include the perspectives and recommendations of IIS managers and the key partners that can advance modernization goals.

In January 2021, ONC awarded ASTHO a grant to develop and implement the COVID-19 Immunization Data Exchange, Advancement and Sharing (IDEAS) Program, the primary objectives of which are to:

- Explore and assess ways to establish and scale sharing of COVID-19 immunization data between state IISs and state, community, or regional health information exchanges (HIEs).
- Build on existing relationships between states and HIEs to promote vaccination data sharing.

To ensure successful achievement of these objectives, ASTHO also engaged key immunization and HIE experts in the following partner organizations to guide and support program implementation: the American Immunization Registry Association (AIRA), Association of Immunization Managers (AIM), Civitas Networks for Health (Civitas)—formerly known as the Strategic Health Information Exchange Collaborative (SHIEC), Mathematica, and Guidehouse.

As part of laying a solid foundation on which to build a strong technical assistance program for IDEAS, and to support ONC’s efforts to assess the nation’s public health data systems, ASTHO engaged in a comprehensive environmental scan to characterize the dynamics and factors influencing IIS and HIE vaccination data sharing status and opportunities, including within the context of the COVID-19 pandemic. This report describes the background, methods, and findings of the scan, and includes considerations for policymakers related to collaboration between IISs and HIEs.

Immunization Programs and Immunization Information Systems (IISs)

CDC funds 64 immunization programs in 50 states, eight territories and freely associated states, and six major cities. These immunization programs are based in state and select territorial and city health agencies. They play a vital role in supporting national public-sector vaccine systems, working with providers to promote vaccine efforts, monitoring vaccine effectiveness, and identifying populations with low vaccination coverage that may require focused outreach and education.

IISs, also known as immunization registries, are “confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical area.”⁴ These systems emerged in the 1990s, in response to a measles epidemic in the late 1980s and concerns over low childhood immunization rates. While early efforts were jump-started by philanthropic funding, IISs are currently funded primarily through CDC.^{5,6}

A total of 61 IISs operate in the bounds of CDC-funded immunization programs. They are a core component of immunization program infrastructure, as they generate information to support clinical decision-making and public health action.⁷ Vaccines administered by a participating provider and documented in the IIS are added to the individual’s immunization history and can be used to determine appropriate immunizations needed at the time of care or at a later date. They also provide a consolidated record to meet mandatory immunization requirements for school entry, employment, or other purposes.

Health Information Exchanges (HIEs)

A variety of data exchange organizations in the United States coordinate partners and provide technical infrastructure and services to facilitate the electronic exchange of health information. These organizations may be known as HIEs, health information organizations, and health data utilities. For simplicity, this report refers to these organizations as HIEs. In 2016, Congress passed the 21st Century Cures Act. The ONC Cures Act Final Rule defines an HIE or a Health Information Network as:

“...an individual or entity that determines, controls, or has the discretion to administer any requirement, policy, or agreement that permits, enables, or requires the use of any technology or services for access, exchange, or use of [electronic health information]: (1) Among more than two unaffiliated individuals or entities (other than the individual or entity to which this definition might apply) that are enabled to exchange with each other; and (2) that is for a treatment, payment, or health care operations purpose as such terms are defined in 45 CFR 164.501 regardless of whether such individuals or entities are subject to the requirements of 45 CFR parts 160 and 164.”⁸

HIEs improve healthcare coordination, quality, speed, and cost-effectiveness by providing enhanced access to all available and relevant patient data and creating a longitudinal patient record.⁹ They serve a broad range of health data organizations and partners, such as healthcare providers, health plans, community organizations, and public sector agencies. There are many types of HIEs that enable the electronic exchange of health data (**Table 1**).

While efforts to support electronic exchange of health information have been ongoing since the 1990s, the current concept of statewide HIEs has its roots in the Health Information Technology for Economic and Clinical Health Act (HITECH Act) of 2009. The HITECH Act promoted the adoption and meaningful use of health information technology and the secure exchange and use of electronic health information. It also funded ONC, which has invested significantly in state-designated HIEs since 2010.¹⁰

TABLE 1. Types and Illustrative Description of Health Information Exchanges (HIEs)

State-designated HIE or Health Data Utility	Community, Regional, or Statewide HIE	Enterprise/Private HIE	Vendor-mediated HIE	National-level Health Information Networks
State agencies or quasi/non-governmental organizations granted authority by legislation, regulation, executive order, or contract to provide statewide technical infrastructure, interoperability services, and develop data exchange policies.	Organizations that provide infrastructure to connect (often unaffiliated) healthcare organizations within a specific geographic area and with shared patients. These organizations may be designated by states for Medicaid or public health uses through various mechanisms.	Supported by a health system or integrated delivery network to facilitate exchange among affiliate provider organizations. May use community or state HIEs to connect to other enterprise networks.	Supported by an electronic health record (EHR) vendor, whereby the vendor offers the technical infrastructure to facilitate data exchange between their customers.	Network of organizations exchanging health data at a national level, with coordinated oversight and governance.

Sources: Information provided by Civitas Networks for Health. [unpublished].

Dixon B. Health Information Exchange: Navigating and Managing a Network of Health Information Systems. 1st ed. (2016)

Everson J. “The implications and impact of 3 approaches to health information exchange: community, enterprise, and vendor-mediated health information exchange.” Learning Health Systems. (2017)

ONC. The Draft Trusted Exchange Framework: [Q&A Session](#).

Public Health Data Systems in the Context of COVID-19

The COVID-19 pandemic strained the information systems that form the basis of the U.S. public health data infrastructure. Public health practitioners were confronted with challenges related to massive increases in data throughput and volume, manual data collection and entry, limited interoperability across information systems, legal and policy concerns related to data sharing, and siloed and aging data systems.

The public health information systems used to track communicable disease were not sufficient to manage the volume of incoming data and queries, or the level of analytic needs that the COVID-19 pandemic generated. Similarly, the tools used to transmit reportable data to the appropriate authorities were not designed for the high volumes of data during the peak of COVID-19. IISs are subject to similar challenges, where the new demands for increased capacity and functionalities exposed shortcomings in these systems.¹¹

COVID-19 immunization and testing data was not harmonized across data collection systems, often lacking race and ethnicity data, due in part to inconsistent reporting of these data elements at the patient point of care.^{12,13} Without defined common data elements to collect COVID-19 data, integrating information from multiple jurisdictions was a challenge. Additionally, establishing data sharing agreements across jurisdictions requires significant effort. These barriers create temporal delays in data access, impact data quality, and reduce the timeliness of analysis and decision-making.

Timely and reliable vaccination data are critical for COVID-19 pandemic response, and secure data sharing is necessary to ensure public health and healthcare practitioners have access to the data they need—when they need it—to inform decision-making. This can be achieved through the integration of bidirectional information exchange with IISs and other related systems, and specifically with HIEs.

ASTHO conducted an environmental scan to characterize the dynamics and factors influencing IIS and HIE vaccination data sharing status and opportunities, including those within the context of the COVID-19 pandemic. Information was collected through (1) a scan of secondary sources (e.g., published and gray literature, and raw data sets), (2) a scan of laws impacting immunization data sharing, and (3) qualitative data collection activities (e.g., focus groups and key informant interviews). These data collection methods are described further below.

Scan of Secondary Sources

The purpose of the scan of secondary data sources was to collect, review, and categorize existing information that describe IIS and HIE status, factors, and dynamics that influence vaccination data sharing. Development of a data extraction instrument, identification and review of resources, and analysis took place between March and July 2021. In June 2022, sources were reviewed to identify and incorporate any data sets that had been updated since the previous year.

Collection of Secondary Sources and Analysis

ASTHO identified and refined key domains of interest and research topics within those domains with input from ONC, CDC, and project partners (e.g., AIM, AIRA, Civitas, Mathematica, and Guidehouse). This process relied primarily on a deductive approach to develop data collection domains, though inductive methods were used as new sub-topics were identified during scanning activities. The resulting domains focused on factors influencing IIS and HIE vaccination data sharing, and included:

- IIS and HIE partnership status and history
- Governance and legal factors
- Funding
- Participants
- Technical factors
- Inter- and intra-jurisdictional factors
- COVID-19-specific factors

These domains formed the basis of a data extraction instrument. Jurisdictions included in the instrument were defined as the 64 states, territories, and cities with CDC-funded immunization programs. HIEs included in the instrument primarily represented state designated entities and community/regional HIEs (i.e., the first two columns in **Table 1**), though as described in the limitations section, fully excluding other HIE models was not feasible.

Collection of secondary sources involved desk research, direct requests from data set owners, and compilation of suggested source documents from key national partners and subject matter experts. ASTHO identified more than 50 data sources through this process, including readily available material from the published and gray literature, in addition to raw, unpublished datasets from partner organizations. Every attempt was made to obtain the most recent data available, in addition to sources that represented each jurisdiction in the dataset.

ASTHO finalized our initial collection of secondary sources in June 2021. Between March and July 2021, reviewers categorized and analyzed the data to detect themes and gaps in information. Between June and August 2022, data sets that had been updated since the original data collection (e.g., annual surveys) were collected and incorporated into our analysis.

Legal Scan

ASTHO conducted a legal scan in 2021, identifying IIS laws using Casemaker with search terms including “immunization,” “immunization information,” and “immunization registry.” ASTHO reviewed search results for relevancy toward collecting and sharing IIS data. Reviewers collected and noted key components of the relevant laws, including but not limited to:

- Whether reporting immunizations was mandatory or voluntary.
- Requirements of specific providers.
- If both child and adult vaccines are reported.
- Who may access immunization data from a public health authority.

Findings from the legal scan are incorporated into this report and discussed in further detail in a companion report by ASTHO on statutes and regulations impacting public health data sharing.

Qualitative Data Collection

The purpose of qualitative data collection was to gain further insights on the policy, operational, and COVID-19 response environment that impacts IIS and HIE connectivity, and to supplement data gaps identified in the scan of secondary sources. Data collection methods included focus groups and key informant interviews with state health agency and HIE representatives, in addition to policy and technical subject matter experts.

Focus Groups

ASTHO conducted four state-level virtual focus groups over a series of seven virtual convenings in July 2021. Participants included state health agency and HIE representatives from four states. These states were selected on the recommendation of ONC, as each was the target implementation site of a Strengthening the Technical Advancement and Readiness of Health via Health Information Exchange (STAR HIE) Program Supplemental awardee.^{iv} Focus groups ranged from five to twelve people, and participants included STAR HIE program participants with relevant or critical roles within the health agency and HIE, including: HIE leadership and technical experts (12), immunization program and/or IIS leadership and technical experts (4), and where appropriate, public health vital records and informatics experts (5), public health and HIE attorneys (5), and IIS vendor representatives (6).

Focus groups were conducted in two one-hour sessions per participant group. The first session aimed to identify the challenges, pressures, and other factors influencing IIS/HIE partnerships from the specific vantage points of participants. The second session focused on identifying an ideal end-state for IIS/HIE partnerships and included a discussion of the barriers and strategies for addressing them. Focus group facilitators used a semi-structured discussion guide. The first portion of the discussion guide incorporated pre-determined questions that were applied across all four jurisdictions; the second portion probed jurisdictions on consistent topics, though specific questions were tailored to reflect challenges and strategies raised during the first portion of the focus group. Notes from the focus groups were analyzed to identify common themes.

Interviews

ASTHO conducted two sets of key informant interviews. The first set included select health agency personnel that were unable to join the focus groups, to ensure key perspectives were represented for each of the jurisdictions. Interviewers used a semi-structured interview guide that covered the discussion topics included in the focus groups, for consistency. Notes from these interviews supplemented the thematic analysis described previously. A second set of interviews was conducted with national experts with relevant technical and policy experience June through July 2021, to gain additional background and context on IIS/HIE partnerships. Resources identified through these interviews were incorporated into the scan of secondary sources, as appropriate.



^{iv} Supplemental STAR HIE Program awardees were funded to advance IIS-HIE vaccination data sharing to support COVID-19 response and other public health emergencies. The STAR HIE program is described in further detail in the “Funding” section of this report.

Limitations

There were several limitations associated with the scan of secondary sources. First, many resources were more than five years old and may reflect outdated information. Additional primary data collection may be required to collect current, unpublished information on some of the rapidly evolving aspects of IIS and HIE capabilities and connectivity. Second, existing data sources were not identified to fully address all research topics within each domain. Some—but not all—of these data gaps were addressed through the qualitative data collection activities. Third, secondary sources did not consistently report numerators and denominators, so it was not always possible to summarize quantitative data consistently. Fourth, while ASTHO prioritized review of resources describing state designated entities and/or community/regional HIEs (as defined in **Table 1**), not all secondary sources fully described their study sample or used the same definitions of HIE types. Therefore, the data do not represent a single consistent sample of HIEs. Finally, jurisdiction-level data in our matrix were not validated by health agency or HIE representatives in the jurisdictions.

