

# Health Information Organizations' Role in Expanding Public Health Data Exchange: Results from a National Survey

Sarah Rosenthal, Julia Adler-Milstein, Vaishali Patel

Submitted to: JMIR Public Health and Surveillance  
on: August 01, 2024

**Disclaimer:** © The authors. All rights reserved. This is a privileged document currently under peer-review/community review. Authors have provided JMIR Publications with an exclusive license to publish this preprint on its website for review purposes only. While the final peer-reviewed paper may be licensed under a CC BY license on publication, at this stage authors and publisher expressly prohibit redistribution of this draft paper other than for review purposes.

Table of Contents

Original Manuscript..... 4

Supplementary Files..... 21

Figures ..... 22

Figure 1..... 23

Figure 2..... 24

Figure 3..... 25

Figure 4..... 26

Figure 5..... 27

# Health Information Organizations' Role in Expanding Public Health Data Exchange: Results from a National Survey

Sarah Rosenthal<sup>1</sup> BA; Julia Adler-Milstein<sup>1</sup> PhD; Vaishali Patel<sup>2</sup> PhD

<sup>1</sup>Division of Clinical Informatics and Digital Transformation University of California, San Francisco San Francisco US

<sup>2</sup>Technical Strategy and Analysis Division Office of the National Coordinator for Health IT Washington US

## Corresponding Author:

Sarah Rosenthal BA  
Division of Clinical Informatics and Digital Transformation  
University of California, San Francisco  
10 Koret Way, Rm 301  
San Francisco  
US

## Abstract

**Background:** The COVID-19 pandemic revealed major gaps in public health agencies' (PHAs) data and reporting infrastructure which limited public health officials' ability to conduct disease surveillance, particularly among racial/ethnic minorities disproportionately affected by the pandemic. Leveraging existing Health Information Exchange Organizations (HIOs) is one possible mechanism to close these technical gaps as HIOs facilitate health information sharing across organizational boundaries.

**Objective:** To assess current HIO connectivity with PHAs and HIOs' capabilities to support public health data exchange.

**Methods:** We conducted a nationwide survey of all HIOs in 2023 to capture current and potential support for PHAs. We report descriptive statistics on services and data available to support PHAs, funding sources, and barriers to public health reporting.

**Results:** Of the 135 HIOs that received the survey, 90 were determined to be eligible, and 77 completed the survey, yielding an 86% response rate. Of the 66 (86%) of HIOs in 45 states electronically connected to PHAs. Among HIOs connected to PHAs, the most common public health reporting supported by HIOs was immunization registry (64% of HIOs), electronic laboratory result (63%), and syndromic surveillance (61%). 58% of HIOs connected to PHAs provided data to address COVID-19 information gaps, and 64% provided at least one type of data analytic service to PHAs to support COVID-19 pandemic response. Top HIO reported barriers to support PHA activities included limited PHA funding (32% of HIOs) and PHAs' competing priorities (23%).

**Conclusions:** Our results show that many HIOs are already connected to PHAs and that they are assuming an emerging role to facilitate public health reporting. HIOs are well-positioned to provide value-added support for public health data exchange and address PHA's information gaps as ongoing federal efforts to modernize public health data infrastructure and interoperability continue.

(JMIR Preprints 01/08/2024:64969)

DOI: <https://doi.org/10.2196/preprints.64969>

## Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**

Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.  
Only make the preprint title and abstract visible.

No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain visible to all users.  
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in [http](#)

## Original Manuscript

## Health Information Organizations' Role in Expanding Public Health Data Exchange: Results from a National Survey

### Abstract

**Background:** The COVID-19 pandemic revealed major gaps in public health agencies' (PHAs) data and reporting infrastructure which limited public health officials' ability to conduct disease surveillance, particularly among racial/ethnic minorities disproportionately affected by the pandemic. Leveraging existing Health Information Exchange Organizations (HIOs) is one possible mechanism to close these technical gaps as HIOs facilitate health information sharing across organizational boundaries.

**Objectives:** To assess current HIO connectivity with PHAs and HIOs' capabilities to support public health data exchange.

**Methods:** We conducted a nationwide survey of all HIOs in 2023 to capture current and potential support for PHAs. We report descriptive statistics on services and data available to support PHAs, funding sources, and barriers to public health reporting.

**Results:** Of the 135 HIOs that received the survey, 90 were determined to be eligible, and 77 completed the survey, yielding an 86% response rate. Of the 66 (86%) of HIOs in 45 states electronically connected to PHAs. Among HIOs connected to PHAs, the most common public health reporting supported by HIOs was immunization registry (64% of HIOs), electronic laboratory result (63%), and syndromic surveillance (61%). 58% of HIOs connected to PHAs provided data to address COVID-19 information gaps, and 64% provided at least one type of data analytic service to PHAs to support COVID-19 pandemic response. Top HIO reported barriers to support PHA activities included limited PHA funding (32% of HIOs) and PHAs' competing priorities (23%).

**Conclusion:** Our results show that many HIOs are already connected to PHAs and that they are assuming an emerging role to facilitate public health reporting. HIOs are well-positioned to provide value-added support for public health data exchange and address PHA's information gaps as ongoing federal efforts to modernize public health data infrastructure and interoperability continue.

## Introduction

The ability to collect and analyze timely and complete data is essential to public health efforts to control disease outbreaks. The COVID-19 pandemic revealed major gaps in public health agencies' (PHAs) data and reporting infrastructure. These included outdated information systems, insufficient technical expertise (particularly due to staff turnover), and lack of reporting standards and submission templates.<sup>1-3</sup> Such shortcomings limited public health officials' ability to conduct disease surveillance, particularly among racial/ethnic minorities disproportionately affected by the pandemic.<sup>4</sup> In response, the Centers for Disease Control and Prevention (CDC) expanded the Data Modernization Initiative (DMI), a multi-year, multi-billion-dollar effort to increase PHAs' access to better, more timely, and actionable data to improve health equity and to protect public health.<sup>5</sup>

A key priority of DMI is to "accelerate data into action," which involves addressing gaps in public health data, reducing the complexity of exchange, and providing more actionable, timely data.<sup>5,6</sup> One mechanism to accomplish this could be leveraging existing Health Information Exchange Organizations (HIOs). These entities were established over the past decade to facilitate health information sharing across organizational boundaries, and some have created large repositories of data that are relevant to public health reporting, which could help address gaps in health equity-related information. Furthermore, HIOs could be strong partners for PHAs because they typically operate as state, local, or regional entities with a deep understanding of and experience with local health care environments. HIOs may be well-positioned to actively support electronic reporting to PHAs, improve data quality, and produce unique insights on a community's longitudinal health and specific trends, particularly within disadvantaged populations through combining clinical and demographic data.

Federal policy has sought to decrease PHAs' burden related to data exchange by enabling connections with an array of providers through health information networks, rather than relying on one-to-one connections with each individual provider. During the COVID-19 pandemic, Office of the National Coordinator for Health IT's (ONC) Strengthening the Technical Advancement and Readiness of Public Health via Health Information Exchange Program (STAR HIE Program) enabled HIOs to develop services to support PHAs' need for timely and quality information.<sup>7</sup> Relatedly, the COVID-19 Immunization Data Exchange, Advancement, and Sharing (IDEAS) Program provided financial and technical assistance to connect HIOs and state health agency immunization information systems.<sup>8,9</sup> Looking beyond the pandemic, efforts are now focused on health information networks' participation in the Trusted Exchange Framework and Common Agreement (TEFCA). TEFCA is a national framework that has developed baseline governance, legal, and technical requirements to enable secure information sharing across different networks nationwide.<sup>10</sup> Public health is among the six exchange purposes currently authorized under TEFCA, and there are plans to support specific types of public health reporting, such as electronic case reporting, and to facilitate exchange between PHAs, directly supporting CDC's DMI efforts.<sup>11</sup>

To generate an understanding of the current state and future potential of HIOs to support PHA needs, we conducted a national survey of HIOs to assess: (1) current connectivity between HIOs and PHAs, including participation in TEFCA; (2) services provided to facilitate public health reporting; (3) services provided to support PHAs' COVID-19 response; (4) how HIOs address information gaps for PHAs; (5) HIO funding sources to support public health services; and (6) HIO-reported barriers to supporting PHAs. Our results serve to inform how the CDC's DMI and TEFCA can better engage HIOs to achieve their objectives.

