Requests for OMB Review and Approval For
Office of the National Coordinator for Health Information Technology
National Survey of Health Information Exchange Organizations

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Supporting Statement for
Office of the National Coordinator for Health Information Technology
National Survey of Health Information Exchange Organizations

A. Justification

1. Circumstances Making the Collection of Information Necessary

The Office of the National Coordinator for Health Information Technology (ONC) is seeking the approval for a revision to collection of the "National Survey of Health Information Exchange Organizations (HIOs)", OMB No. 0955-0019 Exp 10/31/2027.

Electronic health information exchange (HIE) was one of three goals specified by Congress in the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act to ensure that the $30 billion federal investment in certified electronic health records (EHRs) resulted in higher-quality and lower-cost care. Subsequent legislation and regulations have continued to prioritize the sharing of data electronically across EHRs and other health information systems. Within the Department of Health and Human Services, the Office of the National Coordinator for Health IT (hereafter ONC) is responsible for coordinating across the federal government, industry, and the health care community to achieve nationwide interoperability of electronic health information exchange. Health information exchange organizations (HIOs) play a pivotal role facilitating health information exchange across disparate providers, labs, pharmacies, public health agencies, and others. This information collection request will gather data from HIOs across the nation through the administration of a survey of HIOs to generate the most current national statistics and associated actionable insights to inform policy efforts. The timely collection of national data from our survey will assess current capabilities of HIOs to support effective electronic information sharing within the U.S. health care system and further aims to achieve nationwide interoperability.

Since prior to HITECH there has been ongoing assessment of trends in the capabilities of HIOs to support clinical exchange through nationwide surveys of HIOs. These prior surveys and studies have collected data on organizational structure, financial viability, geographic coverage, scope of services, implementation and use of standards, perceptions of information blocking, support for public health exchange, and participation in networks and the Technical Exchange Framework and Common Agreement (TEFCA). Continuing the ongoing data collection will be critical to construct a current and comprehensive picture of HIOs' role in facilitating exchange and ensuring rapid access to important health care data and information when it matters most, including vital data to address public health emergencies.

The survey will collect data on HIO capabilities to support electronic health information exchange, their maturity, and challenges they face. There are five key areas that require assessment: (1) adoption of technical standards; (2) perceptions related to information blocking; (3) network-to-network connectivity and TEFCA; (4) public health data exchange; and (5) organizational demographics, including technical capabilities offered by HIOs and the challenges they face in supporting electronic health information exchange.

The survey is being revised (previously approved in 2022 and 2024; OMB Control No: 0955-0019) to reflect progress made and ongoing efforts in areas including public health, TEFCA, and information blocking to ensure alignment with current priorities such as improving public health interoperability and Make Health Tech Great Again. These updates were developed in consultation with subject matter experts (SMEs) to improve the relevance, clarity, and usefulness of the data collected in all five key areas of the survey. For example, certain questions with low response rates and have lower relevance to current priorities have been removed or reorganized. Some question and response wording have also been updated to ensure consistency with current policy efforts. For example, in the TEFCA section, the list of Qualified Health Information Networks (QHINs) were updated to reflect the current list. These changes are intended to reduce respondent burden and improve overall data quality while maintaining continuity with prior surveys where appropriate.

There is an array of policy efforts that are primed to leverage the results from the survey. TEFCA went live and began live exchange in 2023. HIOs are key, potential participants and/or qualified health information networks (QHINs) and understanding their plans to participate in and experiences with TEFCA is crucial given their current role in facilitating HIE across the nation. This survey will be essential to understand the experiences of all players in nationwide information exchange and how to update the program over time. Identifying and coordinating action to stop information blocking behaviors remains a major ONC priority. HIOs are important actors who must both facilitate information flow and depend on other actors, like hospitals and health systems and developers of certified health IT, to enable networked exchange in their service areas. Understanding HIOs' information blocking experiences helps with monitoring the impact of information blocking policies and helps identify specific behaviors and the types of actors who limit health information exchange and block information access. There are five key areas that require broader assessment: (1) organizational demographics, including services provided; (2) public health; (3) implementation/use of standards; (4) network-to-network connectivity and TEFCA; and (5) information blocking, including technical capabilities offered by HIOs and the challenges they face in supporting electronic health information exchange.