The limitations to the legal scan methodology were that state health authorities were not surveyed to determine completeness or accuracy of the laws discovered in the search. While every effort was made to capture most of the state IIS laws, there may be other state statutes or regulations, particularly around data privacy, that impact the collection or sharing of IIS data that were not captured through this type of legal scan.

Both the interviews and focus groups were subject to recall bias. The focus groups may have also been impacted by issues related to participant composition and inter-organization and interpersonal dynamics. Availability of participants, level of participation during the focus groups, and pre-existing relationships and dynamics between participants may have contributed to response bias. Variation in participant composition across the two one-hour sessions may have also skewed aspects of the discussion. Other forms of primary data collection (e.g., surveys) may have addressed aspects of this type of response bias.



Findings: Factors Impacting IIS and HIE Connectivity

IIS and HIE Partnership Dynamics and History

ASTHO's environmental scan yielded information on previous and ongoing explorations of IIS and HIE partnership, including benefits and challenges associated with collaboration.^{14,15,16} To characterize the broader history of IIS and HIE partnership, we also identified high-level milestones and measures of connectivity over the years. Many of the challenges, benefits, and factors impacting IIS and HIE partnership highlighted here are explored in further detail in subsequent sections of this report.

Benefits and Challenges of IIS and HIE Data Sharing

ASTHO's scan of secondary sources and focus groups highlighted specific benefits to public health and healthcare that may result from expanded IIS and HIE connectivity, including:

- Enhanced public health reporting, data quality, and analytics to support response to current and future health threats.
- Improved identification of populations or areas with low vaccination coverage to inform public health and healthcare action.
- Consolidated demographic, public health, and clinical records to create a more complete picture of the health of and risk factors within a particular community.
- Increased data quality and completeness (e.g., for race/ethnicity, contact information).
- Improved provider access to more complete, longitudinal patient immunization records, supporting delivery and coordination of care.
- Reduced burden for public health agencies to onboard providers to the IIS, and for providers who otherwise may be asked to perform duplicative data entry.

Findings from the scan of secondary sources and focus groups also revealed evolving challenges associated with IIS and HIE partnership, including:

- Competing demands and priorities, especially in the context of COVID-19 response.
- Real and perceived policy barriers limiting data exchange.
- Challenges building trust impacting collaborative efforts.
- Incomplete understanding/exploration around the value proposition for data sharing, in addition to the roles, responsibilities, and capabilities of each system.
- Potential vulnerabilities for IISs should HIEs falter or not support the technologies and standards required by the IIS.

FROM THE FIELD: IIS and HIE Roles and Pathways to Partnership

In ASTHO's focus groups, both HIE and IIS representatives expressed a commitment to serving as responsible data stewards. Health agencies recognized that while there may be some discomfort in sharing data within and across agencies, there were efforts to shift away from the mindset of 'data ownership' to 'data stewardship.'

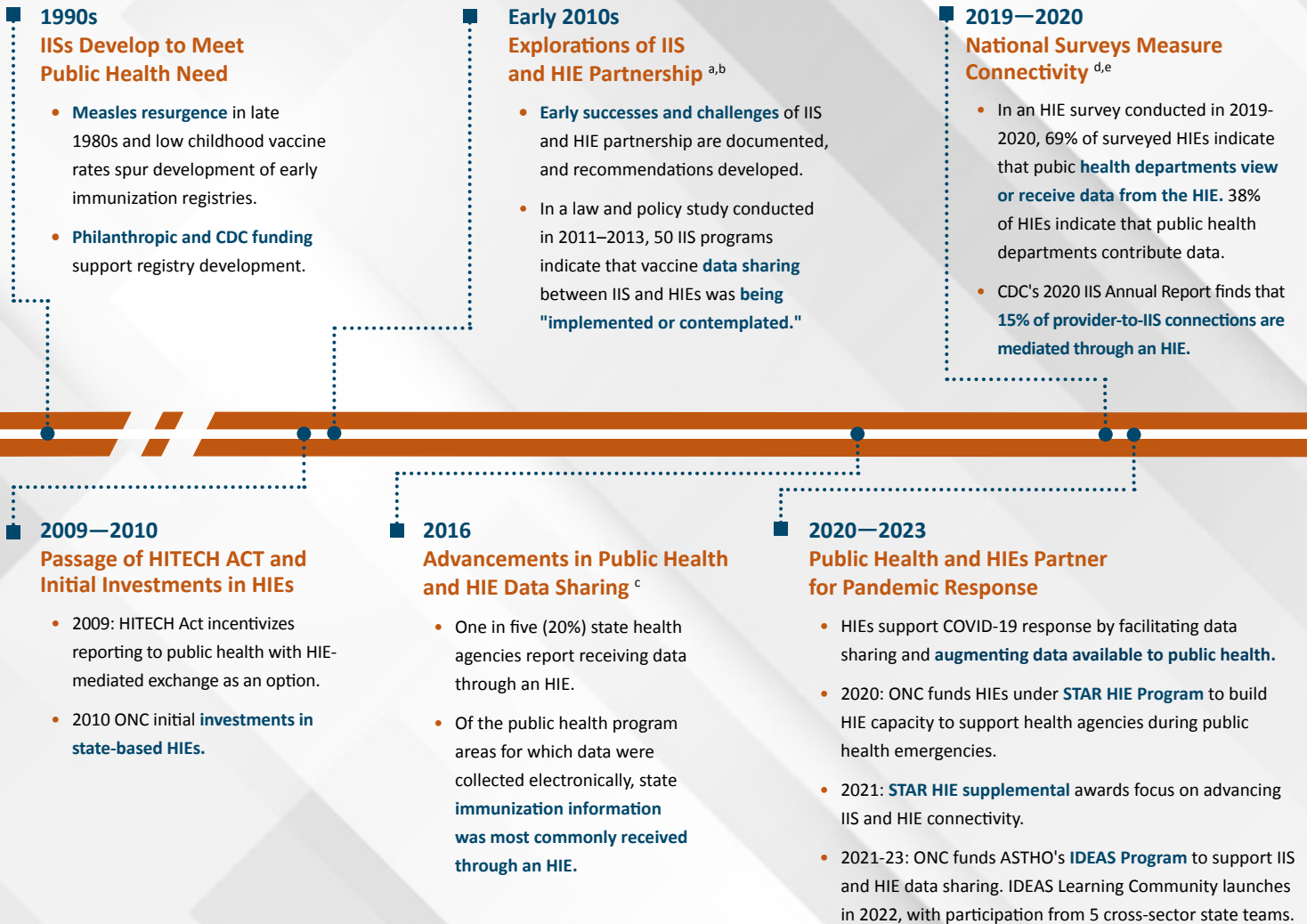
Challenges around conveying the aim and value proposition of data sharing may also have hindered collaborative projects. Focus group participants identified routine meetings with key parties from the state health agency and HIE as a promising practice. They also indicated that discussions aimed at better understanding one another's systems and functionalities would benefit IIS and HIE collaborations longer term. Such conversations would allow HIEs and IISs to identify gaps that might be addressed by reciprocal data sharing.

IIS and HIE Partnership over Time

Despite challenges, we have seen movement towards IIS and HIE connectivity. Recent and ongoing efforts, such as ONC's STAR HIE and IDEAS programs, in addition to the Immunization Integration Program (IIP) Collaborative, have provided forums for IIS and HIE leaders to explore data sharing and interoperability efforts.^{17,18,19}

Figure 1 summarizes key milestones and various measures related to HIE and public health coordination, in addition to HIE and IIS data sharing specifically.

FIGURE 1. Measures of IIS and HIE Partnership over Time



Abbreviations: HITECH, Health Information Technology for Economic and Clinical Health Act; STAR HIE, Strengthening the Technical Advancement and Readiness of Health via Health Information Exchange; IDEAS, COVID-19 Immunization Data Exchange, Advancement and Sharing.

Sources:

- HLN Consulting. "IIS and HIE: Is there a Future Together?" AIRA Repository. (2013)
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- CDC. "2020 IIS Annual Report (IISAR)." (2020)

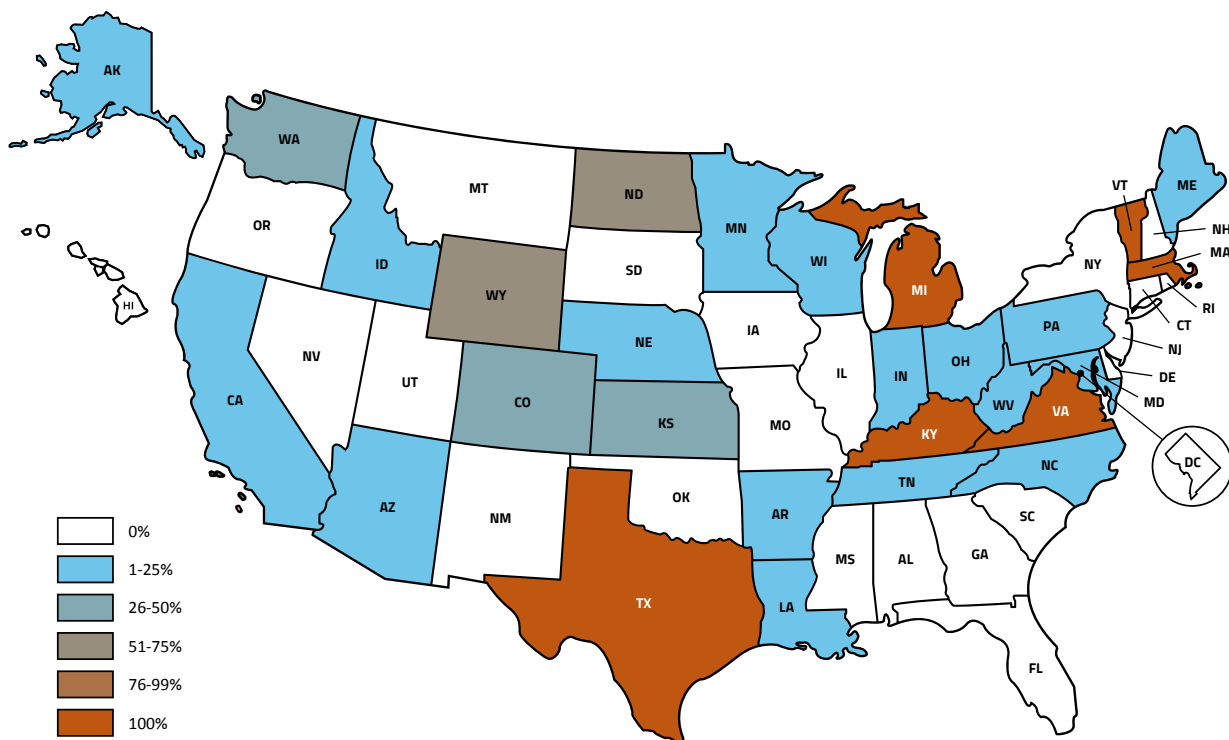
To characterize the more recent status of IIS and HIE connectivity, we drew from two surveys: CDC’s 2020 Immunization Information Systems Annual Report (IISAR) and a 2021 HIE Vaccine Data Information Survey conducted by Civitas (formerly SHIEC). Both surveys indicate that there is a wide range of public health and HIE connectivity for immunization data sharing across the nation, and room for further advancement of data exchange.

The IISAR survey gathers data regarding the volume of HIE-mediated provider site^v connections with IISs. In 2020,²⁰ approximately 15% (17,819/121,134) of provider sites connected to an IIS were mediated through an HIE.^{vi} One potential reason for the low percentage of provider sites leveraging an HIE to transport vaccination data may be that they already established a direct connection to the IIS, which may make the creation of a new transport mechanism less of a priority.

Figure 2 characterizes the percentage of HIE-mediated connections to IISs in the states and District of Columbia. Just more than half (55%, or 28/51) of jurisdictions had some level of HIE-mediated connections, while 23 jurisdictions (45%, or 23/51), indicated that they had no HIE-mediated connections to the IIS. Among the 28 jurisdictions using HIEs to mediate some level provider-IIS connections:

- Seventeen jurisdictions had 1-25% of their provider connections mediated by an HIE.
- Three jurisdictions had 26-50% of their provider connections mediated by an HIE.
- Two jurisdictions had 51-75% of their provider connections mediated by an HIE.
- Six jurisdictions had 100% of their provider connections mediated by an HIE.

FIGURE 2: Percent of Provider Site Connections to IISs Mediated by an HIE, by Jurisdiction, 2020



Source: Map created with data from CDC “2020 IIS Annual Report (IISAR)” (2020). Map includes data from state and Washington, D.C. IISs (excludes other city IISs).