## Methods

### Identifying HIOs

We sought to survey all local, regional, and state HIOs operating in the United States and its territories that supported live electronic health information exchange across their network as of March 1, 2022, and that facilitated exchange between independent entities (defined as institutions with no financial relationship with exchange occurring between entities where at least one is independent of the others). To build our distribution list, we relied on contacts compiled from previous national surveys conducted by our research team biennially between 2007 and 2019. We then worked with Civitas Networks for Health (Civitas), which is a national HIO member organization with more than 50 HIOs, to update the distribution list. Our final list consisted of 135 potential HIOs. To be consistent with previous years, we did not include HIO networks led by single vendors or a consortium of vendors, such as Epic's Care Everywhere Network or the CommonWell Health Alliance.

### Survey Instrument Development

We started with the survey instrument fielded in 2019 and added a new section that captured public health reporting capabilities. The updated instrument consisted of screening questions to determine eligibility to participate in the survey followed by five sections: Organizational Demographics, Public Health Reporting, Implementation and Use of Standards, Network-to-Network Connectivity and TEFCA, and Information Blocking. *Screening questions* asked respondents to determine whether, as of March 1, 2022, the organization was supporting operational electronic health information exchange among independent entities. Respondents whose organizations met these criteria were prompted to complete the rest of the survey. The *organizational demographics section* captured general HIO characteristics such as the types of services provided, governance details, number of unique individuals within their master patient index (MPI), and geographic coverage. For geographic coverage, we first asked in which state(s) the HIO operated. For each state that they indicated, we asked which health service area(s) (HSAs) the HIO covered. In the *network-to-network connectivity and TEFCA section*, we asked about plans to participate in TEFCA – planning, unsure, or not planning – and their participants' abilities to fulfill exchange purposes included in TEFCA (government benefits determination, public health, payment, treatment, health care operations, and individual access).

The new *public health section* first asked if the HIO was currently connected to any PHA. We defined connectivity as a PHA providing data to and/or receiving data from the HIO. Those not connected to any PHA did not. If they were connected to a PHA, they were asked to list the specific PHA(s) that they were connected to (with a maximum of 5 entities that could be listed); the type of PHA (state, local/county, or other); and describe the nature of the connection(s) (provides data, receives data, or bi-directional). We then asked HIOs to report the status – in production, in testing or planning, available but PHA not able/willing, or not available – of services to providers to facilitate reporting to PHAs and services provided to PHAs to support COVID-19 response efforts (seven total – e.g., dashboarding, outbreak monitoring and alerting). We also asked what types of data HIOs provided to supplement data reported to PHAs (eight total – e.g., hospital lab results, race/ethnicity), funding sources for public health data exchange (seven total – e.g., participant fees, federal funding), and barriers to supporting public health reporting (eleven total – e.g., PHA lacks staffing, limited funding from HIO participants). For each of the eleven barriers listed, HIOs were asked to report the extent to which they experienced it – ranging from “not at all” to “to a great extent”. (For this paper, we did not use questions in the remaining two sections – Standards and Information Blocking.)

We completed two rounds of pilot testing (first with four HIOs and then with three HIOs), refining

the survey based on their input after each round. A Microsoft Word version of the final survey instrument is available in the Appendix.

## Survey Administration

We fielded the survey via an online platform between January and July 2023, sending the survey to the director of each HIO, the respondent from previous HIO surveys, or the person in the organization indicated by the contact confirmation form (fielded one month before the survey asking the respondent from the 2019 survey if they were still the correct respondent for the survey and if not, to please list an alternate). We offered respondents a financial incentive (a \$50 gift card if they completed the entire survey; \$10 gift card if they answered the screening questions but screened out). Non-respondents received a minimum of five follow-up email messages and one phone call.

Of the 135 organizations that received the survey, 45 were determined to be ineligible as they no longer were operational, did not pursue live health information exchange, did not facilitate exchange between independent entities, or had merged with another HIO. Of the 90 remaining HIOs that met our inclusion criteria, 77 completed the survey, resulting in an 86% response rate. This response rate is consistent with prior HIO surveys.<sup>12-17</sup>

## Analysis

We conducted descriptive analyses limited to the HIOs that reported being connected to at least one PHA. First, we produced descriptive statistics on the number of unique individuals HIOs reported in their MPI, as well as the total (not de-duplicated) number of individuals across all HIOs. Next, to assess the connectivity between HIOs and PHAs, we counted the total number of connections they reported (within the maximum of five PHA connections). We examined the type of connection both at the HIO-level (e.g., the percent of HIOs that had a bi-directional connection with a PHA) and the HIO-PHA dyad-level (e.g., the percent of total connections that were bi-directional). Third, to assess geographic coverage, we combined HIO-PHA connection dyads with data on the states HIOs reported operating in. For HIOs that operated in multiple states, we manually coded the correct state based on the name of the PHA listed. We then created a map depicting the density of these connections using counts of HIO-PHA connections aggregated by state.

Lastly, we produced descriptive statistics for responses to questions on: (1) services to facilitate public health reporting to PHAs; (2) services provided to PHAs to support COVID-19 response efforts; (3) availability of data to address pandemic-related and health equity-related information gaps; (4) plans to participate in TEFCA and the percent of HIOs whose participants were currently able to make or respond to requests for information related to public health, as defined by TEFCA; (5) funding sources to support public health reporting; and (6) barriers to public health reporting. To describe barriers to public health reporting, we reported on the percent of HIOs that experienced the barrier “to a great extent”.

## Results

### Characteristics of HIOs Electronically Connected to PHAs

We found that 66 (86%) of HIOs were electronically connected to a PHA (i.e., at least one PHA provides data to and/or receives data from the HIO). On average, HIOs connected to PHAs reported that they had over 9 million individuals within their MPI which assigns patients a unique identifier to enable electronic exchange and is an indicator of HIO size (Table 1). Together, HIOs that were connected to PHAs had a total of 539 million individuals in their MPIs, reflecting overlap in individuals across MPIs.

Table 1. HIO Connections with PHAs and Broader Networks.