Organizational demographics, which include HIOs' overall HIO capabilities, including services provided, are critical to assess. With many options available for how providers, public health agencies, labs, and other key health care stakeholders can engage in HIE, and a growing number of newer approaches scaling rapidly, it is critical to track how

HIOs are positioning themselves. Thus, collecting the latest data on HIO services including those related to AI, information access, and data availability, this survey will provide important insights into the evolution of this HIE infrastructure. In turn, results will reveal gaps that require renewed policy attention. Collecting current data on HIO funding sources and sustainability will also reveal whether these efforts are continuing the trend that began in 2015 of aligning their value proposition with new models of care delivery and payment. That is, with the rise of alternative HIE approaches (particularly those provided by EHR vendors), HIOs may no longer be able to sustain themselves by only supporting simple HIE transactions that move data across organizations. Instead, they may need to demonstrate added value through functionalities and analytics that support health system transformation efforts (e.g., ADT notifications, PDMP integration and alerting, quality reporting, MIPS, etc.). Understanding the specific approaches to sustainability pursued by HIOs today in the context of delivery system reform efforts will demonstrate not only to their viability but also the infrastructure to support broader health policy and public health goals.

Continuing to track HIOs' capabilities to facilitate public health exchange between health care providers and public health agencies is crucial to inform ongoing public health data modernization efforts and planning and preparation for future public health emergencies. HIOs, given their unique role in convening data across stakeholders in their region, may be able to support linking data from disparate sources together to support public health agencies' activities, such as public health surveillance, as well as potentially preventing and responding to public health emergencies. Past survey results have been analyzed and reported on and used by ONC as well as CDC and other stakeholders to better understand HIOs capabilities to support public health agencies.[1,2] We have revised the survey to better understand the role and capabilities of HIEs and HIOs in supporting public health data exchange reporting and response to pandemics.

Measuring the implementation/use of standards for transporting and codifying health information, ensuring that HIOs adopt and conform to standards is critical to enable the sharing of information across systems and to ensure that information can be easily integrated once received. There are often multiple standards available to accomplish the same HIE use case and, even when the same standard is selected, there is often ambiguity and optionality in the implementation guide that result in poor standards conformance. Unfortunately, when implementing standards, there is little room for flexibility and even one small difference in how a standard is implemented results in failure. It is therefore critical to assess conformance to specific standards, including the use of specific standards implementation guides to identify gaps in conformance. This has implications for data quality, and increasingly tools are being developed to assess conformance to

1 Richwine C. Health Information Exchange Organization Capabilities to Support Public Health Data Exchange. Office of the National Coordinator for Health Information Technology. Data Brief: 86. June 2026.

2 Rosenthal S, Adler-Milstein J, Patel V. Public Health Data Exchange Through Health Information Exchange Organizations: National Survey Study. JMIR Public Health Surveill 2024;10:e64969 doi: 10.2196/64969

standards. We have updated the survey to monitor HIOs use of such tools. Assessment of use of standards is necessary to inform policy and private-sector efforts to promote better coordination among stakeholders on standards selection and conformance. For example, standards used to encode laboratory test results can be difficult to implement though ultimately coded results would be helpful to secondary use of these data for a variety of purposes, including public health, research and artificial intelligence. Examining the extent to which HIEs have these data encoded would be informative to ONC's efforts related to enabling lab interoperability. Past results from this survey have been published and used to inform standards development efforts, and we plan to continue to use these results for this purpose.[3]

It is also important to assess approaches to HIE coordination at the federal level. The number of HIE networks has grown from just a handful of local HIOs two decades ago to nearly 100 disparate networks at the local, regional, and national levels. The result is that health care providers must use a variety of different networks and methods to exchange health information, increasing the complexity and costs of health information exchange. Current efforts, notably the Trusted Exchange Framework and Common Agreement (TEFCA), seek to better coordinate varied approaches to HIE. The goal of TEFCA is to establish universal governance for nationwide connectivity, simplify connectivity, and enable individual access to their health information. Since participation in TEFCA is voluntary, it is critical to assess how HIOs anticipate participating in TEFCA, and their engagement in related activities such as connecting to each other, to gain insight into progress towards nationwide connectivity under TEFCA. We have used past survey findings to report on HIO plans for participation in TEFCA, and given that TEFCA has gone live, we are using these data to report on experiences and actual participation of HIOs in TEFCA, as well as barriers to participate.[4]