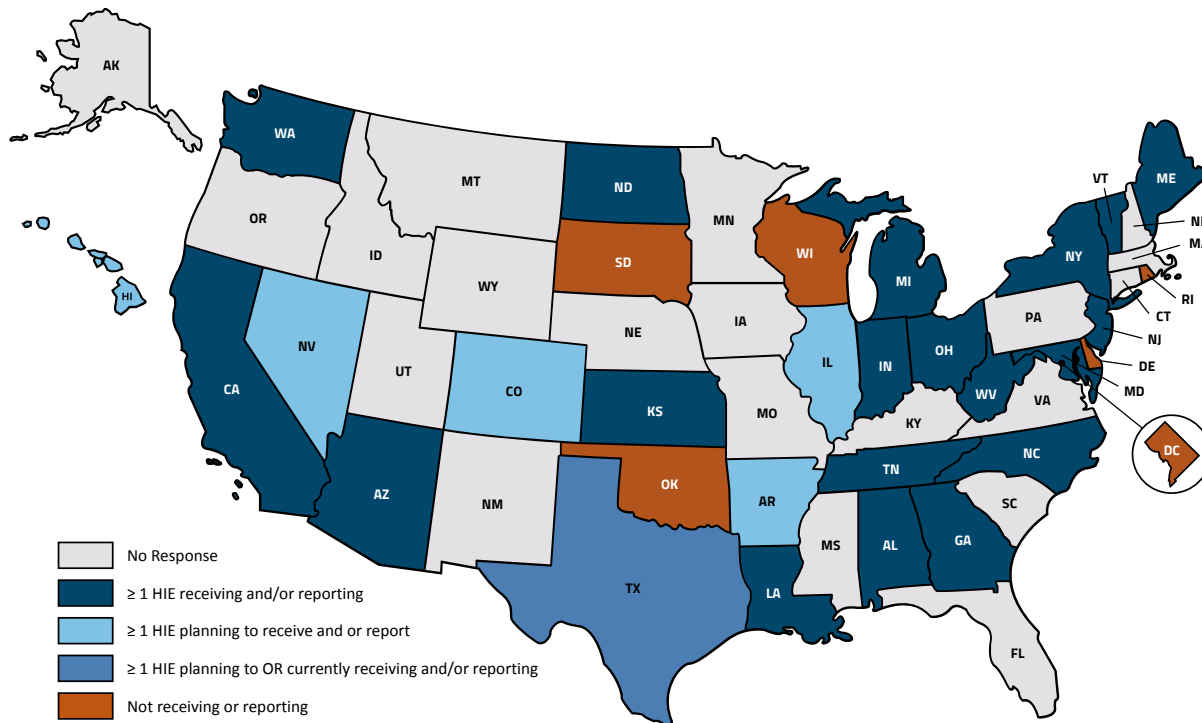
^v For the purposes of the IISAR, a provider site is the physical site that provides vaccination services and that maintains permanent records.

^{vi} This measure includes data from all IISs that responded to the 2020 CDC IISAR (not only the 51 IISs included in Figure 2).

In their 2021 HIE Vaccine Data Information Survey,²¹ Civitas collected information on whether HIEs were receiving and reporting vaccination administration data to/from the public health authority for their jurisdiction. Of 46 HIE respondents, 29 (63%) indicated that they were receiving and/or reporting vaccination administration data with their public health jurisdiction. We mapped the location of these HIEs back to the states in which they were based (**Figure 3**). The 29 HIEs that indicated they were receiving and/or reporting vaccination administration data with their public health jurisdiction are located in 20 states. **Figure 3** also illustrates states in which respondent HIEs indicated that they planned to receive and/or report vaccination data, and those that were not doing so at the time of the survey. The number of direct feeds in addition to the mode and type of data exchanged (e.g., unidirectional, bi-directional, complete data record) varied across HIEs and jurisdictions.^{vii}

Both figures suggest a patchwork of IIS and HIE connectivity across the country. While the specific factors influencing this status may vary from jurisdiction to jurisdiction, this report aims to characterize the more significant drivers and considerations behind IIS and HIE data sharing.

FIGURE 3. States with HIEs Receiving and/or Reporting Vaccination Data With Their Public Health Jurisdiction, 2021



Source: Map created with data from Civitas “HIE Vaccine Data Information Survey” (March 2021) [unpublished].

Survey Question: “Is your HIE organization currently receiving and reporting vaccination administration data to the public health jurisdiction?”

Free-text responses were coded into “receiving and/or reporting,” “planning to receive and/or report,” and “not receiving or reporting.”

See footnote for updated information provided by Civitas in 2022.

^{vii} These data points do not represent a full market scan, as Civitas only received 46 HIE responses. Since the 2021 HIE Vaccine Data Information Survey, Civitas has conducted additional research on this topic. As of Sept. 2022, Civitas confirmed that seven additional states (AK, AR, CO, NE, NV, PA, RI) have one or more HIE receiving and/or reporting vaccination administration data with their public health jurisdiction. An additional state (OK) has an HIE that is planning to receive and/or report vaccination data.

Governance and Legal Factors

Public health information systems' governance structures are often generated separately from HIEs and other state health IT efforts. The legal authority and parameters to operate IISs and HIEs may derive from different statutes, regulations, and other policies, which can lead to conflicting guidance or challenges interpreting guidance around IIS and HIE connectivity. This section covers IIS and HIE authority and governance, data sharing agreements, reporting requirements, and consent models.

Forms of Authority

The authority to govern and operate IISs is based primarily in state and local laws, regulations, and policies.²² Within this state and local legal landscape, a variety of statutes and regulations grant authority to operate IISs. A 2011-2013 IIS law and policy study²³ found that immunization programs' legal authority to operate IISs for adults relied primarily on state and local laws that authorized the operation of IISs specifically (53%, or 27/51), or general public health authority granted through statutes or regulations (26%, or 13/51). Other forms of authorization were granted through laws that authorized sharing of immunization information without specific mention of IISs (16%, or 8/51), and those that authorized sharing of healthcare information without specific mention of immunization information (6%, or 3/51). Similarly, authority to operate IISs for children stemmed primarily from laws that specifically authorized IISs (68%, or 36/53) or general public health authority (19%, or 10/53).

To capture a more current landscape of IIS authority, ASTHO completed a legal scan of all 50 states, Washington D.C., and Puerto Rico in 2021 to identify laws governing immunization information systems. This scan relied entirely on searches for statutes and regulations that authorized the collection and reporting of immunizations for public health purposes. The findings were limited to scan results, and states were not surveyed to verify interpretation of identified laws. Of the 52 jurisdictions evaluated, most (83%, or 43/52) had laws enabling the collection of immunization data through an IIS.

According to Civitas, 39 states have policies in place designating varying levels of HIE authority or service for Medicaid and public health needs, as of 2022.²⁴ At least five states are reviewing policies to further define roles and responsibilities for designated data exchange authority and services. Some states have authorized HIE services for statewide data exchange for multiple uses, while other states focus on Medicaid data exchange. State-level approaches for designating responsibility and authority for operating statewide health information exchange varies. Many states have created a new public or private entity to manage and operate information exchange. Other approaches involve contracting with an existing HIE or management through an existing governmental organization.

Governance

The location of the IIS within a health agency may influence the data system governance structure, in addition to policy and technical decision-making. As of 2017, almost one third of immunization programs did not manage the IIS, with 9% of immunization programs reporting the IIS was housed in a centralized IT department, and 20% reporting that the IIS was managed elsewhere (e.g., epidemiology, infectious disease divisions, etc.).²⁵ AIM's 2019 survey of immunization program managers²⁶ provides additional insights on what groups have decision-making authority to modify the IIS or deploy new functionalities. There was variation with regards to whether these decisions could be made within the immunization program: 28 immunization programs indicated that they required approval from another program, department, or agency to modify their IIS, while 23 programs did not require approval from other programs or entities.^{viii}

HIE governance models exist on a continuum and have evolved over time to meet changing needs for statewide information exchange. The HIE strategy may be driven by state-level public-private advisory groups or by the state-designated HIE. Factors contributing to variations in governance model may include geographic considerations, population size and distribution, population and provider mobility across regions and existing HIE service areas, and the environment of trust and cooperation amongst data exchange partners and interested parties.²⁷

^{viii} For jurisdictions that require approval for IIS modifications outside of the immunization program, the types of parties involved in decisions about system changes may include Attorney General's Offices, Offices of Privacy and Security, centralized IT departments/agencies, and others.

A 2021 scan of HIE governance models²⁸ identified a range of approaches, with variations in the level of state government involvement (**Table 2**). Civitas found that:

- Eight states have state-led HIE services.
- Twenty-five states and Washington, D.C. have designated public-private utilities or entities, with state oversight.
- Eight states have orchestrator models. Of those, six have state agencies and two have designated non-profit organizations serving as the orchestrator for state-level HIE services.
- Nine states have market-driven networks, with varying levels of state involvement.
- At least two states are transitioning governance models due to business and strategic changes.

Further research may be needed to determine how these models may impact HIE and IIS connectivity.

TABLE 2. HIE Governance Models, 2021

State-led HIE Services	Designated Public-Private Utility/Entity with State Oversight	Orchestrator	Market-driven Networks
State agency provides HIE technical services and oversight framework.	Independent non-profit entity authorized by state government to operate a statewide HIE network.	State agency or designated non-profit organization provides leadership, coordination, and connecting services across multiple regional HIEs.	Public and private sector interoperability services operated with varying levels of state involvement. Examples include enterprise HIEs, vendor-mediated HIEs, or Health Center Controlled Networks.

Source: Information provided by Civitas Networks for Health [unpublished].

Evolving policies around state designation of HIEs are also impacting HIE governance. According to Civitas,²⁹ some states are updating state-designation policies to expand data exchange and accountability by creating health data utilities (HDUs). Civitas describes HDUs 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 through specific, defined use cases in accordance with applicable state and federal laws protecting patient privacy... HDUs emphasize multistakeholder organizational, use case, and data governance and most will be designated non-profit organizations or independent state agencies. In all cases, state and stakeholder governance, oversight, and accountability is paramount.”³⁰

HIE leaders in the field have proposed the development of an HDU maturity model to further define the HDU concept, which may also clarify a pathway to expanded partnership with public health agencies.³¹

In summary, there are challenges and opportunities to better align IIS and HIE forms of authority and governance approaches. Policy and operational decisions around the scope, management, and modification of IIS and HIE functionalities should consider the broader environment of vaccination data sharing. Doing so can help reduce the potential for contradictory policies, redundant processes, and decision-making that fails to realize mutually beneficial options. Efforts to identify and align the current factors impacting IIS and HIE authority and governance may also present opportunities to identify gaps that the other can address and/or better define roles and responsibilities.

Data Sharing Agreements

Governance policies and practices that enable data exchange between IISs and HIEs are often codified through data sharing agreements (DSAs). As noted by ASTHO's focus group participants, establishing DSAs is a critical first step when entering into a functional IIS and HIE data sharing relationship. Establishing these formal agreements, however, can present significant challenges. Focus group participants noted that the effort involved in establishing DSAs and governance processes surpassed the effort involved in addressing technical issues associated with data sharing. Re-instituting agreements that have expired could also present challenges, especially in the midst of public health emergencies, when the staff required to review and approve agreements may have been directed to other priorities. Establishing processes for regular review and revision of IIS and HIE DSAs may help ensure these agreements stay current.

Focus group participants also indicated that a clear value proposition and data sharing use case(s) were beneficial in establishing these agreements. Further exploration and communication of the benefits of IIS and HIE data exchange may facilitate the development and expansion of DSAs between these systems.

Reporting Requirements

A variety of provider entities may be required to report data to an IIS, such as public health providers, pharmacies, Vaccines for Children (VFC) providers, and private providers. ASTHO's 2021 legal scan specifically identified 23 out of 52^{ix} jurisdictions that mandated reporting to the IIS. Eleven jurisdictions had statutory mechanisms for enforcing IIS reporting. These ranged from civil fines, to reporting to professional licensing boards, all the way up to criminal misdemeanor charges.

With regards to HIEs, a 2013 legal scan by NORC at the University of Chicago found that 59% of states had enacted legislation promoting the use of HIEs.³² Limited detail around the types of legislation passed was included in NORC's report, however, it was noted that some of these legislative efforts included mandatory provider participation in statewide HIEs.

Future legal scans should be considered to assess HIE reporting requirements and enforcement mechanisms. An understanding of how these mandates align with IIS mandates may be helpful in identifying areas where these two systems can support mandated reporting and reduce duplicate data entry for providers. Identification of areas in which these reporting requirements diverge may also highlight opportunities where one data system is well-positioned to augment provider data in another system.



^{ix} Beginning on Jan. 1, 2022, Virginia's law mandating reporting to their IIS took effect, bringing the total number of jurisdictions with some form of mandated immunization reporting to 24.