Demographics for HIOs Connected to PHAs		
Number of public health connections for those with at least one connection (Max.: 5 connections)	Mean: 3.06 Median: 3.00	
Number of individuals in MPI for those with at least one connection	Mean: 9,628,424 Median: 5,500,000	
	N	%
State vs. Local/County PHA Connections N=66 HIOs connected to at least one PHA		
Only state	32	48
Only local	7	11
Both state and local	27	41
PHA-HIO Exchange Connection at the HIO-level (N=66 HIOs connected to at least one PHA)		
Bi-directional exchange with at least one PHA	52	79
HIO receives data from PHA only	4	6
HIO sends data to PHA only	10	15
PHA-HIO Exchange Connection at the dyad-level (N=187 total connections between HIOs and PHAs)		
Bi-Directional exchange	85	45
HIO receives data from PHA only	30	16
HIO reports data to PHA only	72	39
TEFCA Network Participation N=66 HIOs connected to at least one PHA		
Plan to participate in TEFCA	41	62
Plan to participate in TEFCA and have the capability to address the TEFCA public health use case	34	52

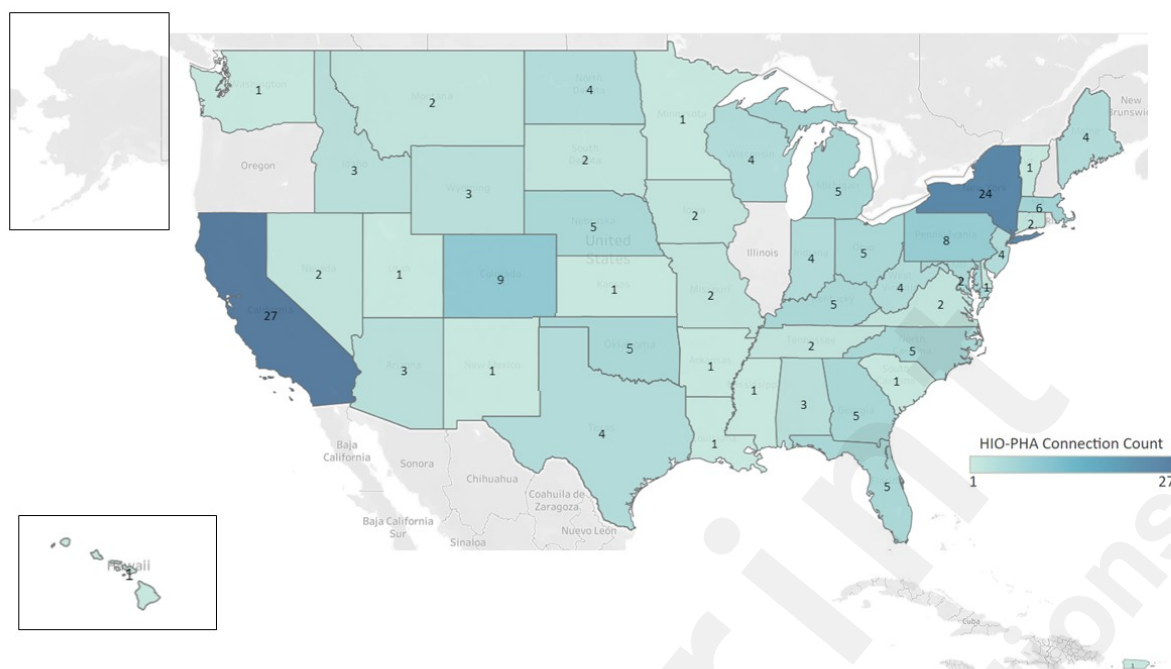
## Connectivity between HIOs and PHAs

Each HIO had on average three connections to state or local PHAs, yielding a total of 187 HIO-PHA connections across all HIOs. Almost half (48%) of HIOs were connected only to state PHAs, with 41% connected to both state and local PHAs and 11% connected only to local PHAs. Most HIOs (79%) had bi-directional exchange in place with at least one PHA (Table 1). When examining this based on the 187 HIO-PHA connections, 45% involved bi-directional exchange.

Forty-five states as well as Puerto Rico and Washington D.C. had at least one connection between an HIO and a PHA (Figure 1). California and New York had the most HIO-PHA connectivity, with the largest number of operating HIOs (11 and 7, respectively) and 27 and 24 HIO-PHA connections, respectively.

Figure 1. Map of HIO-PHA Connections. Note: N=187; N=12 “Other” Connections (e.g., federal, registry, unspecified). Certain states (such as NY and CA) with high numbers of operating HIOs may

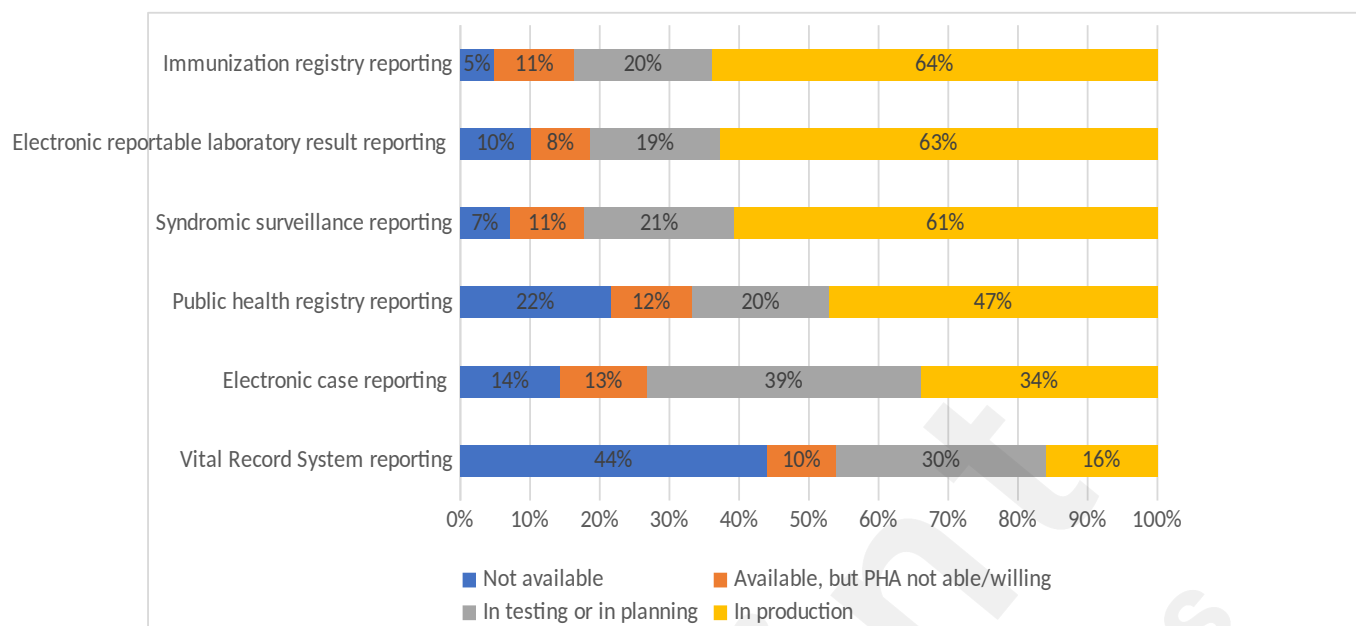
have more connections.



