**2024 Health Information Organization (HIO) Survey and Civitas Member Survey**

The nationwide survey of HIOs is being led by Civitas in collaboration with Dr. Julia Adler-Milstein at the University of California, San Francisco and is sponsored by the Office of the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC).  As you know, the field continues to change rapidly, and this survey will enable us to focus on new achievements and identify challenges to create a current and accurate picture of Civitas’ HIO member efforts.  **We request your time to complete our survey. Participation is completely voluntary and will contribute to a research study.**Thank you in advance for your time.

The survey includes questions in five broad areas:

1. Organizational Demographics
2. Public Health
3. Implementation/Use of Standards
4. Network-to-Network Connectivity and TEFCA
5. Information Blocking

There is a sixth section of questions, only asked of Civitas members, that cover a range of supplemental topics.

We will not make ANY responses to questions publicly available or attribute responses to any specific organization. These data will only be presented in aggregate and will be published in a peer-reviewed journal (which we will be happy to send to you) and other publicly available publications and presentations. Please see below for more details on data access and data reporting.  
  
**Data Access: Who Will Have Access to Individual, Identified Survey Responses**  
The Civitas leadership team and the UCSF research team that are collecting the data will have access to fully identified survey responses.  In addition, the Office of the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) that is funding the survey will be given a dataset containing identifiable survey responses in the first five sections only. ASTP/ONC may choose to share all or part of the dataset with ASTP/ONC contractors only for the purpose of conducting contracted work and abiding by the same reporting/disclosure terms as described below. The sixth section will only be made available to Civitas and the UCSF research team.   
   
**Data Reporting: What Data & Derivative Results Will be Reported in Journals, Data Briefs, or Public Documents**  
No individual respondents or responses will ever be identified or reported.  All data will be reported at an aggregate level (e.g., across all survey responses).  For example, we may report that 10% of HIOs in the US have payers as participants.  A subset of data may be reported at the regional level (i.e., aggregated by state or healthcare market/HRR).  Civitas, UCSF, ASTP/ONC, and any ASTP/ONC contractors receiving the data will abide by these terms.  
  
If you serve as overarching infrastructure for sub-exchanges or otherwise manage multiple distinct health information exchanges, please let us know so that we can send you another link to the survey.  This will ensure that you fill out only one response per exchange. We also ask that you respond to survey questions only from the perspective of your organization. Please do not attempt to summarize multiple efforts that may be affiliated with your organization (For example, if you are a state-level HIO, please do not respond on behalf of local HIOs with whom you work.)

To thank you for your time, upon completion of the survey you will be offered a $50 amazon.com gift certificate. If you are not eligible for our survey, you will be offered a $10 amazon.com gift certificate.

If you have any questions, please contact the project investigator, Dr. Julia Adler-Milstein (Julia.Adler-Milstein@ucsf.edu or 415-476-9562). Questions for Civitas may be directed to Jolie Ritzo ([jritzo@civitasforhealth.org](mailto:jritzo@civitasforhealth.org) or 207-272-4725).

**Screening Questions**

We would first like to ask you about the type of organization for which you are responding:

1. As of today is your organization: (select one)

Supporting\* “live” electronic health information exchange across your network

Building (or planning for) the infrastructure or services to support\*, or pilot testing, electronic health information exchange across your network (End of survey)

No longer pursuing or supporting\* electronic health information exchange (End of survey)

Never pursued or supported\* electronic health information exchange (End of survey)

2. Does electronic health information exchange take place between independent entities\*\*?

Yes

No (End of survey)

\* Supporting is defined as offering a technical infrastructure that enables electronic health information exchange to take place.

\*\*Independent entities are defined as institutions with different tax identification numbers; HIE between independent entities requires that ***at least one*** entity is independent of the other(s).