Consent Models

Consent models outline how individuals give permission to share and access their information. Generally, consent policies describe whether individuals are: (a) required to grant consent for their data to be reported or disclosed by a data system (an “opt-in” policy); or (b) automatically enrolled into the system with the ability to discontinue participation (an “opt-out” policy). Within each of these broad consent frameworks, there are further nuances for both IISs and HIEs (e.g., implied and implicit consent, opt-in with restrictions, opt-out with exceptions).^{33,34}

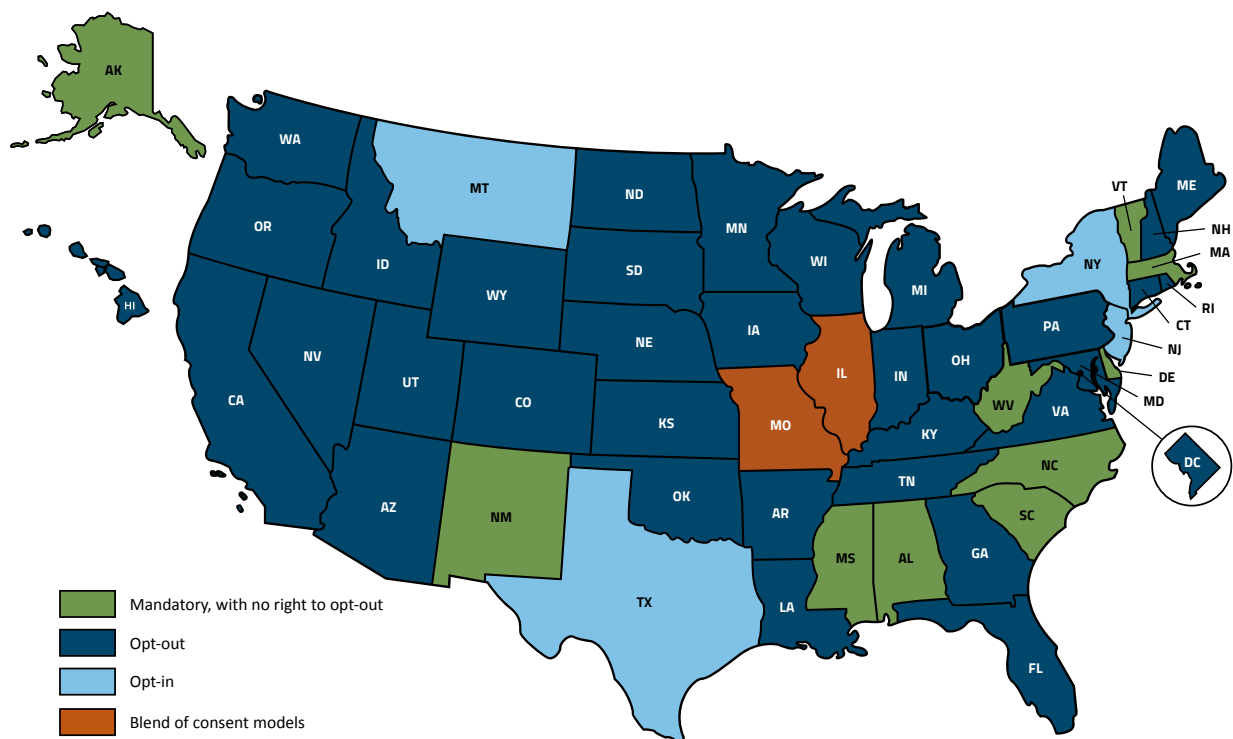
Misalignment of consent policies across data exchange partners—and lack of understanding around these policies—can create barriers to data sharing. The variety of sources in which these policies may be articulated (e.g., statute, regulation, and other policies) adds a layer of complexity for any efforts to characterize this landscape, as does the fact that HIE consent policies can apply statewide or solely to state-operated HIEs.³⁵

According to data collected by CDC in 2020-2021,³⁶ most jurisdictions (66%, or 34/51) were found to use opt-out adult consent policies for IIS reporting (**Figure 4**). Reporting was found to be mandatory, with no right to opt out, in ten jurisdictions (20%, or 10/51), and five jurisdictions (10%, or 5/51) used opt-in consent policies. Two jurisdictions (4%, or 2/51) had a blend of opt-in, opt-out, and mandatory reporting models. ASTHO’s legal scan matched CDC’s data, finding that 34 of 52 jurisdictions implied consent from the individual with an opt out option.

A 2022 scan conducted by Civitas³⁷ identified current HIE consent models in the states and Washington, D.C., and found that the majority of states (80%, or 41/51) have an opt-out policy (**Figure 5**). A minority of states utilize opt-in (8%, or 4/51) or use a blend of opt-in and opt-out policies depending on specific circumstances (6%, or 3/51). One state’s policy indicated that, because protected health information can be shared for treatment purposes under HIPAA without individual consent, no further consent was required for exchange through the HIE. Only two states did not have current, specific policies addressing HIE consent.

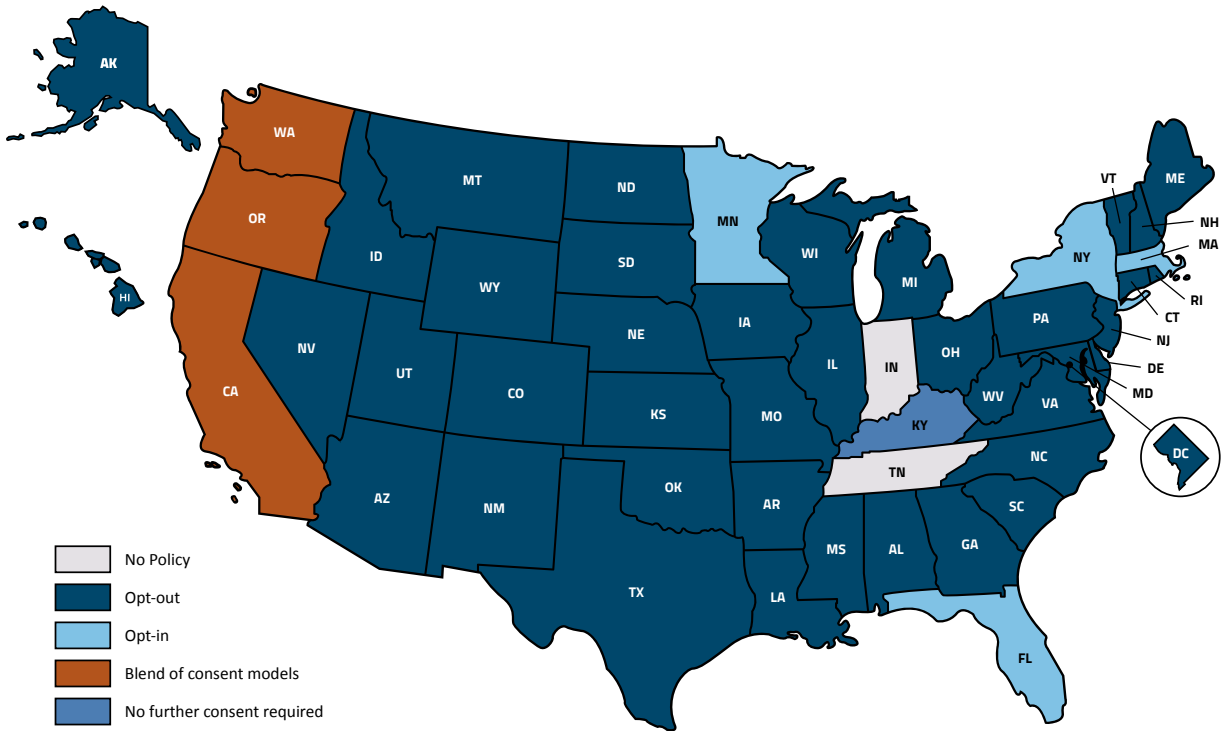
A 2016 resource from George Washington University³⁸ also highlighted how HIE consent policies may be documented in a variety of ways. At the time, most HIE consent policies were articulated in state statutes (53%, or 16/30), followed by state policies without the force of law (27%, or 8/30), and state regulations (13%, or 4/30). One jurisdiction established portions of its consent policy in both state statute and regulation, and another included the policy in its state HIE plan.

FIGURE 4. IIS Adult Consent Policies by Jurisdiction, 2020–2021



Source: Map created from data contributed by CDC.

FIGURE 5. HIE Consent Policies by Jurisdiction, 2022



Source: Map created with information provided by Civitas Networks for Health. [unpublished 2022 scan].

According to **Figures 4 and 5**, there are 24 states where IIS and HIE consent policy do not fully align, which may create barriers for vaccination data sharing. Of the 27 states (including Washington, D.C.) where consent policies appear to align, all but one are opt-out for both IIS and HIE.

ASTHO’s legal scan identified 28 out of 52 jurisdictions with laws explicitly allowing provider access to immunization data for treatment purposes without explicit individual consent, although this number could be higher because some states do not denote this in the law if the providers are already considered authorized IIS users with their own log-in credentials for reporting immunizations to the system. The large number of jurisdictions that allow IIS data to be shared with providers for treatment and healthcare purposes could create additional avenues for data sharing with HIEs even if state laws do not explicitly include the HIE as an authorized IIS user. However, inconsistencies in consent requirements can create confusion for sharing between IISs and HIEs in states that may not require individual consent to report an immunization to the IIS but do require an opt-in consent to report to the HIE.

An updated HIE legal scan and comparison of IIS and HIE consent laws may support identification of areas in which legislative action is required to facilitate data sharing, or where organization-level policies may need to be better oriented to reflect a statute-level interpretation that permits data sharing. In addition, better understanding from IIS programs on how they view HIEs for the purpose of data access and exchange is necessary to determine if there are limitations in practice to sharing data.



FROM THE FIELD: Legal and Policy Considerations Raised in Focus Groups

Real and perceived legal barriers were identified as a common theme during ASTHO's focus groups. Some of the health agencies indicated that they lacked the legal basis to share immunization data on patients not already included in the HIE's master patient index or were unable to support a full IIS database extract that would allow the HIE to persist the data. One state noted that unspecific or broad data sharing requests were being rejected by the health agency's legal team, reinforcing the importance of specific data sharing requests and use cases. Additionally, some state health agency representatives indicated that some of the proposed use cases may qualify as "research," which would require approval from an institutional review board.

Federal policy was raised both as a facilitator and challenge for IIS-HIE collaborations and data sharing. Certain federal HIPAA privacy and security rules were relaxed during the Public Health Emergency for COVID-19, offering additional flexibilities and support for data sharing projects. For example, the Office of Civil Rights issued [guidance](#) highlighting how HIPAA supports the use of health information exchanges in sharing data to improve the public's health. This guidance likely facilitated data sharing, especially in situations where data sharing between entities is not yet institutionalized.

Funding

IISs and HIEs have been developed and maintained through separate funding mechanisms, which result in different business models and incentives to pursue specific activities. In this section, we describe historical funding sources for IISs and HIEs, resources made available through COVID-19 response dollars, and opportunities for sustaining IIS and HIE collaboration.

Historical Funding Sources

IISs funding sources vary across jurisdictions and include a blend of investments from federal, state, and local governments, in addition to non-profit and philanthropic organizations.³⁹ Currently, two primary federal funding streams support immunization programs and their respective IISs across the United States: CDC's Public Health Service Act Section 317 (Section 317) Immunization Grants program and the VFC program. Section 317 was established by the Vaccination Assistance Act of 1962 to support U.S. jurisdictions in purchasing vaccine doses and was expanded to support direct service delivery and vaccination infrastructure following a series of measles outbreaks between 1988 and 1991.^{40,41} The VFC program, which provides vaccines at no cost to children who are Medicaid eligible, uninsured, underinsured, or American Indian or Alaska Native, was created in 1993 with the passage of the Omnibus Budget Reconciliation Act.

Over time, the technical attributes, functional standards, and number of required data elements in IISs have grown, increasing the cost to develop and maintain these systems.⁴² Investments to support and strengthen IIS infrastructure, however, have not kept pace. The proportion of IIS funding from non-federal sources has decreased over the years, and IISs have become increasingly reliant on federal dollars.⁴³ Meanwhile, federal funding through CDC has remained relatively flat. This dynamic results in insufficient resources to manage and operate IISs, while these systems are increasingly asked to accommodate expanded demand and new functionalities.