## Services Provided by HIOs for Public Health Reporting and COVID-19 Response

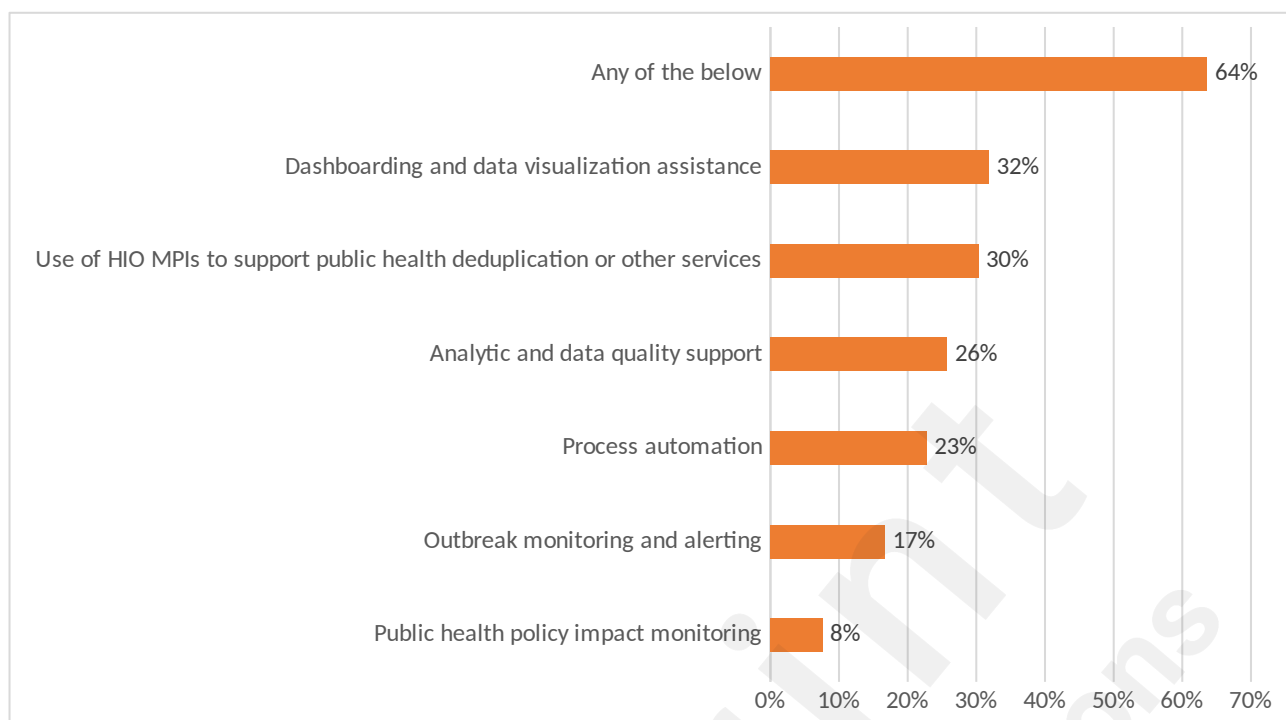
HIOs' provision of services to enable their participating providers to electronically report public health data to PHAs varied by type of reporting (Figure 2). The most common types of public health reporting currently in production by HIOs were immunization registry reporting (64% of HIOs), electronic laboratory result reporting (63%), and syndromic surveillance reporting (61%). An additional 19-21% of HIOs were in the planning or testing phases for these public health reporting activities. Although fewer HIOs were currently in production with electronic case (34%) or vital record system reporting (16%), additional HIOs reported being in the testing or planning stages with these types of reporting.

Figure 2. Services Offered to Participating Healthcare Providers to Support Public Health Reporting (N=66 HIOs).



In addition to supporting public health reporting between health care providers and PHAs, HIOs provided additional services to PHAs to support COVID-19 response. Almost one-third (32%) of HIOs connected to PHAs provided dashboards or other visualization services, 30% used their MPI to support deduplication of public health data, and 26% provided analytic and data quality support to PHAs (Figure 3). The least commonly provided services to PHAs related to outbreak monitoring and alerting (17%) and public health policy impact monitoring (8%). Overall, about two-thirds of HIOs (64%) connected to PHAs provided at least one of these services to PHAs.

Figure 3. Services Provided to PHAs to Support COVID-19 Response (N=66 HIOs).



## Addressing Gaps in Information

Most HIOs indicated that they currently provided data to address PHA gaps in missing information related to COVID-19 reporting (58%) or could do so (30%) (Table 2). Among those HIOs that currently provided data to PHAs to address gaps in information, a majority (81%) reported that PHAs often electronically received or queried these types of data. Of those HIOs that did or could provide data, available data elements included: hospitalization information (93%), demographic information other than race/ethnicity (91%), health information (88%), hospital lab results (88%), race/ethnicity data (86%), and updated contact information (86%).

Table 2. Addressing Pandemic-Related and Health Equity-Related Information Gaps (N=66 HIOs).

Provision of data to PHA(s) to fill gaps in COVID-19-related data (e.g., missing demographic information)		
	N	%
Yes	38	58
No but could do so	20	30
No and could not do so	1	2
If yes or could do so, what types of data are or could be provided?		
Hospitalization information	54	93
Other demographics	53	91
Health information (e.g., chronic health conditions)	51	88
Hospital lab results	51	88
Race/ethnicity	50	86
Updated contact information	50	86

Commercial lab results	46	79
Immunization data	41	71
Other	4	7
Among HIOs providing data to PHAs to fill gaps in COVID-19 related data (N=38), frequency of PHA(s) electronically receiving or querying these types of data.		
Often	31	81
Sometimes	6	16
Rarely	1	3
Never	0	0

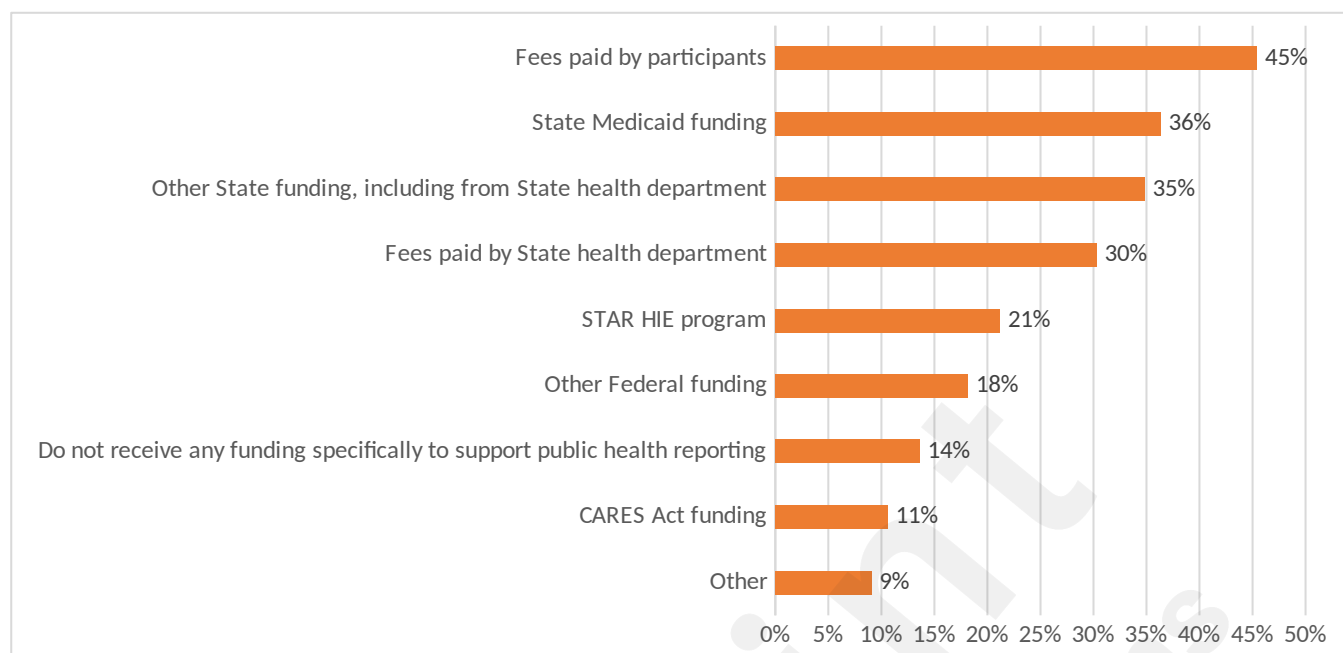
## TEFCA Participation

Almost two-thirds of HIOs connected to PHAs (62%) planned to participate in TEFCA, and over half (52%) both planned to participate and had the capability for the TEFCA public health exchange purpose, as measured by their participants' ability to make or respond to public health related requests for information (Table 1).