**Organizational Demographics**

1. Since March 1, 2023, have you merged or are you planning to merge with another HIE?

No, not planning to do so

Currently considering

Yes, plan to merge. If public, with whom:

Yes, recently merged. If public, with whom:

1. Which of the following general categories apply to your organization: (Select all that apply)

Multi-state HIE

Single, statewide HIE

Community or local HIE

Governmental, state-designated HIE

Non-governmental, state-designated HIE

Enterprise HIE (i.e. primarily facilitate exchange between strategically aligned organizations)

Health Information Service Provider (HISP)

Other (please list):

1. What is your legal organizational structure?

State Government/Agency

Private Non-Profit 501c3

Private For-Profit

Other (please specify):

1. \*Which state(s) or province(s) do you consider the primary ones in which you currently have, or are recruiting new, participants in your HIE? This should \***not\*** include state(s) that you connect to via regional/national networks, such as Patient Centered Data Home or eHealth Exchange, or state(s) in which you provide technology for other HIEs that are branded under a different name.

Alabama  Alaska  American Samoa  Arizona

Arkansas  California  Colorado  Connecticut

Delaware  Distr. of Columbia  Florida  Georgia

Guam  Hawaii  Idaho  Illinois

Indiana  Iowa  Kansas  Kentucky

Louisiana  Maine  Maryland  Massachusetts

Michigan  Minnesota  Mississippi  Missouri

Montana  Nebraska  Nevada  New Hampshire

New Jersey  New Mexico  New York  North Carolina

North Dakota  N. Mariana Islands  Ohio  Oklahoma

Oregon  Pennsylvania  Puerto Rico  Rhode Island

South Carolina  South Dakota  Tennessee  Texas

Utah  US Virgin Islands  Vermont  Virginia

Washington  West Virginia  Wisconsin  Wyoming

1. \*For the state(s) selected in question 4, please select the specific hospital service area(s) † in which you currently have, or are recruiting new, participants in your HIE.

† Hospital Service Areas are geographic areas defined by the Dartmouth Atlas.   
*[Populate list of HSAs for each State reported in prior question and have check all option for HSAs in a given state]*

A hospital service area look-up by zip code can be found at: www.dartmouthatlas.org/data/search\_zip.php

If you describe your service area differently or have additional comments on geographic area covered, please comment:

5a. If you have participants in other states or connections to HIEs in other states, please list those states here:

1. Please indicate which of the following options applies to your HIE data architecture model:

Federated

Centralized

Both (Hybrid)

Other (please specify)

1. Which of the following do you currently have as core infrastructure or offer as services to your participants (either directly or via a third party)? (Select all that apply)

|  |  |
| --- | --- |
| **GENERAL SERVICES** |  |
| Provider Directory |  |
| Patient Consent Management |  |
| Community Medical/Health Record: Aggregation of information from across the community served by the HIE |  |
| Patient Electronic Access to their Health Information (e.g., immunization history, lab results) |  |
| Record Locator Service |  |
| Query-based Exchange |  |
| Results delivery (i.e., uni-directional push) |  |
| Alerting/event notification (e.g., Admit-Discharge-Transfer) |  |
| Messaging using the Direct Protocol |  |
| Transform other document types or repositories into CCDAs (e.g., MDS, OASIS, Community Health Record) |  |
| Data normalization |  |
| Intake, assessment, and screening tools |  |
| Exchange of data on individual patients' health related social needs (often referred to as social determinants of health) such as transportation, housing, food insecurity or other |  |
| Connection to prescription drug monitoring program (PDMP) (send or receive) |  |
| Connection to Immunization Information System(s) (IIS) (send or receive) |  |
| Prescription fill status and/or medication fill history |  |
| Provide data to third party disease registries (e.g., Wellcentive, Crimson, ACOs) |  |
| Advanced care planning e.g., POLST/MOLST, power of attorney, patient personal advance care plan) |  |
| Sell de-identified data to third parties |  |
| Integrating claims data |  |
| Other (please list): |  |