Finally, federal regulations prohibiting information blocking should result in more HIE engagement and facilitate HIOs' ability to mediate exchange and provide services to their participants. HIOs offer a key source of data to inform an understanding of whether information blocking is happening and the extent to which different forms of information blocking may be persisting among developers of certified health IT and provider organizations. Information blocking findings from 2019, 2023, and 2025 HIO surveys have helped inform patterns of potential information blocking behaviors. Results showed that over half of HIOs reported that some, most, or all developers of certified health IT engage in information blocking, and this has declined year of year. In terms of frequency, in 2019 many HIOs indicated that some or most developers of certified health IT engaged in information blocking; as of 2025, less than half of HIOs support the same. The most

3 Chang W, Larson J, Strawley C. Standards Adoption among Health Information Exchange Organizations. Office of the Assistant Secretary for Technology Policy. Data Brief: 75. September 2024.

4 Jordan Everson, Wei Chang, Vaishali Patel, Julia Adler-Milstein, The state of health information organizations and plans to participate in the federal exchange framework, *Health Affairs Scholar*, Volume 2, Issue 8, August 2024, https://doi.org/10.1093/haschl/qxae098.

common type of information blocking behavior developers of certified health IT engaged in was setting unreasonably high prices, which 59% of HIOs reported routinely observing.[5] These findings on how and when information blocking occurs informed the implementation of the 21st Century Cures Act and have potential to inform future policy initiatives, especially indicators of progress toward reducing these blocking behaviors over time.

The timely collection of national data from our survey will assess current capabilities to support effective electronic information sharing within our health care system. Further, data collected in key topic areas, such as on TEFCA, standards, public health, and information blocking, offer the opportunity to assess the impact of recent policies to facilitate the exchange of information across the health care system. The HIO survey results will continue to inform future policy making and related activities.

2. Purpose and Use of Information Collection

The goal of this project is to generate the most current national statistics and actionable insights to inform policy efforts. The timely collection of national data from our survey will assess current capabilities of HIOs to support effective electronic information sharing within the U.S. health care system.

Our survey will accomplish this goal by asking HIOs to report current activities in the following key areas:

1. HIO sustainability and related demographics and services that capture the role of HIOs in supporting exchange and interoperability
2. Public health information sharing capabilities
3. Implementation of and use of standards to enable health information exchange and interoperability
4. Planned and current participation in TEFCA and current engagement with inter-HIO and national network connectivity
5. Information blocking practices undertaken by provider organizations and health IT developers

By updating the survey instrument to assess these timely topics from a national census of HIOs, the proposed project fills a critical knowledge gap and will provide policymakers with actionable results to inform progress towards greater interoperability and health information exchange.

3. Use of Improved Information Technology and Burden Reduction

This study will rely on data gathered from a self-administered, web-based survey of leaders of HIOs. The survey will be administered electronically to alleviate burden on the

5 Barker W, Healy D, Patel V. Trends in Health Information Organizations' Experiences of Perceived Information Blocking, 2019-2025. Office of the National Coordinator for Health Information Technology. Data Brief: 85. June 2026.

respondents. The web-based survey permits respondents to complete the instrument at their preferred time. Respondents who begin the survey and are unable to complete it in one session will be able to save their responses and resume work on the survey at a later time.

We will be using the web-based survey tool Qualtrics© and pre-fill responses from last round's survey will be populated where applicable to reduce respondent burden. This tool has been used previously for past surveys of HIOs and it has strong capabilities to support complex survey design (e.g., branching logic) as well as respondent communication and tracking. The tool will be extensively tested to ensure the accuracy of branching and skip logic, accuracy of piped text, clarity of question display, and adherence to other survey usability guidelines.

In addition, to increase response rate, respondents will also be offered the option to complete the survey via MS Word or over the phone with a Research Assistant or Project Manager if they prefer that to the online platform.