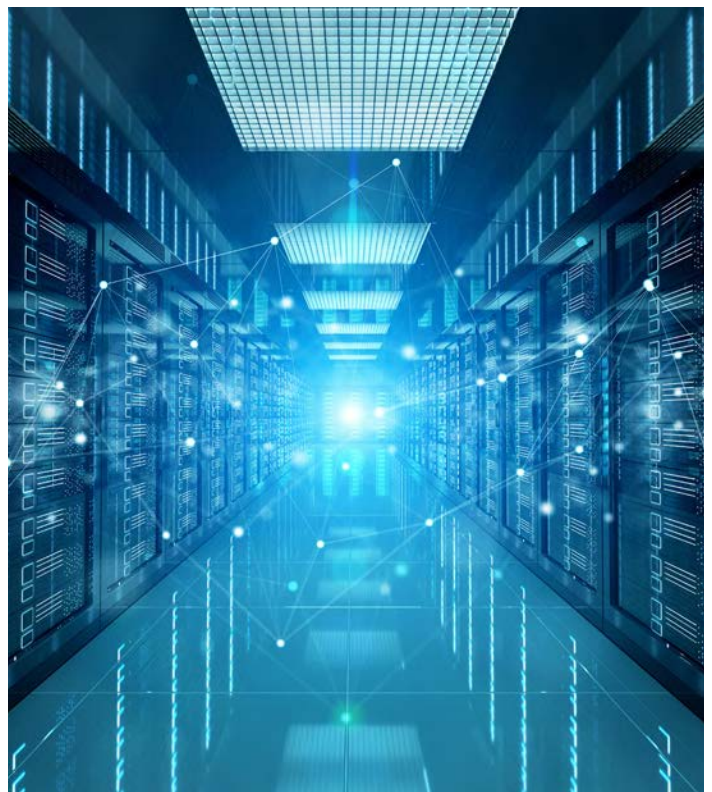
HIE funding sources follow a similar path to IISs. Initially viewed as a local, closed-health system approach to integrate data across communities, early HIE efforts struggled to obtain cost-effective technology, interoperable data sources, and participant buy-in.⁴⁴ A series of federal activities stimulated the creation of HIEs across the country, beginning in 2004 with the creation of the ONC and the Agency for Healthcare Research and Quality's State and Regional Demonstration project. In 2009, following the passage of the American Recovery and Reinvestment Act and the HITECH Act, ONC created the State HIE Cooperative Agreement Program, the Beacon Community Program, the Regional Extension Center Program, and the Strategic Health IT Research Projects Program to provide funds and support to create HIEs.

In 2011, the CMS launched the Medicare and Medicaid EHR Incentive Programs to advance the adoption, implementation, and meaningful use of certified electronic health record technology amongst healthcare providers. In 2018, CMS renamed the EHR Incentive Programs to the Promoting Interoperability Programs, to signal the programs' movement "beyond the existing requirements of meaningful use to a new phase of EHR measurement with an increased focus on interoperability and improving patient access to health information."⁴⁵ Some of the initial data exchanges incentivized by the EHR Incentive Programs included the testing and exchange of public health data (e.g., immunization, syndromic surveillance, reportable labs) and other data, such as a summary of care.⁴⁶ The Promoting Interoperability Programs and subsequent changes to the program through rulemaking required more data exchange, such as through ePrescribing and provider to patient exchange.⁴⁷ Some or all of these data exchanges can be facilitated by an HIE as a transport mechanism.

For HIEs to effectively facilitate the data exchange, they must have the infrastructure to do so. Between 2011 and 2021, CMS allowed state Medicaid agencies to access enhanced federal financial participation (FFP) for technical solutions to build, expand, and then maintain HIEs. Initially, CMS allowed states to receive 90% reimbursement for the costs to design, develop, or implement (DDI) HIE solutions to help providers participating in EHR Incentive Programs meet program requirements, provided these funds were part of a financial strategy that included all payers that benefited from the HIE and that the costs were allocated in accordance to the benefit gained.^{48,49} These funds were available through the Medicaid Management Information System (MMIS) enhancements—which offered a 90% federal match on DDI activities and potential 75% match on operation and maintenance (O&M) costs—or HITECH funding, which only provided for 90% matched DDI enhanced FFP. In 2016, CMS allowed states to claim the same 90 FFP for HIE functionality that included connecting any Medicaid provider to an HIE, as long as their connection helped an EHR Incentive Program-eligible provider meet program requirements.⁵⁰ As before, these funds were available through MMIS or HITECH. By 2021, 49 states had accessed FFP for public health activities with approved Implementation Advanced Planning Documents (IAPDs).⁵¹

Of the states with viable HIEs, some struggled initially to identify the state-share of funding for DDI or the financial participation of various payers to fully utilize the federal enhanced match. State share often comes from general fund revenues or healthcare provider taxes or fees. Common sources of payer participation in the HIE include user or transaction fees or subscriptions to services. Other payer funding mechanisms include health IT funds and per member per month calculations.

As state Medicaid agencies prepared for the Promoting Interoperability Program to sunset in 2021, states that could identify state share funding and develop a cost allocation approach aligned with the fair-share principle during HITECH⁵² explored ways to move HIE projects into their MMIS to access enhanced FFP for DDI and O&M. This transition required that a state Medicaid agency: (1) align their HIE activities to the broader MMIS development and procurement roadmap;^x (2) ensure that the historical HIE and HITECH cost allocation approach could be aligned with the state's MMIS cost-allocation approach without significant reduction in federally available funds; and (3) develop outcomes-based certification for HIE functions to be transitioned to the MMIS.



^x Medicaid Information Technology Architecture, or MITA, roadmap

COVID-19 Funding

The federal government and states provided additional funding to monitor and manage the response to the COVID-19 pandemic. Some of these funds are targeted towards improving technical infrastructure and data exchange to facilitate decision-making for public health. Sustainable, flexible funding is needed to support the operation and maintenance of public health systems in the future.

CDC received a series of supplemental funds to address the pandemic, including the Coronavirus Preparedness and Response Supplemental Appropriations Act, 2020, Coronavirus Aid, Relief, and Economic Security (CARES) Act, Paycheck Protection Program and Health Care Enhancement Act, Coronavirus Response and Relief Supplemental Appropriations Act, 2021, and American Rescue Plan Act of 2021. Through a blend of regular and supplemental appropriations, over \$1 billion have been made available to support CDC's data modernization initiative. In 2021, the House passed the Immunization Infrastructure Modernization Act of 2021 (H.R. 550). If fully authorized, H.R. 550 would provide resources to health agencies to expand and enhance IIS capabilities.⁵³

Some of these resources could be leveraged to support IIS and/or HIE infrastructure. For example, the Coronavirus Response and Relief Supplemental Appropriations Act included support for development and upgrades to IIS infrastructure to support COVID-19 vaccination.⁵⁴ CARES Act funding directed to state, local, and tribal governments included allowable uses for health information technology and digital tools to support the public health response (e.g., technology to support patient engagement and remote monitoring, case management, health information exchange with state and local public health partners, and enhanced reporting). As such, public health authorities could direct funding to HIEs for technical services to support the response.

ONC also used funding provided by the CARES Act to provide \$20 million to support collaborations between HIEs and public health, including a focus on immunization data sharing. Funded efforts include:

- **STAR HIE Program:** This program directed resources to five HIEs to “strengthen and expand the ability of HIEs to support public health agencies in their response to public health emergencies.”⁵⁵ This effort includes a focus on developing innovative data services that support public health and communities disproportionately impacted by COVID-19.
- **STAR HIE Program (Supplemental Award):** Expanding on the original STAR HIE program, 17 additional HIEs received supplemental awards to improve COVID-19 vaccination data through HIE and IIS connectivity.
- **IDEAS Program:** This ASTHO-led program, documented in this report, aimed to assess the IIS-HIE landscape and develop a financial and technical assistance program to advance IIS-HIE vaccination data sharing. Through this program, ASTHO funded five state teams (comprised of representatives from the state health agency and their selected HIE counterpart) to advance state-level data sharing projects and engage in peer-to-peer learning through a learning community.



FROM THE FIELD: Federal Partners' Influence in Supporting IIS and HIE Collaborations

Participants in ASTHO's focus groups mentioned the importance of guidance from federal partners—and specifically, the agencies that funded their programs—when establishing program priorities. IIS-HIE collaborations may be further supported from the federal level through grants that promote public health and HIE partnerships via joint grant responses or aligned project objectives.

Sustaining an IIS and HIE Collaboration

According to ASTHO's focus groups, a critical area preventing a deeper IIS and HIE integration is a lack of funding for long-term connectivity. Partners engaged as part of this environmental scan noted that, if used appropriately and in-line with each state's needs, one-time funding to help IISs to modernize and HIEs to facilitate IIS operations and data exchange would be helpful to improve the public health infrastructure. The risk, however, is that one-time funding may create a technological leap forward that either goes unused or becomes outdated over time. Public health agencies struggle to maintain sufficient personnel and may lack a technological roadmap for updating their systems, especially as those updates relate to integrating with HIEs.

One approach to provide sustainable funding for an IIS specifically and public health infrastructure generally may be to leverage existing pathways for federal assistance to states seeking to build technical solutions. Building on what CMS has allowed for Prescription Drug Monitoring Programs, the federal government could explore allowing other traditional public health interoperability infrastructure to be considered eligible for enhanced match under current processes (e.g., IAPDs and Operational Advanced Planning Documents [OAPDs]). While state funding will be needed for the Medicaid enhanced match, Medicaid funding could be more strategically aligned with CDC funding to further strengthen IIS infrastructure.

CMS defines a module as a “packaged, functional business process or set of processes implemented through software, data, and interoperable interfaces that are enabled through design principles in which functions of a complex system are partitioned into discrete, scalable, reusable components.”⁵⁶ As an example, CMS approved the cost of HIE activities within MMIS IAPDs and OAPDs and has certified at least one state's MMIS module that uses HIE functionality using its outcomes-based certification approach.^{xi}

Under HITECH, CMS provided enhanced FFP to on-board “Medicaid public health providers to interoperable systems and HIEs connected to Eligible Providers so that Eligible Providers are able to meet Meaningful Use measures focused on public health reporting and the exchange of public health data, including activities such as validation and testing for reporting of public health measures described in 42 CFR 495.22 and 495.24.”⁵⁷ Furthermore, CMS has increased Medicaid provider reliance on the public health reporting structure through finalized rules for the Promoting Interoperability Program.⁵⁸

Leveraging the MMIS request for funding and module certification process could help alleviate some of the challenges facing public health data modernization. It provides a potential pathway for sustained development and operations and maintenance costs for both public health and HIEs. It also promotes further Medicaid and public health agency collaboration to make it easier for both entities to obtain and integrate data more holistically for the betterment of population health. Finally, it provides an additional “carrot” for state legislators to plan for and allocate a dramatically reduced state share to modernize and maintain their public health system.

^{xi} For example, CMS approved enhanced match under the MMIS IAPD process for the Maryland to use their HIE for care coordination, image exchange, and population health monitoring and reporting. Additionally, CMS approved planning funding for Washington State's public health strategy.

Participants: Data Contributors and Data Users

A variety of participants report and retrieve data from IISs and/or HIEs, including providers, payers, consumers, and federal entities. An understanding of how data reporters overlap or diverge across systems can help decision-makers better characterize areas where there may be opportunities to reduce duplicative data entry and enhance information in one system through data exchange with another. Similarly, clarity around the data users for each system is important, as overlapping users may point to opportunities to consolidate records for one-stop data access.

Notably, the types of data queries needed may vary by data-user. Single patient queries may be sufficient for providers and consumers, while payers may benefit from bulk queries of their members. Federal entities, such as Veterans Affairs (VA) or Department of Defense (DOD), may require single patient queries when serving in a provider function, in addition to bulk queries for trends analysis. The Helios FHIR Accelerator, supported by HL7, CDC, and ONC, is working in this space to advance IIS bulk query capacity, which would make these queries less burdensome for public health.

Providers

Authorized providers either report information to an IIS, query information from an IIS, or both, depending on the need and scope of the organization. IISs most consistently indicated receiving adult vaccination administration reports from the provider types and settings summarized in **Figure 6**.⁵⁹ ASTHO's environmental scan did not yield comparable data on provider types querying IISs.

Similarly, HIEs also have a variety of provider types that report and query data. In a 2019 survey of state and community HIEs,⁶⁰ HIE respondents reported that they each connected to multiple hospitals (median: 24); thousands of providers (median: 3,000); and multiple EHR vendors (median: 12). **Figure 7** describes provider and other participant types that view, receive, or contribute data to HIEs. While this figure is not specific to vaccination data, the same study reports that vaccination data was the fourth most common data type exchanged by HIEs (83%, or 74/89 respondent HIEs).

ASTHO also identified data on provider-to-IIS connections that were mediated by an HIE (**Figure 2**). Jurisdictions may recommend, or even require, an entity to connect to the IIS via an HIE to increase the incentive for establishing only one connection to report information to and from the IIS, as well as to exchange data with other HIE providers. These HIE-mediated connections require effort from all parties involved to establish (including the jurisdiction's IIS and HIE staff, and healthcare provider and EHR vendor staff), which can cause these projects to take more time than establishing a connection to only one system.