|  |  |
| --- | --- |
| **Services related to VALUE-BASED PAYMENT MODELS** |  |
| Activities related to quality measurement (e.g., generating, validating, reporting, etc.) |  |
| Closed-loop referrals tracking |  |
| Connection to social service referral platform(s) (e.g., FindHelp Unite Us, homegrown) |  |
| Identification of gaps in care |  |
| Care coordination platform |  |
| Registry services, including operating as a clinical data registry or qualified clinical data registry (QCDR)[[1]](#footnote-3) |  |
| Providing data to allow analysis by networks/providers |  |
| Analytics (e.g., risk stratification, patient to provider attribution) |  |
| Other (please list): |  |

7a. (If Community Medical/Health Record is checked) Does your Community Medical/Health Record contain:

Only health information (e.g., diagnoses, procedures, medications)

Health AND non-health information (e.g., transportation, education, and/or housing data)

1. Does your HIEuse patient data in any of the following ways related to artificial intelligence (AI): (Select all that apply)

Provide data to third parties (e.g., companies, researchers) to be used for developing AI models

Develop your own AI models to commercialize

Develop your own AI models and deploy for participants (individually or collectively)

Deploy AI models developed by third parties on behalf of participants (individually or collectively)

Other. Please specify:

1. If yes to options 2, 3, or 4 in question 8**:** What types of models have you developed and/or deployed:

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Yes** | **No** | **Don’t know** |
| 1. Non-Machine Learning Predictive Models (e.g., LACE+ Readmission model based on logistic regression) |  |  |  |
| 2. Machine Learning Models (e.g. Readmission model leveraging random forest or neural network) |  |  |  |
| 3. Generative AI Models/Large Language Models (e.g., to create text summaries) |  |  |  |

9a. If yes to any of the above in 9:How has your HIE used artificial intelligence models? Please check all that apply.

Predict health trajectories or risks for inpatients (such as early detection of onset of a disease or condition like sepsis; predicting in-hospital fall risk)

Identify high risk outpatients to inform follow-up care (e.g., readmission risk)

Monitor health (e.g., through integration with wearables)

Assist diagnosis or recommend treatments (e.g., identify similar patients and their outcomes)

Generation of chart summaries

Patient-facing health recommendations and self-care engagement

Prediction of quality gaps

Other operational process optimization (e.g., supply management). Please specify:

Other clinical use cases. Please specify:

None of the above

Don’t know

9b. If yes to any of the above in 9: Were any state policies (e.g., legislation, regulations) or organizational policies (e.g., participant agreements) created and/or adjusted to allow development or use of artificial intelligence models?

9c. If yes to any of the above in 9**:** What was the motivation for building capabilities related to artificial intelligence models?

9d. If yes to any of the above in 9**:** What types of participants are asking for/interested in artificial intelligence models? (e.g., health systems; independent practices)

9e. If yes to any of the above in 9**:** What is your approach to governance of artificial intelligence models – assessing models for bias, assessing model drift over time, etc?

1. Do **entities participating in your HIE** **cover** 100% of your operating expenses?

Yes

No

1. Are you confident that your HIE will be financially viable **over the next 3 years**?

Very confident

Somewhat confident

Neither confident nor unconfident

Somewhat unconfident

Very unconfident

Don’t know

1. Please estimate to the best of your knowledge what percent of your revenue comes from each of the following sources:

State grants (including Medicaid):

Federal grants:

Other grants:

Revenue from participants:

Other. Please specify:

1. Has your state Medicaid organization ever provided funding to support your HIE?

Yes – initial, one-time funding only

Yes – ongoing funding only

Yes – both initial and ongoing funding

In the process of obtaining approval for funding

No

Other: Please explain:

1. Does your HIE formally partner with your state Medicaid organization to provide data for quality reporting?

Yes, our HIE provides data for state quality reporting only

Yes, our HIE provides data for federal quality reporting only

Yes, our HIE provides data for state and federal quality reporting

We are in the process of working with state Medicaid to provide data for quality reporting