4. Efforts to Identify Duplication and Use of Similar Information

Dr. Julia Adler-Milstein is a leading researcher and expert on HIOs. She has led numerous national surveys of HIOs over the past two decades. She has published more than 30 peer-reviewed publications from these surveys in leading journals, such as Health Affairs and the Journal of the American Medical Informatics Association. Dr. Adler-Milstein, with the support of the Robert Wood Johnson Foundation, has conducted a survey of HIO leaders bi-annually, and published key findings in a series of publications in Health Affairs. The Robert Wood Johnson Foundation no longer funds the bi-annual survey. Separately, in 2015, Dr. Adler-Milstein conducted a survey consisting of 60 leaders of HIOs regarding information blocking practices. This survey was independently funded with some consultation provided by ONC staff. Most recently, with support from ONC, Dr. Adler-Milstein conducted a national survey of HIOs in 2019, 2023, and 2025. Papers that describe these results were published in the Journal of the American Medical Informatics Association (April 2021), Health Affairs (May 2021), Health Affair Scholars, (August 2024), and JMIR Public Health and Surveillance (November 2024). ONC has also self-published data briefs (here and here) in June 2026, reporting on results from the most 2025 survey.

In addition to these survey efforts, Civitas Networks for Health (hereafter Civitas) (formally known as Strategic Health Information Exchange Collaborative (SHIEC)) has conducted an annual survey of its membership that includes more than 70 HIOs. Since 2023, Civitas and ONC have agreed to collaborate on future proposed surveys to reduce duplication and build on each other's separate efforts to produce a comprehensive measurement strategy.

ONC considers it critical to continue supporting the HIO survey to examine how HIOs have evolved and the role they play in enabling interoperability and the success of various policy initiatives. This information will be key to informing policy strategies to

advance the exchange of health information and support public health efforts going forward. Furthermore, continuing tracking topics of the 2025 survey will provide insights into the implementation of the TEFCA and information blocking rule, as well as the evolution of standards and public health exchange.

5. Impact on Small Businesses or Other Small Entities

Health information exchange organizations vary in size; it is possible that some may be considered small businesses. The survey is voluntary, and the information being requested or required has been held to the absolute minimum required for the intended use of the data.

6. Consequences of Not Collecting the Information

The survey of HIO leaders has occurred almost bi-annually since 2005 with the most recent survey conducted in 2025. Data collection will occur once every two years beginning late 2026/early 2027.

If information is not collected in 2026, ONC will lack the needed information to understand the current state of HIOs to support public health preparedness, limiting our ability to tailor investments in public health data infrastructure in the near-term that could impact our ability to improve information exchange to support public health. Information that will be gathered in this survey is critical to construct a current and comprehensive picture of HIOs' role in facilitating exchange and ensuring rapid access to important health care data and information when it matters most, including vital data to address public health emergencies. Broader ONC efforts, particularly around TEFCA, information blocking, and AI governance, also require timely data on the current state of HIOs.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This data collection request is fully consistent with the guidelines. There are no special circumstances required for the collection of information in this data collection.

8. Comments in Response to the Federal Register Notice/Outside Consultation

The 60-day FRN soliciting public comment on this survey data collection, required in 5 CFR 1320.8(d), was published in the Federal Register on April 20, 2026, at 91 FR 21006. There was one comment received from the public. We addressed the public feedback and revised the instrument to incorporate suggested new questions and topics into the survey.

9. Explanation of any Payment/Gift to Respondents

As with prior years, respondents will be offered a small incentive ($10) for completing the screening questions that enable us to determine whether they are operational, planning, or defunct and a larger incentive ($50) for completing the entire survey if they are eligible (i.e., not defunct). We have found with previous surveys that financial incentives help improve response rate.

10. Assurance of Confidentiality Provided to Respondents

We will not make ANY individual responses to questions publicly available or attribute responses to any specific organization. These data will only be presented in aggregate and may be published in peer-reviewed journals and shared on the ONC website.

The information for this study is being collected by the Division of Clinical Informatics & Digital Transformation, Department of Medicine, University of California, San Francisco (UCSF), on behalf of ONC and in partnership with Civitas. Based on the UCSF's Human Research Protection Program Institutional Review Board (IRB) review, an exempt certification was granted for this study (25-45802).

11. Justification for Sensitive Questions

No questions of a sensitive nature are asked in this data collection.

12. Estimates of Annualized Hour and Cost Burden

We will target sending the survey to approximately 100 key senior respondents from HIOs such as executive directors who will be knowledgeable about the topic areas covered in the survey. We assume an 85% response rate of 100 respondents. The survey was pre-tested with a total of three separate respondents, from which we derived the 60-minute burden per respondent burden estimate.