FIGURE 6. Percent of IISs Indicating Data Submission by Adult Vaccination Provider Type or Setting, 2020

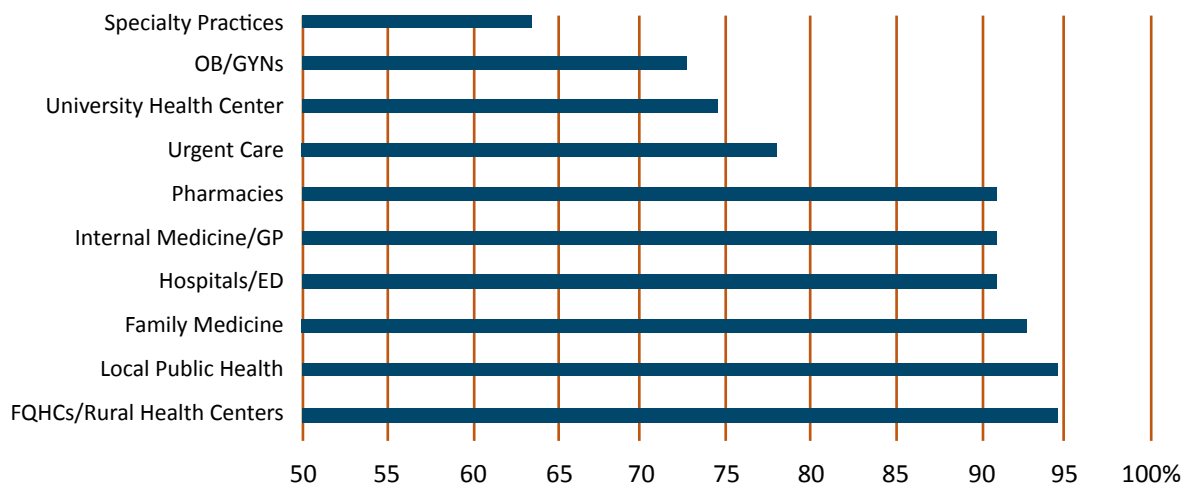
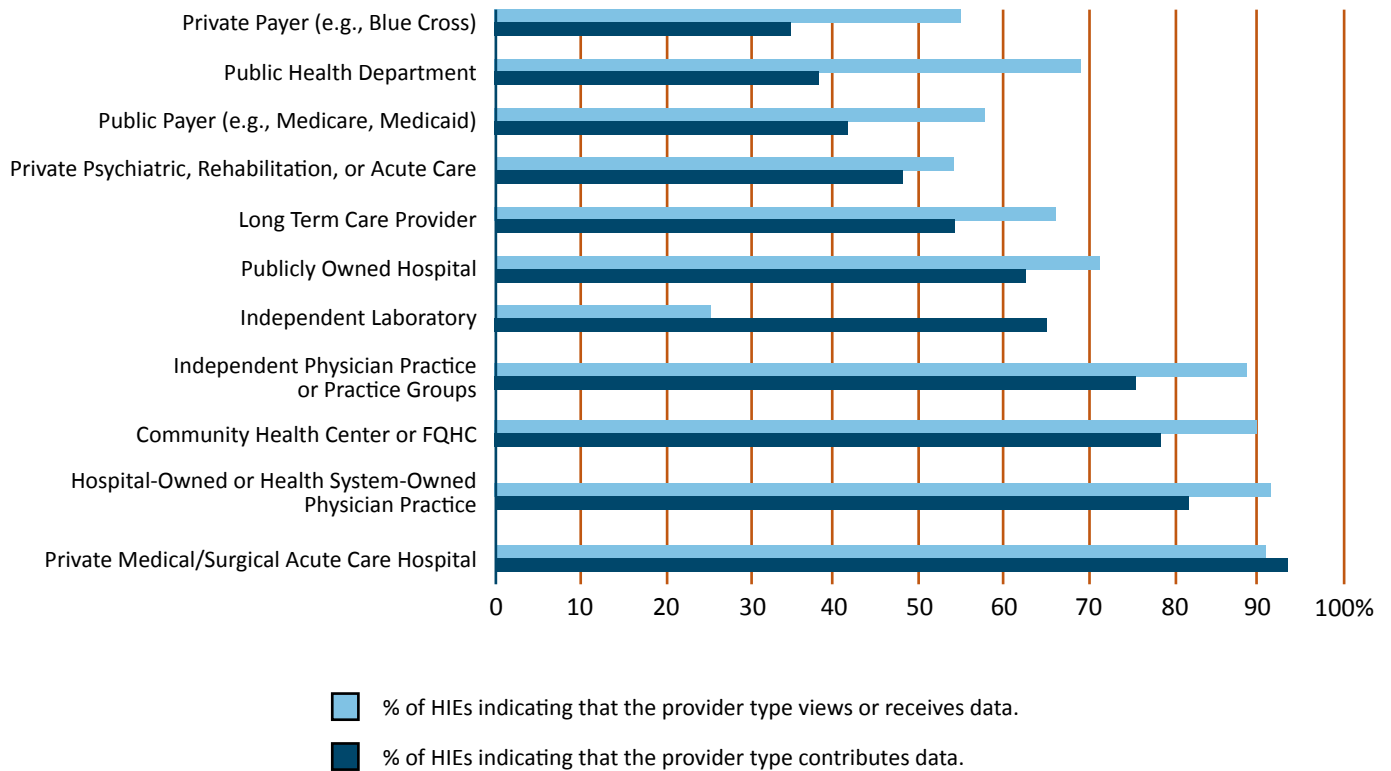


FIGURE 7. Percent of State and Community HIEs Indicating Data Viewing, Receipt, or Contribution by Provider/Other Participant Type, 2019



Source: Chart created with data from Adler-Milstein J, Garg A, Zhao W, Patel, V. “A Survey Of Health Information Exchange Organizations In Advance Of A Nationwide Connectivity Framework.” Health Affairs (2021).

**Note that these findings are not specific to vaccination data sharing.*

Payers

The number of immunization programs reporting that health plans submit data to the IIS are split. In AIM’s 2019 survey of immunization program managers,⁶¹ roughly half of immunization programs (49%, or 24/49) indicated that health plans contribute data to their IIS; the other half (47%, or 23/49) did not. Information moved from IISs to health plans through a variety of means: 13 of 34 (38%) immunization programs indicated that they provide IIS data to the health plans, eight (24%) provided reports, and 13 (38%) provided health plan access to the IIS.

Due to limitations of claims data or other available data sources, state Medicaid agencies may require access to IISs to enable reporting of immunization rates among Medicaid recipients to CMS. AIM’s 2019 survey found that 24 of the 49 immunization programs (49%) indicated that they currently share data with their state Medicaid agency. An additional eight respondents (16%, or 8/49) indicated that they were working to implement data sharing with their state Medicaid agency within the next year.⁶² HIEs are also connected to public and private payers, allowing them to view, receive, or contribute data (**Figure 7**). More HIEs indicated that public and private payers’ access of the HIE was for viewing and receiving data, rather than for reporting purposes.⁶³

Consumers

Historically, individuals have required access to immunization history for vaccine verification at the time of school entry, for employment purposes, or for sharing with a healthcare provider to include in a complete patient record. The COVID-19 pandemic has exacerbated the need for access to immunization records, as various public and private sector entities required proof of vaccination to access services or public spaces.

Consumer access to immunization records can look very different in each jurisdiction based on the options available. A 2022 AIRA survey⁶⁴ found that 28 IISs offer consumer access to immunization records directly through a consumer portal, with an additional four IISs offering this type of access for COVID-19 immunizations only. Many other jurisdictions were working on this functionality, with nine IISs in planning phases. A 2021 Civitas survey of HIEs⁶⁵ found that a minority (7%, or 3/41) provided individual or family access to electronic official immunization records. Other efforts initiated during the COVID-19 pandemic have provided additional pathways for consumers to access their immunization records. For example, the Verifiable Clinical Information (VCI™) initiative—a public and private coalition of clinical organizations, state governments, technology providers, and other partners—supports government agencies and clinical organizations in issuing verifiable vaccination credentials to consumers. VCI™ leverages SMART Health Cards to provide verified clinical information and offers an open-source, standardized framework for generating and verifying clinical information.⁶⁶

Federal Entities

One major limitation of vaccination data reporting and sharing is that federal entities are generally not tied to state laws or requirements for reporting to IISs or through HIEs. Military and VA hospitals and clinics do not always report immunizations to the jurisdiction's IIS or through HIEs. While CDC mandated that pharmacies and long-term care facilities receiving federal allocations of COVID-19 vaccine report all immunization data to the jurisdiction's IIS, the VA and DOD were not held to this same mandate. According to AIRA 2020 data, only 15 IISs reported receiving vaccination data from military or VA hospitals and clinics.⁶⁷ Efforts are underway to advance provider-to-IIS data exchange between VA facilities, DOD, and the Federal Bureau of Prisons via CDC's Immunization Gateway (IZ Gateway), which will improve data completeness within participating IISs. Our environmental scan did not yield data on participation of federal entities in HIEs.

Technical Factors

CDC uses its IIS Functional Standards to formalize technical and data standards for IISs, while HIEs generally conform to interoperability standards to exchange data. Differences between these standards, in addition to IIS and HIE adherence to standards, can influence readiness for connection and data exchange. Generally, IISs and HIEs have the best chance to benefit from each other if they: use the same vocabularies and coding systems among themselves and integral data exchange partners; maintain high quality data that is deduplicated and complete, particularly for data needed for record matching; and use a standard messaging format and transmission method for data exchange. In this section, we discuss IIS and HIE technical and data standards, adherence to standards, and actionable steps to improve IIS and HIE connectivity.

IIS and HIE Technical and Data Standards

CDC's IIS Functional Standards define the operational, programmatic, and technical capabilities that all IISs should achieve to capture complete, accurate, secure, and confidential data in a timely manner. The functional standards include infrastructure, such as collecting demographic information on the immunized population, data and system security, and data exchange. They also include goal-based functional standards, which tie specific functional standards to overarching immunization program goals.⁶⁸

Immunization programs work to align as closely as possible with CDC’s IIS Functional Standards for timely and accurate reporting of immunization data. If an HIE interacts with an IIS, it does so primarily as a transport mechanism for sending or receiving immunization data. If the HIE is not capable of meeting the standards used by an individual IIS, the jurisdiction might disallow connections through the HIE to avoid IIS data corruption.

CDC measures conformance to functional, technical, and data standards in the IISAR survey. The IISAR influences federal funding offered under the Section 317 program.⁶⁹ HIEs, on the other hand, braid and blend multiple public and private funding sources. HIEs respond to state or local market demand for their services, adopt interoperability standards to exchange data to meet privacy and security safeguards as developed by national or local standards, meet state-level regulations, and develop functionality based on exchange partner needs. Because HIEs can support multiple semantic and interoperability standards, and are capable of normalizing and transforming data, they can receive records in one format (e.g., consolidated clinical data architecture) and transform the data to meet required messaging formats for public health systems.

FROM THE FIELD: Concerns about Data Security Influence Pathways to Partnership

ASTHO’s focus group participants indicated that concerns about data security often posed more significant barriers to data sharing than technical issues did. Public and political sentiment regarding public health data collection, use, and sharing, and concerns about cyberattacks or data breaches contributed to internal and external hesitancy around data sharing. Data use agreements with strict parameters for data security and use were identified as a potential option for addressing security concerns.