No

Other: Please explain:

1. If you have a **Master Patient Index (MPI)**, please ESTIMATE:

Total number of unique (resolved) individuals in your MPI:        Do not know

Total number of unique individuals in your MPI **with more than only demographic data**:        Do not know

1. Within the past year, please estimate **the number of acute care hospitals** (individual facilities both within health systems and independent, including VA, public, and private) that are directly connected (not via another network) to your HIE:

|  |  |
| --- | --- |
|  | HOSPITALS |
| Provide data | Do not know |
| Receive or view data | Do not know |

1. Please report whether each type of entity is involved in your HIE in the following ways:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Answer Options** | **Provide Data to your HIE** | **Receive/Query for Data from your HIE** | **View Only Access to Data from your HIE, via portal login** | **Entity Not Involved in your HIE** |
| Behavioral Health providers |  |  |  |  |
| Long-term, post-acute care facilities |  |  |  |  |
| Home health agencies |  |  |  |  |
| Social service agencies |  |  |  |  |
| Community Based Organizations (CBOs) |  |  |  |  |
| Pharmacies |  |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Answer Options** | **Provide Test Results to your HIE** | **Receive/Query Data from your HIE** | **View Only Access to Data from your HIE** | **Entity Not Involved in your HIE** |
| Hospital-based labs |  |  |  |  |
| Physician office-based labs |  |  |  |  |
| Commercial Labs |  |  |  |  |
| Other Independent labs (NOT including commercial) |  |  |  |  |
| Mobile labs (e.g., Point of Care Labs for COVID-19) |  |  |  |  |
| Public health labs |  |  |  |  |
| Other: |  |  |  |  |

**Public Health**

***HIE Support for Public Health***

Screening: Is your HIE connected to any state, tribal, local, or territorial public health agencies (PHAs)? (Connected means that the public health entity sends data to your HIE, receives/queries for data, and/or has view only access to data from your HIE.) Select all that apply.

Yes, state

Yes, local

Yes, tribal

Yes, territory

None of the above (skip to Section E)

**SECTION A: Summary of Current Connectivity to PHAs**

Please report how many PHAs engage with your HIE in the following manner:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Total number of unique PHAs connected with your HIE in any way** | **Number of PHAs that send data to your HIE** | **Number of PHAs that receive or query for data from your HIE** | **Number of PHAs with view only access** |
| State-level |  |  |  |  |
| Local-level |  |  |  |  |
| Tribal-level |  |  |  |  |
| Territorial-level |  |  |  |  |

Note: Any connections to registries or federal and national public health networks are addressed later in this survey. Please do not include them here.

1a. Please report how many registries engage with your HIE in the following manner:

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Total number connected with your HIE in any way** | **Number of registries that send data to your HIE** | **Number of registries that receive or query for data from your HIE** |
| All Types of Registries |  |  |  | |
| Registries Affiliated with a PHA |  |  |  | |

2. If any tribal PHAs: Please break down the number of PHA connections by region (as defined by the Tribal Epidemiology Center Map which can be found [here](https://tribalepicenters.org/12-tecs/)):

|  |  |
| --- | --- |
|  | **Total Number of Unique Tribal PHAs connected with your HIE in any way** |
| Northwest |  |
| California |  |
| Rocky Mountain |  |
| Inter-Tribal Council of Arizona, Inc. |  |
| Navajo |  |
| Albuquerque Area Southwest |  |
| Great Plains |  |
| Oklahoma Area |  |
| Great Lakes |  |
| United South and Eastern Tribes |  |
| Alaska |  |

2b. If any state, local, territorial: What states/territories are the PHA entities connected to your HIO located in? Select all that apply.