## Funding Sources

HIOs reported three main funding sources to support their services to PHAs: participant fees, state and federal grants. While HIOs most cited participant fees (which could include PHAs if they participated in the HIO) as a funding source (45%), state funding represented another major source, with 36% of HIOs using State Medicaid funding, 35% using other State funding, and 30% reporting fees paid by the state to support the services they provided to PHAs (Figure 4). Federal sources of funding included the STAR HIE program (21%), CARES Act funding (11%) and other federal sources (18%).

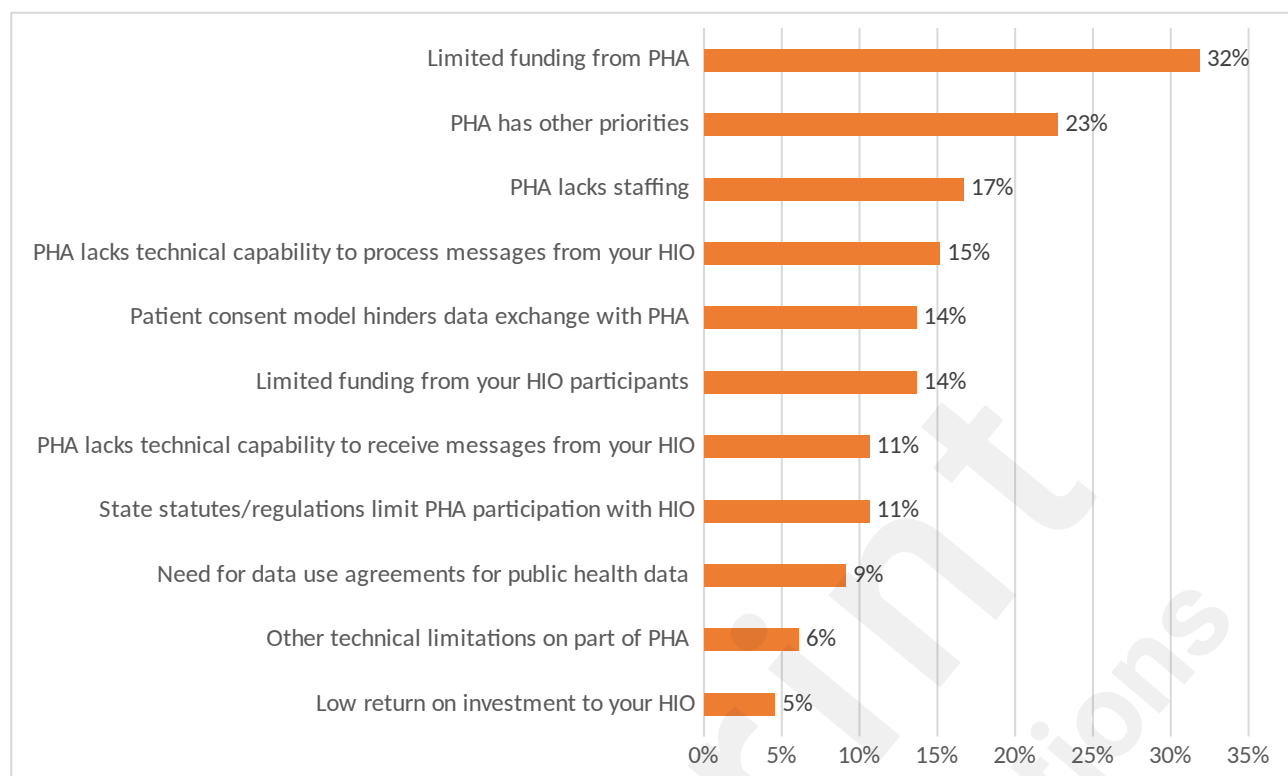
Figure 4. Funding Sources for Public Health (N=66 HIOs).



## Barriers to Supporting PHAs

32% of HIOs cited limited funding from PHAs as a barrier to public health reporting “to a great extent,” and 14% cited limited funding from their participants (Figure 5). HIOs also indicated PHAs’ other priorities (23%) and lack of staffing (17%) as barriers. This was followed by PHAs lacking the technical capability to process (15%) and receive (14%) messages from the HIOs.

Figure 5: HIO Reported Barriers to Public Health Reporting. Note: Percentage of HIOs that reported experiencing the barrier to “a great extent” (N=66).



## Discussion

Our study captures timely national data on HIO support for PHAs. Based on our results, HIOs appear to be providing value-added services that could be expanded to further support public health data exchange needs as PHAs modernize their infrastructure. We found that a majority of HIOs were connected to at least one state or local PHA across most states within the U.S. Among HIOs connected to PHAs, about half enabled or planned to enable public health reporting between health care providers and PHAs, and over half provided services to PHAs that addressed gaps in information and supported data analytics. However, barriers to further expanding their support likely need to be addressed to surpass the current level of engagement.

We found that the type and nature of the HIO-PHA connections varied. HIOs reported fewer connections to local PHAs, and only half reported bi-directional exchanges across their broader set of PHA connections. These findings suggest that there is a need to expand the degree of connectivity across existing connections to increase bi-directional exchange and expand local PHA connections. Plans to participate in TEFCA among those connected to PHAs was high, suggesting that these HIOs could help support public health data exchange through this mechanism as TEFCA expands.

A primary though still nascent role that HIOs connected to PHAs serve is enabling public health reporting between participating health care providers and PHAs, particularly related to reportable laboratory results, syndromic surveillance, and immunization reporting. The provision of these services will likely expand given that some HIOs reported these types of reporting are in testing or planning phases, and only few reported inability or lack of willingness on the part of PHAs to engage with them. The ONC IDEAS program, which specifically sought to establish and scale sharing of vaccine data between state immunization information systems and HIOs, may have helped HIOs support immunization exchange, which was the most frequent type of public health reporting.

Given HIOs' access to millions of records in their MPIs and shared data from their participants, leveraging these data for a variety of public health purposes is promising. About two-thirds of HIOs connected to PHAs supported at least one type of data analytic service, such as dashboards, and processing of data, such as deduplication through use of their MPIs. For example, a Maryland HIO linked COVID-19 electronic laboratory reports to their MPI to support outbreak investigations.<sup>18</sup> In Indiana, the statewide HIO supported public health surveillance and response by sharing timely, accurate data via a population level dashboard.<sup>19</sup>

HIOs' MPIs and shared data from participants was also leveraged to address data gaps. Most HIOs connected to PHAs reported they currently or could provide data to fill gaps related to key clinical information such as hospitalization data, along with demographic information, including race/ethnicity and contact information. These latter data were key pieces of information that PHAs were often missing, impeding their response to the pandemic, particularly for marginalized populations, and may help the CDC's DMI effort to improve the collection of equity-related data.<sup>20</sup>

While HIOs' current capabilities to support PHAs are encouraging, they indicated several barriers to doing so. HIOs' reported that the primary funding for public health reporting came from participant fees and state funding. Yet one-third of HIOs cited limited funding from PHAs and HIO participants as major barriers to enabling public health reporting. Although about one-fifth of HIOs relied on STAR HIE program and, to a lesser extent, the Cares Act to support public health reporting activities, these federal funding sources are no longer available. Findings from an evaluation of the original STAR HIE Program grantees showed that funding not only helped HIOs build capabilities to support public health use cases but also incentivized partnerships between HIOs and PHAs that would extend to future collaborations.<sup>21</sup> In its absence, funding from CDC's DMI program may help sustain and expand HIOs support for public health reporting, and other services.