The collection and secure storage of protected health information and personally identifiable information is necessary to achieve IIS and HIE integration. We assume its presence throughout the following section. In addition to collecting and securely storing data on immunizations, there are key IIS functional standards that improve the likelihood of collaboration with an HIE. They include:

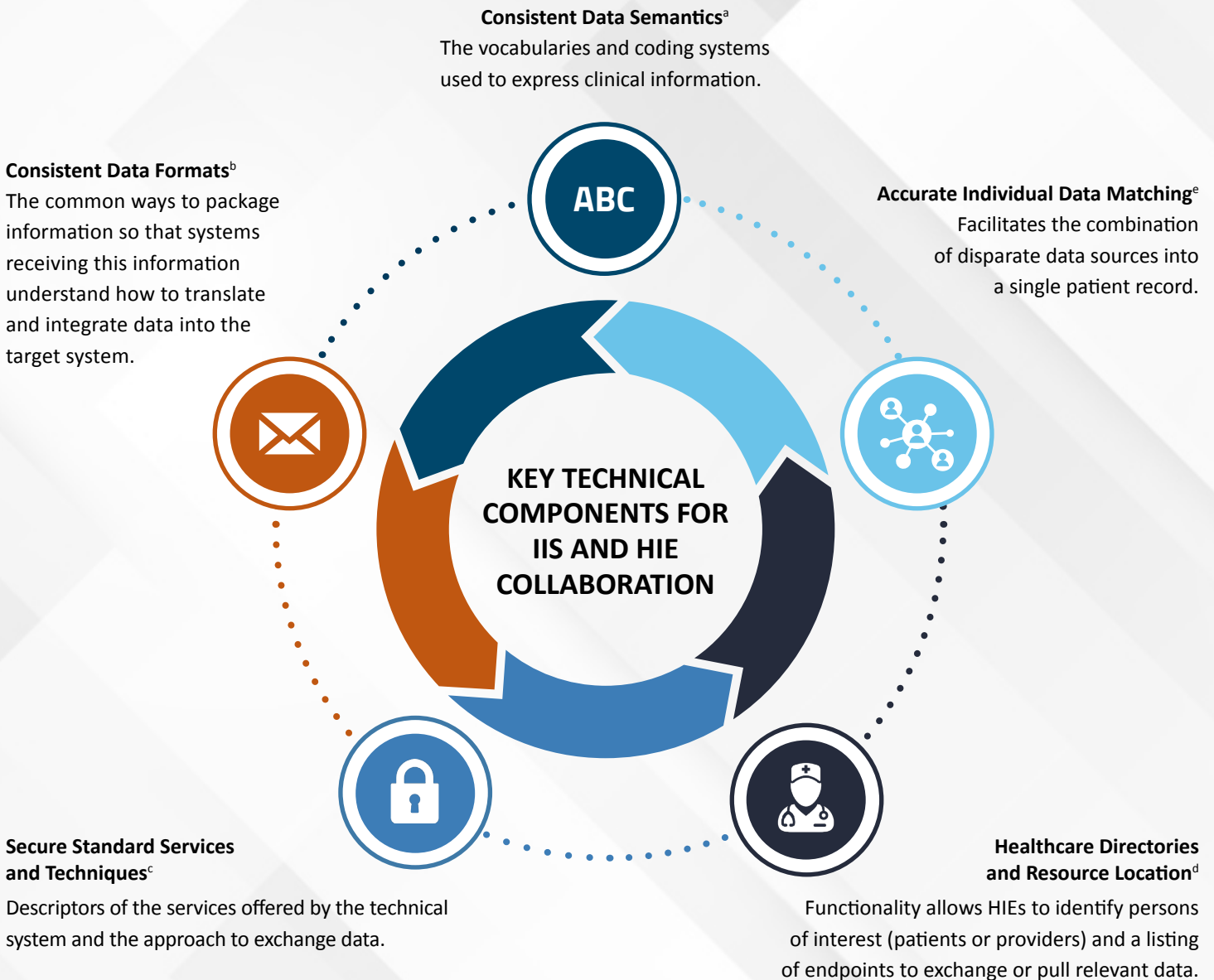
- Storing and ensuring the quality of data necessary for patient matching.
- Resolving duplicated and incomplete patient records.
- Exchanging data in accordance with interoperability standards. This includes implementing Simple Object Access Protocol (SOAP) standard Interface, Web Services Definition Language (WSDL), or other transport solutions as endorsed by CDC and following Health Level Seven (HL7) implementation guides.

CDC maintains a list of 68 endorsed data elements within two data domains: patient demographic or vaccine event.⁷⁰ If they pass data quality checks during testing and throughout production, these data elements must be stored in the IIS and can be supplemented by external sources, such as patient-level data coming from EHRs and/or HIEs.



Figure 8 describes technical components that are important for IIS and HIE collaboration, including consistent data vocabularies and formats, secure data exchange services, healthcare directories, and accurate data matching.

FIGURE 8. Key Technical Components for IIS and HIE Collaboration



^a **Consistent Data Semantics:** It is likely HIEs support common vocabularies and coding systems, such as SNOMED-CT and LOINC. It is less clear whether and to what extent they support CVX codes (the codes used to indicate the product used in a vaccination).

^b **Consistent Data Formats:** Both HIEs and IISs use HL7, although HIEs tend to use the latest versions, while IISs use varying versions depending on the availability of implementation guides or capabilities of provider systems. HIEs are more likely to use FHIR than IISs.

^c **Secure, Standard Services and Techniques:** IISs offer HL7 messaging and SOAP standards. Ideally, HIEs and IISs would align on data transfer protocols as they develop and mature.

^d **Healthcare Directories and Resource Location:** IISs can leverage HIE resources for moving data to augment IIS functionality, such as combining vaccination schedule forecasting with HIE messaging to operationalize immunization clinical decision support.

^e **Accurate Individual Data Matching:** HIEs passing information to an IIS must be able to submit all pertinent and correct information to an IIS and vice versa. This requires that both systems understand the primary keys for identifying individuals, either by passing necessary data for matching or leveraging a single unique person ID across systems.

*Technical component categories adapted from the Shared Nationwide Interoperability Roadmap.

Adherence to Technical and Data Standards

While IISs consistently use standard vocabularies and coding systems, certain demographic data may not be available or of high quality. For example, since demographic data comes from source systems and are not required elements to facilitate immunization reporting, providers—through their EHRs—can be onboarded to an IIS without these data. This leads to missing race, ethnicity, sexual orientation, and gender identity data. IISs vary in the degree to which they specify electronic reporting standards, formats, and platforms in laws and regulations. Some are prescriptive, requiring specific formats and versions of HL7 standards to be used for certain use cases, while others are determined locally and include older versions of HL7 or flat files. AIRA’s Measurement and Improvement Initiative, launched in collaboration with CDC in 2015, provides IISs with information and guidance to better align with the IIS Functional Standards. AIRA testing processes assess IIS capabilities through a three-stage process. Validation, the final summary stage, acknowledges and shares results for IISs as they progress toward alignment with community-selected standards and tests. The IIP Collaborative, working in coordination with CDC, is also supporting adoption of standard IIS protocols to support increased interoperability between IISs, EHRs, and HIEs.⁷¹ IISs offer transport and HL7 Query and Submission capabilities, but not all are in complete alignment with defined standards. As of 2022, the transport protocol, SOAP and WSDL, has been fully implemented in alignment with defined standards in 56 IISs. Query and response exchanges have been fully implemented in alignment with defined standards by 22 IISs. Submission and Acknowledgment exchanges have been fully implemented and aligned with defined standards by 45 IISs.⁷²

For HIEs, data and interoperability standards are noted in ONC’s Interoperability Standards Advisory. They are not required, however, to use these standards; as noted above, HIEs generally adapt to exchange partner requirements. While our environmental scan yielded information enumerating transmission formats in use by HIEs,⁷³ ASTHO did not identify sources characterizing HIEs’ adherence to specific technical or data standards.

Intra- and Inter-Jurisdictional Factors

IISs and HIEs are part of many geographies—economic, physical, and political—that strongly influence the formation and maintenance of, interactions between, and policies impacting these systems. While geopolitical (e.g., state and/or city-level) boundaries typically define the service areas of IISs, HIEs often operate regionally, and/or along specific healthcare system catchment areas.⁷⁴ This context creates complexities for IIS-HIE collaborations, as service areas covered by each do not always align. Communities can span across more than one jurisdiction or HIE service area, and populations are mobile. These factors underscore the importance not only of IIS-to-HIE coordination, but also IIS-to-IIS and HIE-to-HIE coordination—especially when tracking patients over time for multi-dose/booster vaccine delivery.

IIS and HIE Coverage and Service Areas

CDC’s 317 program funds 64 jurisdictions (50 states, eight territories, and six cities), and a total of 61 IISs operate within these jurisdictions.⁷⁵ Fifty-eight of those IISs are considered state/territory-wide systems. A 2019 survey of HIEs identified a total of 89 state and regional HIEs in the country, with 44 states reporting state-wide HIEs. The study also found that 81% (2,770/3,436) of U.S. health service areas fall within the catchment area of at least one HIE.⁷⁶ The distribution and service areas covered by IISs and state/regional HIEs are not 1:1, which may make it challenging for IIS leadership to determine the most appropriate HIE counterpart to prioritize for new partnership efforts.

Intra-jurisdictional Data Exchange

Within the bounds of the 317 program, two cities (New York City and Philadelphia) operate their own IISs within states that also run a state-level IISs. This dynamic complicates how these systems coordinate and communicate data within the state, as vaccine data captured in city IISs are not always represented in the state IISs. We see more overlap among HIE service areas than we do for IISs. The 2019 survey of state and community HIEs found that there was more than one HIE functioning in 32% of the U.S. health service areas, and more than half of HIEs (57%,) reported connections with another HIE in the same state.⁷⁷ This creates similar complexities for HIE-to-HIE exchange. Some states have used a “system of systems” approach, connecting HIEs within a given service region to facilitate improved coordination and data sharing. This approach may allow IISs to establish a one-to-many connection with HIEs, reducing the burden that would otherwise be associated with establishing multiple IIS-to-HIE connections, and increasing patient data available to the IIS.

Measures of Inter-jurisdictional Data Exchange

The 2019 CDC IISAR^{78,xii} captured inter-jurisdictional data exchange by surveying whether IISs exchange information electronically with other jurisdictions' IISs, consistent with the current CDC HL7 Implementation Guide.⁷⁹ Specifically, the survey assessed (a) whether the IIS sent at least one Query-by-Parameter message to another jurisdiction's IIS, and (b) whether the IIS sent at least one Vaccination Update message to another jurisdiction's IIS. The majority of IISs (82%, or 50/61) indicated they had not sent either type of message. Nine IISs (15%, or 9/61) confirmed they had sent both message types to IISs in other jurisdictions, and two systems (3%, or 2/61) reported they had only sent Vaccination Update messages. In 2022, 41% (25/61) of IISs engaged in IIS-to-IIS data exchange through the IZ Gateway.⁸⁰

A 2019 survey of state and community HIEs found that 53% of HIEs were connected to HIEs in other states.⁸¹ Increasingly, HIEs appear to be pursuing multi-state affiliations to better deliver services and reduce technical infrastructure and/or administrative costs. Additionally, there are national initiatives featured below that facilitate data exchange between HIEs within and across state lines.

National Initiatives Facilitating Intra- and Inter-jurisdictional Data Exchange

The IZ Gateway is a CDC-led initiative aimed at supporting IIS-to-IIS, IIS-to-provider, and IIS-to-consumer data exchange. During the COVID-19 pandemic, CDC leveraged the IZ Gateway to support immunization information exchange and improve IIS record completeness. Use of CDC's IZ Gateway requires legal agreements for different components of the infrastructure.⁸² According to data collected by CDC in 2020-2021, 48 IISs have a written agreement to engage with CDC's IZ Gateway project as of June 2021.⁸³ Planned enhancements to the IZ Gateway include launching a multi-jurisdictional query capability, which will enable providers to obtain consolidated immunization records for individuals that may have received immunizations in multiple jurisdictions. While the primary use cases for data exchange via the IZ Gateway focus on IIS-to-IIS, IIS-to-provider, and IIS-to-consumer information sharing, exploration of an IIS-to-HIE data exchange use case may be beneficial.

From the HIE perspective, Civitas's Patient Centered Data Home™ (PCDH) initiative aims to advance data exchange across HIEs by developing HIEs' capacity to retrieve an individual's data from across networks and push it back to a 'home' location for use later. Forty-five HIEs are participating in PCDH, though ASTHO did not identify the extent to which vaccination data is exchanged through this effort.⁸⁴

Finally, once operationalized, TECCA will support availability of baseline clinical information across the country. This will support the exchange of a core data package across HIEs, IISs, and other systems. The 2019 survey of state and community HIEs found that over half of HIEs (56%) reported that they planned to participate in TECCA, while 41% indicated that they were unsure of their participation.⁸⁵ ASTHO did not identify health department data describing plans to participate in TECCA, though CDC's involvement with ONC in co-developing an approach for public health to participate in TECCA may support IIS and other public health system adoption.

^{xii} 2019 IISAR data reported here, as the 2020 IISAR survey instrument did not collect information on this measure.



COVID-19-Specific Factors

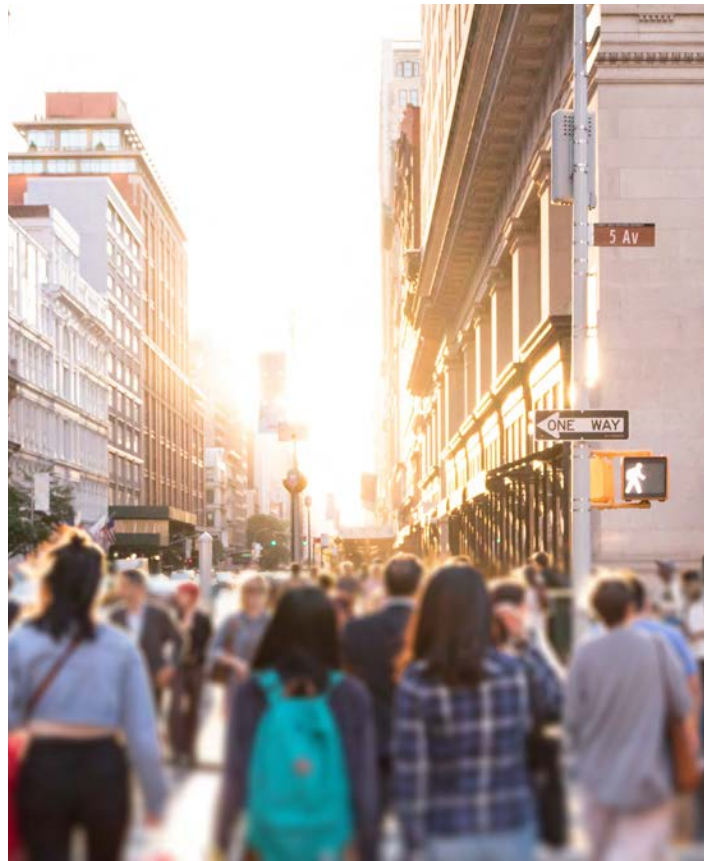
During the COVID-19 pandemic, IISs strived to accommodate new demands, while HIEs augmented services and partnership efforts with public health. Our environmental scan captured information on emergency response capabilities prior to COVID-19, roles in supporting pandemic response, and activities around supporting vaccine uptake in priority populations.