Alabama  Alaska  American Samoa  Arizona

Arkansas  California  Colorado  Connecticut

Delaware  Distr. of Columbia  Florida  Georgia

Guam  Hawaii  Idaho  Illinois

Indiana  Iowa  Kansas  Kentucky

Louisiana  Maine  Maryland  Massachusetts

Michigan  Minnesota  Mississippi  Missouri

Montana  Nebraska  Nevada  New Hampshire

New Jersey  New Mexico  New York  North Carolina

North Dakota  N. Mariana Islands  Ohio  Oklahoma

Oregon  Pennsylvania  Puerto Rico  Rhode Island

South Carolina  South Dakota  Tennessee  Texas

Utah  US Virgin Islands  Vermont  Virginia

Washington  West Virginia  Wisconsin  Wyoming

If they select more than 1 state: Please breakdown the number of state, local, and/or territorial PHA connections by state/territory:

|  |  |
| --- | --- |
| **Please fill in with states selected above** | **Total Number of Unique PHAs connected with your HIO in any way** |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |

3. What is the purpose of PHA connectivity? (Select all that apply)

To identify opportunities to enrich public health data with HIE data

To make public health data available to your participants

Other (Please list):

**SECTION B: Reporting Services Provided to PHAs**

4a. Which of the following reporting services do you offer to **your participating healthcare providers or PHAs**? Select all that apply with regards to the stage at which you offer those services.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **In production** | **In testing** | **In planning** | **Not available** | **Don’t know** |
| Syndromic surveillance reporting |  |  |  |  |  |
| Immunization registry reporting |  |  |  |  |  |
| Electronic case reporting |  |  |  |  |  |
| Electronic reportable laboratory result reporting |  |  |  |  |  |
| Public health registry reporting (administered by or for public health agencies for public health purposes) |  |  |  |  |  |
| Clinical data and/or specialized registry reporting (administered by or for non-public health agency entities for clinical care and monitoring health care quality and resource use) |  |  |  |  |  |
| Other reporting (e.g., COVID specific, other registry) |  |  |  |  |  |
| Vital Record System reporting |  |  |  |  |  |

4b. If in production for public health registry reporting: What type(s) of public health registry reporting are in production?

4c. Have you encountered PHAs that are NOT willing or able to receive the following types of reporting?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Yes, Many** | **Yes, Some** | **Few/None** | **Don’t know** |
| Syndromic surveillance reporting |  |  |  |  |
| Immunization registry reporting |  |  |  |  |
| Electronic case reporting |  |  |  |  |
| Electronic reportable laboratory result reporting |  |  |  |  |
| Public health registry reporting (administered by or for public health agencies for public health purposes) |  |  |  |  |
| Clinical data and/or specialized registry reporting (administered by or for non-public health agency entities for clinical care and monitoring health care quality and resource use) |  |  |  |  |
| Other reporting (e.g., COVID specific, other registry) |  |  |  |  |
| Vital Record System reporting |  |  |  |  |

1. For each type of reporting that is in production, are any of the following provider types currently using these services (i.e., at least one organization providing data for reporting)? (Select all that apply)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Hospitals** | **Office-based physicians** | **LTPAC settings** | **Urgent Care** | **Other** |
| Syndromic surveillance reporting |  |  |  |  |  |
| Immunization registry reporting |  |  |  |  |  |
| Electronic case reporting |  |  |  |  |  |
| Electronic reportable laboratory result reporting |  |  |  |  |  |
| Public health registry reporting |  |  |  |  |  |
| Clinical data registry reporting and/or specialized registry reporting |  |  |  |  |  |
| Other COVID-19 related reporting (e.g., registry) |  |  |  |  |  |
| Vital Record System reporting |  |  |  |  |  |

**SECTION C: Receiving Data from PHAs**

*Note: Please respond to the remaining questions for all PHAs, not only the primary*

. Which of the following types of data do you **receive** from PHAs with which you have established connectivity? (Select all that apply)