Other barriers cited by HIOs relate to PHA capacity to engage in electronic public health reporting, including a limited workforce, competing priorities, and technical capabilities to process and receive messages from HIOs. To address staffing issues, both CDC and ONC have programs that seek to bolster the public health workforce.<sup>22,23</sup> The ONC program has provided \$75 million to educational institutions seeking to increase the number of public health professionals trained in public health and informatics, particularly among underrepresented communities. While PHAs understandably dealt with many competing priorities during the pandemic along with outdated IT systems, CDC's DMI and other public health infrastructure grants are providing substantial resources to PHAs to advance their health IT infrastructure to enable data exchange and analytics.<sup>23-25</sup> Recently proposed regulations call for updating standards used to exchange public health data in both EHR systems and public health data systems, which if implemented would bolster the capabilities of these systems to support the seamless exchange of public health data through HIOs and other networks.<sup>26,27</sup> Only a minority of HIOs cited barriers related to patient consent models, and state laws or regulations hindering connections between HIOs and PHAs. However, inconsistencies in consent requirements between what can be shared with a PHA without patient consent versus what can be shared with a HIO, particularly in states requiring opt-in consent for HIOs can be complex.<sup>9</sup> As these federal initiatives are implemented, it will be important to track to what degree they address the identified barriers and increase HIO-PHA engagement on public health reporting and analytics.

## Limitations

Our study has several limitations. HIO survey data are self-reported and are not independently verified. Reporting bias may overestimate the degree to which support for public health reporting

and other data exchange is occurring. However, due to our 86% response rate and the restricted the number of PHAs to which HIOs could report being connected, we likely underestimate the number of individual HIO-PHA connections. Additionally, our findings are from the HIO perspective and do not capture the perspective of their connecting PHA partners. PHA perspectives on the barriers, connectivity and services provided by HIOs would be valuable to gain a complete understanding of the role of HIOs in enabling public health data exchange.

## Conclusion

Our findings reveal that many HIOs already have connections with PHAs and that they are assuming an emerging role to both facilitate data exchange between health care providers and PHAs, and to help PHAs directly by addressing gaps in information and providing analytic services. Many HIOs that are connected to PHAs also plan to participate in TEFCA and could further enable public health data exchange through that mechanism. Modernization of the public health data systems and the informatics training of the public health workforce may reduce some key barriers to fostering greater partnership between PHAs and HIOs. Concerns regarding HIOs' ability to sustain and further expand their efforts to facilitate PHA connectivity will need to be addressed as efforts are made to further advance public health data exchange nationwide.

## **Bibliography**

1. Basit MA, Lehmann CU, Medford RJ. Managing Pandemics with Health Informatics: Successes and Challenges. *Yearb Med Inform.* 2021;30(1):17-25. doi:10.1055/s-0041-1726478
2. Jiang J (Xuefeng), Cram P, Qi K, Bai G. Challenges and dynamics of public health reporting and data exchange during COVID-19: insights from US hospitals. *Health Affairs Scholar.* 2024;2(1):qxad080. doi:10.1093/haschl/qxad080
3. Baker M, Ivory D. Why Public Health Faces a Crisis Across the U.S. *The New York Times*. <https://www.nytimes.com/2021/10/18/us/coronavirus-public-health.html>. Published October 18, 2021. Accessed July 18, 2024.
4. Huyser KR, Horse AJY, Kuhlemeier AA, Huyser MR. COVID-19 Pandemic and Indigenous Representation in Public Health Data. *Am J Public Health.* 2021;111(S3):S208-S214. doi:10.2105/AJPH.2021.306415
5. Data Modernization Initiative | CDC. Published April 23, 2024. Accessed July 18, 2024. <https://www.cdc.gov/surveillance/data-modernization/index.html>
6. CDC | OPHDST | Overview: The Public Health Data Strategy. Published June 4, 2024. Accessed July 18, 2024. <https://www.cdc.gov/ophdst/public-health-data-strategy/index.html>
7. STAR HIE Program | HealthIT.gov. Accessed July 18, 2024. <https://www.healthit.gov/topic/star-hie-program>
8. ONC Tech Forum: Modernizing Public Health Data Exchange: Lessons Learned and Tools for the Road Ahead | HealthIT.gov. Accessed July 18, 2024. <https://www.healthit.gov/news/events/onc-tech-forum-modernizing-public-health-data-exchange-lessons-learned-and-tools-road>
9. Association of State and Territorial Health Officials. Immunization Information Systems and Health Information Exchanges. Published online March 2023.
10. *Trusted Exchange Framework and Common Agreement (TEFCA)*. Office of the National Coordinator for Health IT; 2023. [https://www.healthit.gov/sites/default/files/page/2023-11/TEFCA\\_2-Pager\\_Digital\\_508.pdf](https://www.healthit.gov/sites/default/files/page/2023-11/TEFCA_2-Pager_Digital_508.pdf)
11. Layden JE, Swain MJ, Brennan N, Tripathi M. Plugging Public Health Data into the Health IT Ecosystem to Protect National Health. *NEJM Catalyst.* 2024;5(8):CAT.24.0129. doi:10.1056/CAT.24.0129
12. Adler-Milstein J, McAfee AP, Bates DW, Jha AK. The State Of Regional Health Information Organizations: Current Activities And Financing. *Health Affairs.* 2007;26(Supplement 2):w60-w69. doi:10.1377/hlthaff.27.1.w60
13. Adler-Milstein J, Bates DW, Jha AK. U.S. Regional Health Information Organizations: Progress And Challenges. *Health Affairs.* 2009;28(2):483-492. doi:10.1377/hlthaff.28.2.483
14. Adler-Milstein J, Bates DW, Jha AK. A Survey of Health Information Exchange Organizations in the United States: Implications for Meaningful Use. *Ann Intern Med.* 2011;154(10):666-671.

doi:10.7326/0003-4819-154-10-201105170-00006

15. Adler-Milstein J, Bates DW, Jha AK. Operational Health Information Exchanges Show Substantial Growth, But Long-Term Funding Remains A Concern. *Health Affairs*. 2013;32(8):1486-1492. doi:10.1377/hlthaff.2013.0124
16. Adler-Milstein J, Lin SC, Jha AK. The Number Of Health Information Exchange Efforts Is Declining, Leaving The Viability Of Broad Clinical Data Exchange Uncertain. *Health Affairs*. 2016;35(7):1278-1285. doi:10.1377/hlthaff.2015.1439
17. 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. doi:10.1377/hlthaff.2020.01497
18. Feldman KA, Hanks A, Williams TW, et al. A State Health Department and Health Information Exchange Partnership: An Effective Collaboration for a Data-Driven Response for COVID-19 Contact Tracing in Maryland. *Sex Transm Dis*. 2023;50(8):S34-S40. doi:10.1097/OLQ.0000000000001702
19. Dixon BE, Grannis SJ, McAndrews C, et al. Leveraging data visualization and a statewide health information exchange to support COVID-19 surveillance and response: Application of public health informatics. *J Am Med Inform Assoc*. Published online January 22, 2021:ocab004. doi:10.1093/jamia/ocab004
20. DMI and Health Equity | CDC. Published July 19, 2023. Accessed July 18, 2024. [https://archive.cdc.gov/www\\_cdc\\_gov/surveillance/data-modernization/dmi-health-equity.html](https://archive.cdc.gov/www_cdc_gov/surveillance/data-modernization/dmi-health-equity.html)
21. Adler-Milstein JR. Program Evaluation for the Strengthening the Technical Advancement and Readiness of Public Health via Health Information Exchange (STAR HIE) – Cooperative Agreement Program. Published online August 30, 2023.
22. Public Health Informatics & Technology (PHIT) Workforce Development Program | HealthIT.gov. Accessed July 18, 2024. <https://www.healthit.gov/topic/interoperability/investments/public-health-informatics-technology-phit-workforce-development>
23. CDC. Public Health Infrastructure Grant. Public Health Infrastructure Grant. Published July 9, 2024. Accessed July 18, 2024. <https://www.cdc.gov/infrastructure-phig/about/index.html>
24. Public Health Data Modernization Implementation Centers. Public Health Infrastructure Grant. Accessed July 18, 2024. <https://www.phinfrastructure.org/implementation-centers/>
25. Building the Right Foundation | CDC. Published June 16, 2023. Accessed July 18, 2024. [https://archive.cdc.gov/www\\_cdc\\_gov/surveillance/data-modernization/priorities/building-right-foundation.html](https://archive.cdc.gov/www_cdc_gov/surveillance/data-modernization/priorities/building-right-foundation.html)
26. Health Data, Technology, and Interoperability: Patient Engagement, Information Sharing, and Public Health Interoperability.
27. *Health Data, Technology, and Interoperability (HTI-2): Patient Engagement, Information*