Emergency Response Capabilities Prior to COVID-19

Prior to the pandemic, health agency leaders recognized the role and importance of IISs in public health emergency response, though short-term plans to improve IIS capability to support emergency response varied across jurisdictions. In a 2019 AIM survey,⁸⁶ 80% of immunization programs (41/51) indicated that their IIS was used to practice emergency response procedures. Most immunization programs also reported that their IISs included several functionalities that support mass vaccination efforts, including: patient look-up and vaccine tracking (90%, or 46/51), reporting of vaccine doses administered (90%, or 46/51), and vaccine ordering and inventory management (80%, or 41/51).

Plans to improve IIS capabilities to support public health emergency response varied across jurisdictions, with 47% (25/53) of surveyed immunization programs indicating in the 2019 AIM survey that emergency response-related IIS improvements were in-progress or planned within the next 12 months, while 36% (19/53) indicated that no emergency response-related improvements were expected within that timeframe. While actual IIS improvements implemented during the COVID-19 pandemic likely varied from the distribution reported in 2019, these data nevertheless provide a useful pre-pandemic baseline for understanding immunization programs' intentions for emergency response-related system improvements leading up to the pandemic.

ASTHO's environmental scan did not yield national survey data characterizing the type and distribution of HIE emergency response capabilities prior to the pandemic. State and regional studies exploring how HIE services could support emergency response activities were conducted in the past decade, with particular focus on the role of HIEs in providing secure access to patient health records for individuals displaced from their medical home by natural disasters.^{87,88} A national assessment of HIE capabilities to support emergency response to emerging and high consequence infectious diseases may be useful in characterizing the potential roles and readiness of HIEs to support future public health emergencies.



IIS and HIE Roles in Supporting COVID-19 Response

IISs have a critical role in collecting and reporting timely, accurate, and complete data on COVID-19 vaccine administration. During the pandemic, IISs have been used to: (1) support vaccine ordering and inventory management, (2) track doses distributed and administered, (3) monitor storage unit temperature, and (4) record patient-level information on vaccine product and dose(s) administered.⁸⁹ According to data collected by CDC in 2020-2021, all IISs also contributed to CDC's public-facing COVID-19 Data Tracker [dashboard](#), in addition to supporting state, territorial, or other dashboard projects.⁹⁰ Data collected by IISs were used by state and local decision-makers to prioritize outreach activities and provided key metrics on the national status of the COVID-19 vaccination campaign.

HIEs have also supported pandemic response through a variety of activities involving immunization and other public health data. Key dimensions of HIE response efforts are described in **Table 3**. They include but are not limited to interventions related to immunization data.

TABLE 3. HIE Activities in Support of COVID-19 Response

<p>Facilitating Public Health Reporting</p>	<ul style="list-style-type: none"> • Serving as an intermediary between reporting providers and an array of public health data systems (e.g., IISs, electronic laboratory reporting systems, and syndromic surveillance). • Reducing the burden on public health by providing a one-to-many connection with providers.
<p>Augmenting Data Available to State Public Health Officials</p>	<ul style="list-style-type: none"> • Leveraging master patient indexes to match COVID-19 case data with other existing HIE data sources. • Closing the gap on incomplete race, ethnicity, and primary language data, enabling public health practitioners to tailor community outreach and monitor for inequities. • Adding contact information to support public health follow-up (e.g., for contact tracing, vaccine reminders). • Augmenting records with information on comorbidities for more complete individual health risk profiles. • Collecting and reporting data on healthcare facility capacity and resources (e.g., hospital bed availability, intensive care unit capacity, and ventilator usage).
<p>Partnering with Public Health to Generate COVID-19 Dashboards</p>	<ul style="list-style-type: none"> • Visualizing data on vaccine administration and inventory, COVID-19 cases, hospitalizations, healthcare facility bed capacity, etc. • Supporting identification of trends (e.g., upticks COVID-19 cases), and communities that may be at higher risk for severe disease (e.g., areas with low vaccine uptake and high hospitalization rates). • Integrating data sources to provide geographic visualizations of COVID-19 indicators that could be analyzed by race/ethnicity, age, comorbidities, Medicaid enrollment, social vulnerability indicators, etc.
<p>Expanding Access to Public Health Data</p>	<ul style="list-style-type: none"> • Sharing alerts and regular reports with healthcare providers regarding vaccination status of their patients, facilitating follow-up and completion of the COVID-19 vaccination series. • Delivering real-time alerts to providers and payers regarding COVID-19 test results. • Sending exposure notifications to emergency medical services personnel who provided care to patients with COVID-19.
<p>Providing Analytics and Infrastructure Support</p>	<ul style="list-style-type: none"> • Conducting ad hoc analyses for public health. • Monitoring data quality and working with state health agencies to reconcile issues. • Linking public health systems (e.g., Vaccine Administration Management System and IIS).

Source: "COVID-19 Success Stories for Health Information Exchanges" (2021), provided by ONC [unpublished].

Data to Identify Priority Populations for COVID-19 Immunization

AIM's 2019 survey asked immunization programs about current efforts and future plans to increase the use of IIS data, reports, and tools to identify pockets of low vaccine coverage.⁹¹ These activities can support health officials in identifying and tailoring vaccine education and outreach efforts in communities with low vaccine uptake. Just under half of the immunization programs (47%, or 25/53) confirmed they were currently working to increase the use of IIS data to identify areas with low vaccine coverage. Twenty-two programs (42%, or 22/53) indicated that they planned to begin doing so in the next year. Further data collection to determine how these efforts may have expanded due to COVID-19 may be of interest.

As described in **Table 3**, HIEs can augment the data available to better characterize populations with low vaccine uptake in addition to risk factors that might place individuals at higher risk for complications of COVID-19. Supplemental awardees of the STAR HIE program increased race/ethnicity data completeness by linking IIS data with HIE master patient indices. They also linked IIS data with other clinical datasets and developed risk algorithms to provide a better understanding of co-morbidities that might increase an individual's health risk profile.

The examples above demonstrate how IISs and HIEs leveraged routine functions and expanded capabilities to support data needs associated with the pandemic. The demonstrated value of successful IIS and HIE partnerships during the pandemic may pave the way for ongoing collaborative efforts in the future.



Critical Considerations for Health, Data, And Technology Leaders

Funding Considerations

- Explore pathways for expanding and sustaining investments to cover operating costs, enhance technical solutions, and advance deeper integration between IISs and HIEs.
- IIS and HIE collaborations may be further supported from the federal level through grants that promote public health and HIE partnerships via joint grant responses or aligned project objectives.
- Planning and implementation of funding opportunities, including Medicaid IAPDs and OAPDs, ONC funding, and CDC immunization grants should be aligned at the start of any new effort.



Legal and Regulatory Considerations

- Data sharing and access policies should be updated regularly and include explicit language for public health bidirectional data sharing uses beyond the COVID-19 public health emergency.
- Jurisdictions should work to align laws, regulations, and policies for sharing data to prevent unintended consequences of implementing systems or exchanges that do not comply with the regulations for all parties.
- Given the changing landscape, market, and conclusion of HITECH, HIE governance models should be assessed and adapted for a post-pandemic world, and potentially for greater public health utility.
- An updated assessment of policies impacting HIEs should be conducted. A review of how IIS and HIE reporting requirements align may be helpful in identifying areas where these systems can support public health reporting and reduce duplicate data entry for providers.
- It is essential to have regular communication between IIS and HIE teams regarding consent policies. Consent policies that apply to IISs should be incorporated into the workflow of the IIS-HIE relationship and be specific enough to allow any protected information to be only shared with those parties to whom consent was granted.

Data Utility Considerations

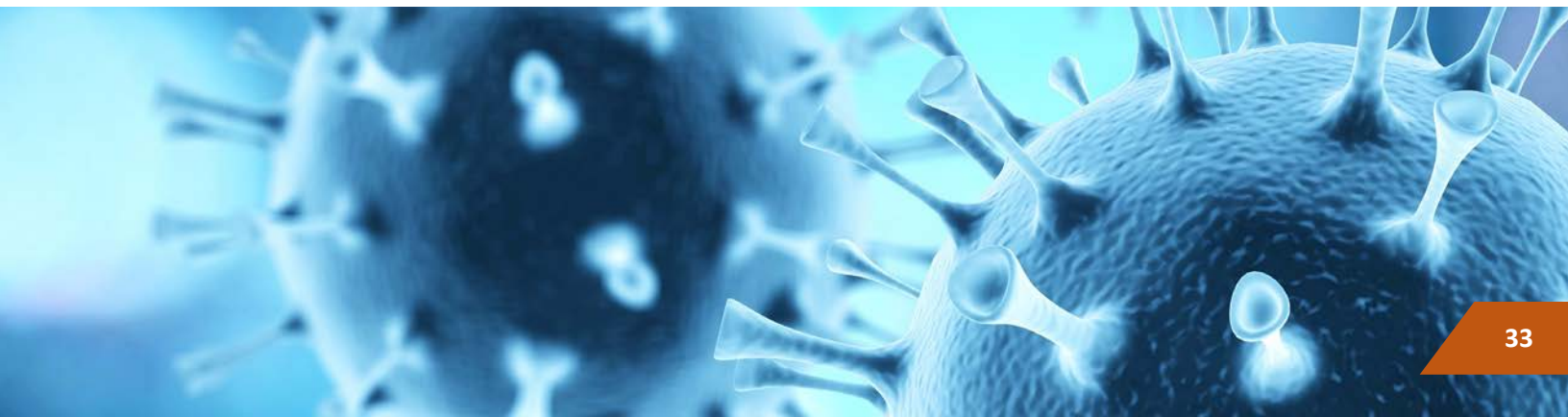
- Align data needs and data sharing activities for CDC reporting requirements, IIS program requirements, and treatment and quality improvement priorities of HIEs.
- Focus on data quality, data reconciliation, and analysis to address data discrepancies and data gaps, align data elements, and improve processes to deduplicate data.
- Assign responsibility to specific entities to perform data quality, data reconciliation, and analysis.
- Advance vaccination data interoperability by strengthening bidirectional sharing between HIE and IIS to (a) complete the patient health record, and (b) enable population-level data queries to help payers and health systems identify and close gaps in vaccination.
- A national assessment of HIE capabilities to support emergency response to emerging and high consequence infectious diseases may be useful in characterizing the potential roles and readiness of HIEs to support future public health emergencies.

Planning and Implementation Considerations

- Engaging end users is critical in the success of the implementation of new or updated systems. Front line staff using the IIS or the EHR connecting to the IIS/HIE will determine the overall success and feasibility of costly enhancements.
- Engage a wide set of partners to inform IIS improvements and HIE priorities to expand communication, buy-in, and awareness.
- Improve IIS access to federal vaccination data sources (e.g., federal pharmacy programs, long-term care/skilled nursing facilities, DOD, VA, Bureau of Prisons, Indian Health Services) to complete the immunization record. More standardized patient identifiers may also be needed to facilitate this integration.
- Enable data integration across public health registries and data systems (e.g., IIS, electronic laboratory reporting, vital statistics) for a more in-depth view into COVID-19 response.
- Define the roles and interactions between IISs, HIEs, CDC's IZ Gateway, and TECCA to identify and prioritize critical pathways for sharing immunization data.

Technical Considerations

- Harmonize semantic and data elements. HIEs, IISs, and data exchange partners such as laboratories, should review the data elements that they maintain, the business rules surrounding those data elements, and identify use cases that may expand how these code sets and data elements may be used under the U.S. Core Data for Interoperability (USCDI) standard for immunizations.
- Standardize transport mechanisms. Offering SOAP Web Services and/or CDC's WSDL is essential and when not implemented, can be problematic for IISs.
- Leverage testing process to improve data quality. Robust testing of interfaces prior to go-live is essential and helps ensure long-term high quality data flows to the IIS. Without proper testing, there is often a decline in data quality over time after the interface goes live.
- "Close the loop" by ensuring acknowledgment messages are transmitted back to the provider through the HIE.



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