Immunization

Reportability Responses (i.e., whether a condition is reportable in a jurisdiction)

Laboratory orders and/or results from public health lab

Data from public health registry (administered by or for public health agencies for public health purposes)

Data from clinical data and/or specialized registry (administered by or for non-public health agency entities for clinical care and monitoring health care quality and resource use)

Data related to COVID-19

Vital records

Other. Please list:

Don’t know

None—do not receive data from public health entities

**SECTION D: Other Services, Barriers and Support for Public Health Exchange**

1. What other services does your HIE provide to PHA(s)?: (Select all that apply)

Analytic and Data Quality Support (beyond those reported above)

Dashboarding and Data Visualization Assistance

Process Automation

Bidirectional Data Sharing/Receiving Data from PHAs

Use of HIE MPIs to Support Public Health Deduplication or Other Services

Outbreak Monitoring and Alerting

Public Health Policy Impact Monitoring

Situational Awareness

Other. Please list:

None

1. Do you receive any of the following funding source(s) to support PHA connectivity? (Select all that apply)

Fees paid by participants

Fees paid by State or local health department(s)

State Medicaid funding

CDC funding (including through State or local health departments)

Other Federal funding

Other State funding, including from State health department

Other. Please list:

Do not receive any funding to specifically support public health reporting

8a. For respondents who indicate any responses other than “Do not receive any funding to specifically support public health reporting”: Based upon your best estimate, to what extent do you think these sources of funding will be available to support PHA connectivity over the next 3 years?

To a great extent

Some extent

Very little

Not at all

Don’t know

1. To what extent have you experienced the following barriers **within the last year** to PHA connectivity?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **To a Great Extent** | **Somewhat** | **Very Little** | **Not at All** | **N/A** |
| Patient consent model hinders data exchange with PHAs |  |  |  |  |  |
| State statutes/regulations limit PHAs participation with HIE |  |  |  |  |  |
| Need for data use agreements for public health data |  |  |  |  |  |
| Limited funding from PHAs |  |  |  |  |  |
| Limited funding from your HIE participants |  |  |  |  |  |
| PHAs lacks staffing |  |  |  |  |  |
| PHAs lacks technical capability to receive messages from your HIE |  |  |  |  |  |
| PHAs lacks technical capability to process messages from your HIE |  |  |  |  |  |
| Other technical limitations on part of PHAs |  |  |  |  |  |
| PHAs have other priorities |  |  |  |  |  |
| Low return on investment to your HIE |  |  |  |  |  |
| Cost to maintain infrastructure that is only used in specific circumstances (e.g., natural disaster, public health emergency) |  |  |  |  |  |
| Other (please list): |  |  |  |  |  |

1. To what extent do you feel prepared to support PHA data needs for a future pandemic?

To a great extent

Somewhat

Very little

Not at all

Don’t Know

**SECTION E: Other Public Health Exchange Capabilities**

1. Does or could your HIE currently provide data to PHA(s) to fill data-related gaps (e.g., missing demographic information)?

Yes

No but could do so

No and could not do so

Don’t know

11a. If Yes or No but could do so: Please indicate what types of data are or could be provided to PHAs fill data-related gaps in information. (Select all that apply)

|  |  |  |
| --- | --- | --- |
|  | **Currently provided** | **Not currently provided but could be** |
| **Clinical Information** | |  |
| Problems |  |  |
| Prescribed Medications |  |  |
| Immunizations |  |  |
| **Laboratory-Related Information** |  |  |
| Laboratory Value(s)/Result(s) |  |  |
| **Encounter-Related Information** | |  |
| Procedures |  |  |
| Admission and Discharge Dates and Locations |  |  |
| Encounters (Encounter type, diagnosis, time) |  |  |
| Reason for Hospitalization |  |  |
| Newborn Screenings |  |  |
| **Health Equity** | |  |
| Home Address or other up-to-date contact information for contact tracing |  |  |
| Race/Ethnicity |  |  |
| Preferred Language |  |  |
| Health-related Social Needs (e.g., housing, food insecurity) |  |  |
| Substance Use Disorder Diagnosis (as defined in 42 CFR Part 2) |  |  |
| Gender Identity |  |  |
| Sexual Orientation |  |  |
| **Other** | |  |
| Other (please list): |  |  |

11b. If yes: How often do PHA(s) electronically receive or query these types of data from your HIE?