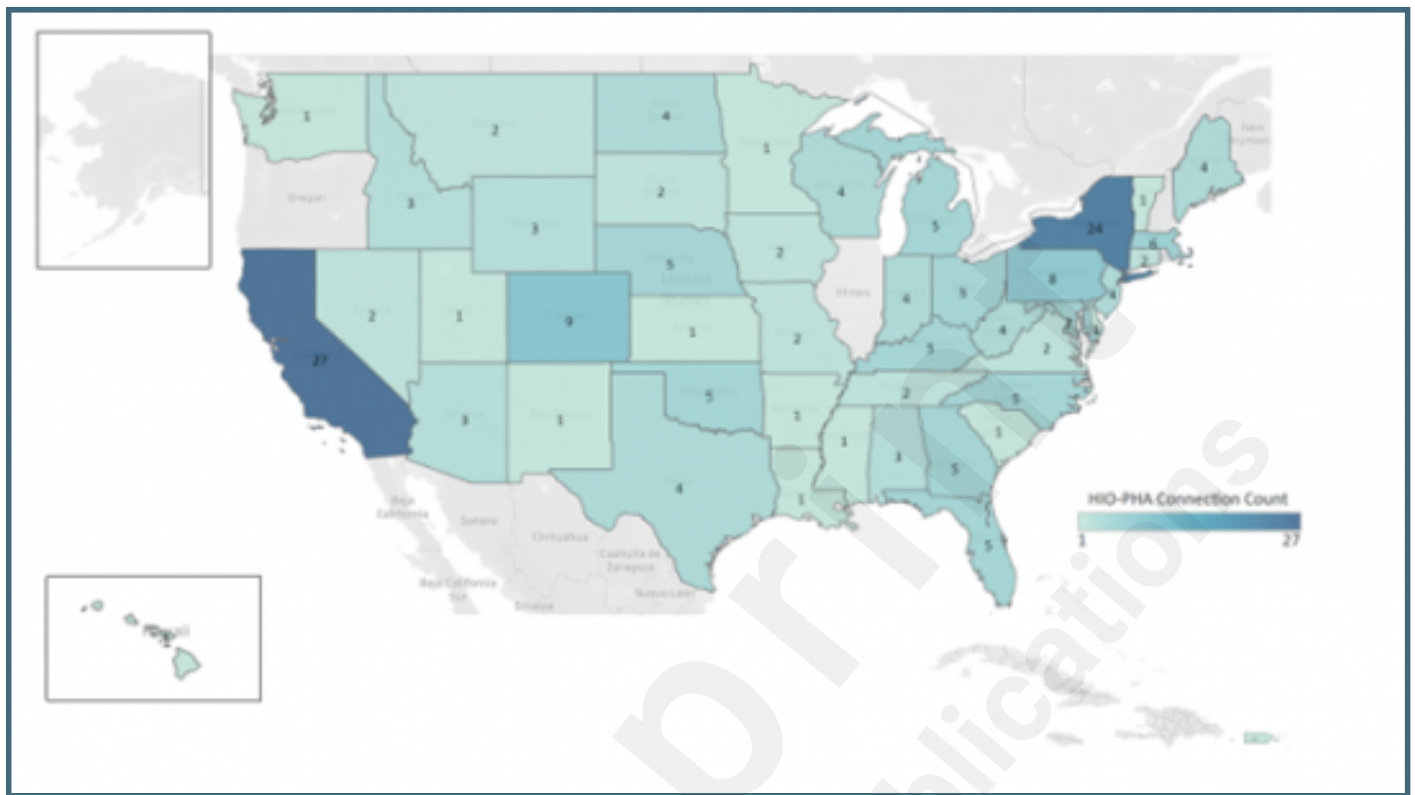
*Sharing, and Public Health Interoperability Proposed Rule*. Office of the National Coordinator for Health IT; 2024. [https://www.healthit.gov/sites/default/files/page/2024-07/HTI-2\\_ProposedRule\\_PublicHealth\\_508.pdf](https://www.healthit.gov/sites/default/files/page/2024-07/HTI-2_ProposedRule_PublicHealth_508.pdf)