Exhibit 1. **Estimated Annualized Burden Hours**

Forms (If necessary)	**Respondents (If necessary)**	**Number of Respondents**	**Number of Responses per Respondent**	**Average Burden per Response**	**Total Burden Hours**
HIO Survey	U.S. based public and private HIOs	85	1	1.0	85
Total					85

Exhibit 2. **Estimated Annualized Burden Costs**

Type of Respondent	**Total Burden Hours**	**Hourly Wage Rate**	**Total Respondent Costs**
Executive Director	85	$129.63	$ 11,018.55
Total			**$** 11,018.55[6]

6Based on US Bureau of Labor Statistics mean hourly wage for Chief Executives (https://www.bls.gov/oes/current/oes111011.htm).

13. Estimates of other Total Annual Cost Burden to Respondents or Recordkeepers/Capital Costs

There are no annualized capital/startup or ongoing operation and maintenance costs involved in collecting the information.

14. Annualized Cost to Federal Government

The estimated cost to the Federal Government for the *2026 Health Information Organization (HIO) Survey and Civitas Member Survey* data collection activities is $280,457.60 over two years or $140,228.8 annually. The contractual costs to the University of California, San Francisco (UCSF), for data collection activities associated with this submission is $225, 248.00 over two years or $112,624.00 annually. The cost of federal employees providing oversight and some analysis is $55,209.60 over two years or $27,604.80 annually.

15. Explanation for Program Changes or Adjustments

This is a revision to OMB No. 0955-0019 Exp 10/31/2027. We have updated the number of respondents based on the most recent available estimates, which reflects the consolidation of HIOs over time. The survey instrument has been updated but requires similar response time as the previous instrument.

16. Plans for Tabulation and Publication and Project Timeline

ONC and UCSF will jointly conduct three types of analyses based on the survey results. First, we will describe response rate and assess longitudinal trends in the number of HIOs in the U.S. Since 2006 we have tracked the number of operational, planning, and defunct efforts. These analyses will enable us to assess whether the number of HIOs has continued to decline since its peak in 2011 or is leveling off at a stable level.

Second, we will conduct descriptive analyses that provide national estimates on survey items. These have traditionally comprised most of our results and they describe U.S. HIO characteristics. This includes general demographics – such as the number and types of participants engaged, the types of data exchanged, the HIE services supported, and geographic coverage – as well as specific measures in the key areas of interest. For example, in the public health capabilities section, we will calculate the proportion of HIOs that are supporting state public health agencies in various ways (e.g., test result reporting, immunization tracking and reporting, etc.). In the standards section, we will calculate the prevalence of adoption of each standard and the associated implementation guide – overall as well as by specific characteristics such as geography or HIO type. In the information blocking section, we will calculate the proportion of respondents who indicated that information blocking was routine, occasional, and rare as well as, for each form of information blocking, the proportion of respondents who indicated it occurred “routinely/often”, “sometimes”, and “rarely/never”. In the organizational demographics section, we will calculate the overall proportion of HIOs that are financially sustainable (using our previous definition of revenue from participants that is equal to or greater than operating costs) and then examine other measures of sustainability, such as the proportion

of respondents reporting different barriers to progress, engaged in different governance models, supporting different models of payment and delivery reform efforts.

Finally, we will conduct more advanced bivariate regression analyses that will identify factors associated with key measures of "success" or "sophistication". These may include support for public health reporting, use of specific standards, reporting of infrequent information blocking, achievement of financial sustainability, and support for value-based payment. Predictors will include various HIO and contextual demographics.

Given that the national HIO maturity has increased and TEFCA is now live and operational, analyses can further shed light on how information blocking practices, support for exchange, and TEFCA have evolved. We will also be able to examine factors associated with greater support for public health reporting capabilities.

We will conduct preliminary analyses and solicit input internally within ONC, federal partners (such as CDC), and Civitas to ensure that they reflect the expertise from these organizations. The results will be published, similar to the 2023 and 2025 findings, in peer-reviewed publications or other public documents, shared via conferences and through blog posts to ensure they are widely disseminated.

The project timeline is two years, starting in August of 2025 and ending in August of 2027. Data collection will occur over three to six months and is scheduled to begin immediately upon receiving OMB approval.

17. Reason(s) Display of OMB Expiration Date is Inappropriate
All data collection materials will display the OMB expiration date.

18. Exceptions to Certification for Paperwork Reduction Act Submissions
There are no exceptions to the certification.