Often

Sometimes

Rarely

Never

Don’t know

11c. If yes: How are PHA(s) accessing these types of data? (Select all that apply)

Single patient lookup through a Portal

Batch query and response

FHIR API query and response

Aggregate data and/or statistics (e.g., dashboard)

SFTP/Amazon S3 file transfer

Other. Please list:

Not applicable

11d. If yes: To what extent is access to these types of data in real-time?

Majority in real-time

Mix of real-time and lagged

Majority lagged

1. What are your current capabilities to electronically receive hospital data on **bed capacity and resource utilization**? Electronic receipt includes standards-based approaches (e.g., SANER, HL7 feed) and does **not** include spreadsheet submission and/or manual data entry.

Actively electronically receiving production data

In the process of testing and validating electronic receipt of data

In planning phase to support this reporting

Not planning to support this reporting

Don’t know

**Implementation and Use of Standards**

1. To what extent does your HIE electronically **receive** datafrom your participantsusing the following methods listed below? (Select one option across a row)

*Please consider the methods used by participant to provide the data to your HIE. Do not include conversions you may do after receipt. With regards to conformance to standards, if the receipt of the data is in partial conformance, please consider that as conformant.*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Routinely/**  **from most participants** | **Sometimes/**  **From some participants** | **Rarely/**  **From few participants** | **Never** | **Don’t know** |
| HL7 v2 messages for event notification (ADT messages) |  |  |  |  |  |
| HL7 v2 messages (e.g., Scheduling, Orders, Labs) |  |  |  |  |  |
| FHIR (any version) |  |  |  |  |  |

1. To what extent does your HIE electronically **send or make available for query** datato your participantsusing the following methods?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Routinely/**  **To most participants** | **Sometimes/**  **To some participants** | **Rarely/**  **To few participants** | **Never** | **Don’t know** |
| Care summaries in a structured format (e.g., CDA) |  |  |  |  |  |
| HL7 v2 messages (any type) |  |  |  |  |  |
| FHIR (any version) |  |  |  |  |  |

1. Which types of **clinical and other health-related information** are made available by your HIE (as part of a clinical document or as a structured data element)? See [U.S. Core Data for Interoperability](https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#draft-uscdi-v5) (USCDI) for further information. (Select all that apply)

|  |  |
| --- | --- |
|  | **Included in your HIE** |
| Data Provenance |  |
| Health Insurance Information (e.g., coverage status, coverage type, member/subscriber/group/payer identifiers) |  |
| **Clinical Information** | |
| Problems |  |
| Prescribed Medications |  |
| Filled Medications |  |
| Medication Allergies |  |
| Non-Medication Allergies & Intolerances |  |
| Functional Status |  |
| Cognitive Status |  |
| Vital Signs |  |
| Pregnancy Status |  |
| Immunizations |  |
| Family Health History |  |
| Health Concerns |  |
| Clinical Notes |  |
| **Imaging/Pathology** | |
| Diagnostic Imaging Order |  |
| Radiology Report (narrative) |  |
| Pathology Report (narrative) |  |
| **Laboratory-Related Information** |  |
| Laboratory Test(s) Ordered |  |
| Laboratory Value(s)/Result(s) |  |
| Laboratory Reports (narrative) |  |
| **Team-Based Care** | |
| Care Plan Field(s), including Goals and Preferences |  |
| Care Team Member(s)  (Provider ID, Provider Name) |  |
| Assessment and Plan of Treatment |  |
| **Encounter-Related Information** | |
| Procedures |  |
| Admission and Discharge Dates and Locations |  |
| Encounters (Encounter type, diagnosis, time) |  |
| Discharge Disposition |  |
| Referrals |  |
| Discharge Instructions |  |
| Reason for Hospitalization |  |
| **Health Equity** | |
| Home Address |  |
| Race/Ethnicity |  |
| Preferred Language |  |
| Health-related Social Needs (e.g., housing, food insecurity) |  |
| Substance Use Disorder (as defined in 42 CFR Part 2) |  |
| Gender Identity |  |
| Sexual Orientation |  |
| **Other** | |
| Other (please list): |  |