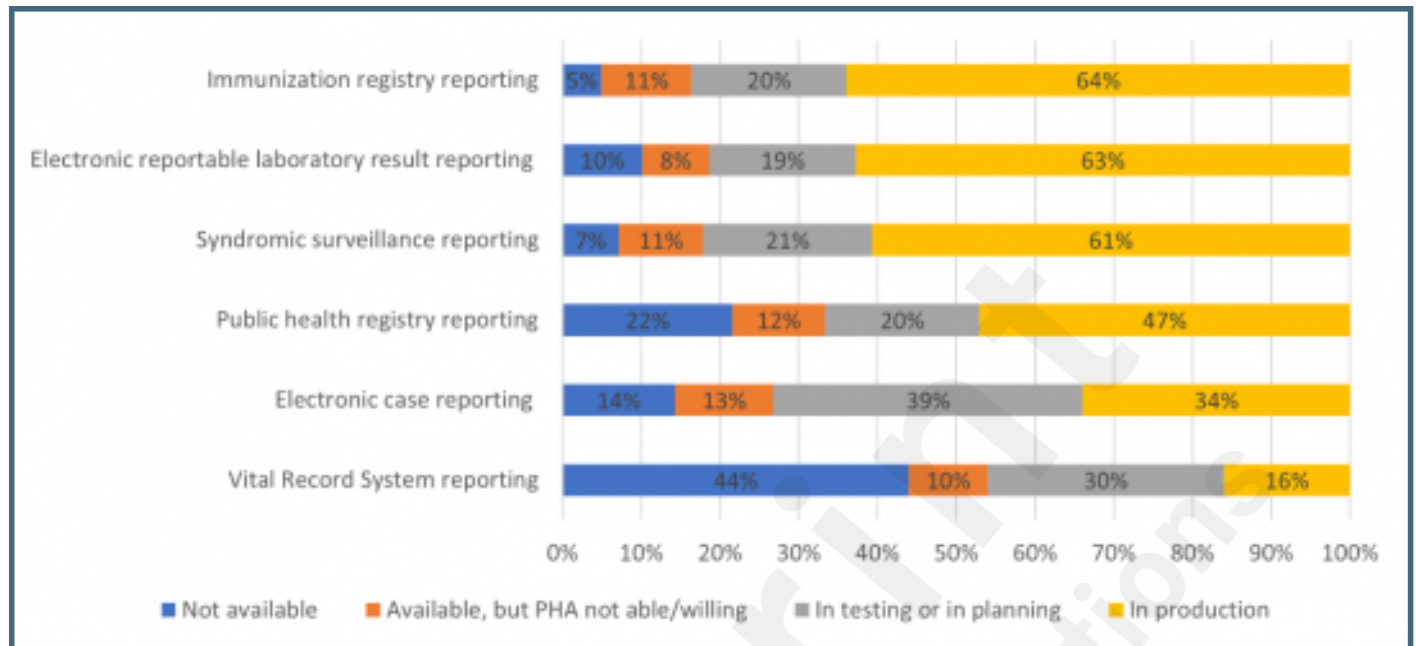
## Supplementary Files

## Figures

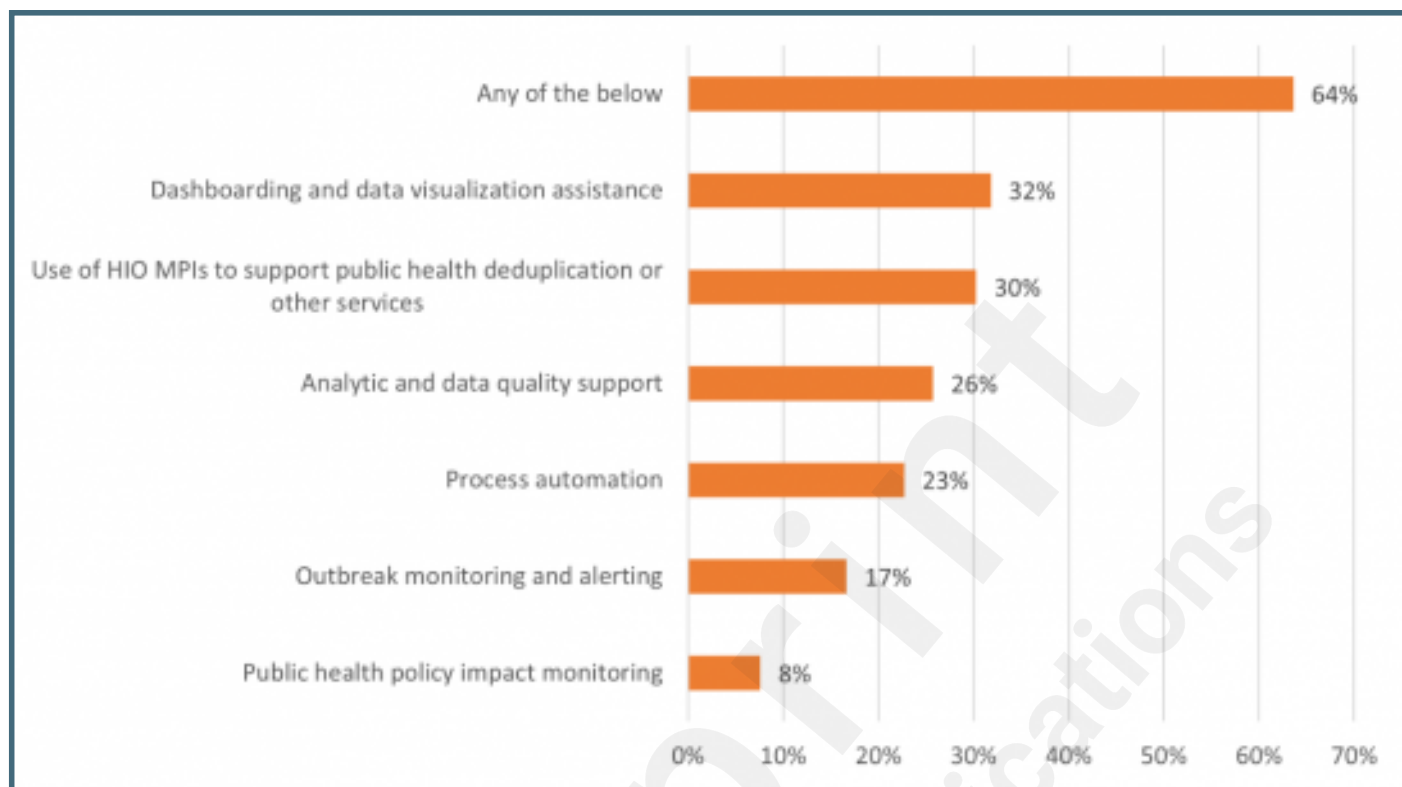
Map of HIO-PHA Connections. Note: N=187; N=12 “Other” Connections (e.g., federal, registry, unspecified). Certain states (such as NY and CA) with high numbers of operating HIOs may have more connections.



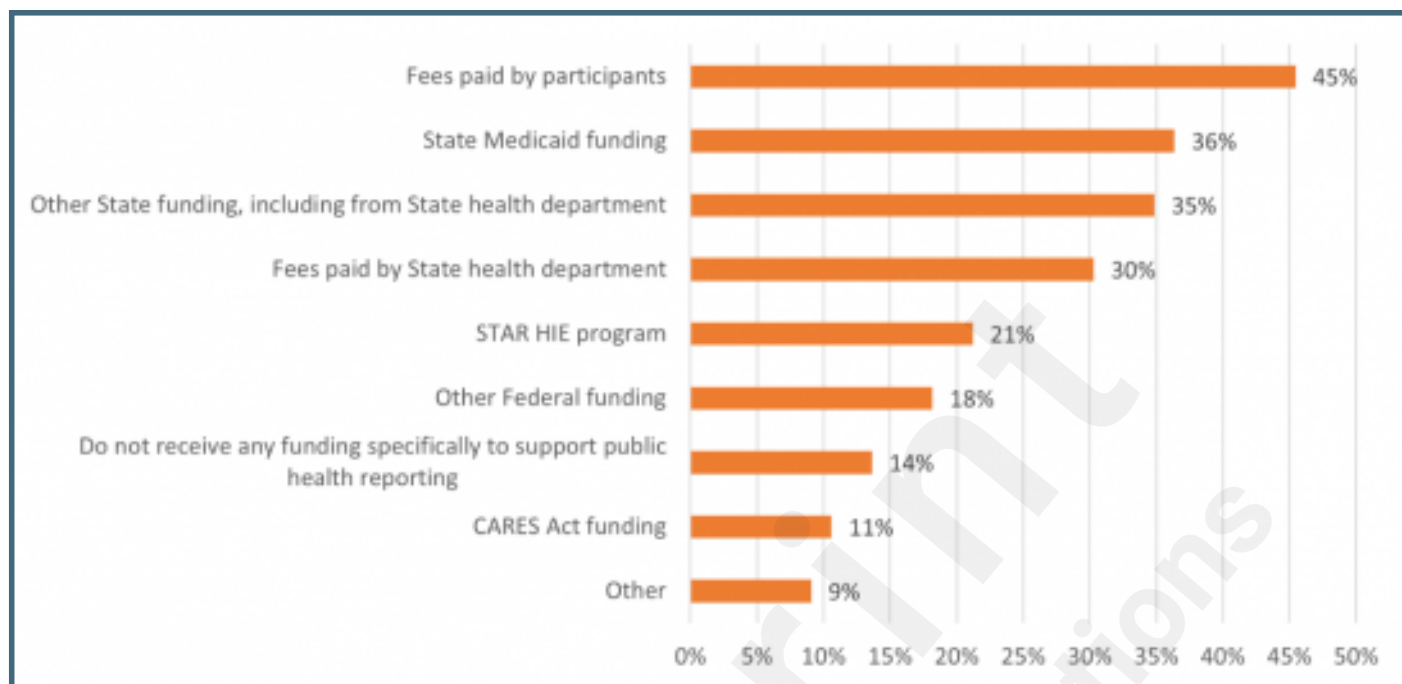
## Services Offered to Participating Healthcare Providers to Support Public Health Reporting (N=66 HIOs).



Services Provided to PHAs to Support COVID-19 Response (N=66 HIOs).



## Funding Sources for Public Health (N=66 HIOs).



HIO Reported Barriers to Public Health Reporting. Note: Percentage of HIOs that reported experiencing the barrier to “a great extent” (N=66).