3a. If selected “Health-related Social Needs” in question 3: Which of the following health-related social needs domains does your organization make available to participants? (Select all that apply)

Housing / Homelessness

Food Security

Transportation

Financial

Utility Assistance

Interpersonal Violence

Employment

Long Term Services and Supports

Health Education

Other. Please specify:

3b. If selected “Health related Social Needs” in question 3: How are health-related social needs data encoded? (Select all that apply)

ICD-10 Z codes

LOINC

SNOMED

Health-related social needs data are not encoded

Encoded using other. Please specify:

1. Do you receive care summary documents from your participants?

Yes

No

Don’t know

4a. If Yes: To what extent does your HIE electronically **receive care summaries in structured versus unstructured format from your participants:**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Routinely/**  **most participants** | **Sometimes/**  **some participants** | **Rarely/**  **few participants** | **Never** | **Don’t know** |
| Care summaries in a **structured format** (e.g., CDA) |  |  |  |  |  |
| Care summaries in an **unstructured format** (e.g., PDF) |  |  |  |  |  |

4b. If care summaries in a structured format “routinely” or “sometimes” is checked above: Do you parse C-CDAs (i.e., extract and make available discrete data elements):

Yes

No

Don’t know

1. Does your HIE map from non-standard laboratory test/result codes to LOINC® codes?

Yes

No (Skip to next section)

Don’t know (Skip to next section)

5a. Within the past year, based upon the volume of test results received (qualitative and quantitative), to what extent did your HIE have to map those results from non-standard codes to LOINC codes?

All or most

Some

Few

None

Don’t know

5b. Have you experienced any of the following issues related to mapping to LOINC? (Select all that apply)

We do not have sufficient expertise to map to LOINC within our organization

We find LOINC and LOINC tools too difficult to use

We do not have the resources (personnel/time) to map to and/or maintain mappings to LOINC

Other issue. Please specify:

No, we have not experienced any issues mapping to LOINC

Don’t know

**Network-to-Network Connectivity and TEFCA**

1. Does your HIE: (Select all that apply)

|  |  |
| --- | --- |
|  |  |
| Sell/provide your infrastructure to other HIEs |  |
| Buy/use infrastructure from another HIE |  |
| Connect to other HIEs in the SAME state |  |
| Connect to other HIEs in a DIFFERENT state(s) |  |
| None of the above |  |

1. Is your HIE currently using the following national networks / frameworks to exchange data? Note: TEFCA questions come next.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Live Data Exchange (send or receive)** | **Implementing** | **Not Using** | **Other (please specify):** |
| **General Purpose Networks:** |  |  |  |  |
| CommonWell |  |  |  |  |
| DirectTrust |  |  |  |  |
| Patient Centered Data Home (Governance Council supported by Civitas) |  |  |  |  |
| e-Health Exchange |  |  |  |  |
| Carequality |  |  |  |  |
| **Specific Purpose Networks:** |  |  |  |  |
| Surescripts |  |  |  |  |
| Patient Ping |  |  |  |  |
| Audacious Inquiry: Pulse/ENS |  |  |  |  |
| Point Click Care: EDie |  |  |  |  |
| **National Public Health Networks:** |  |  |  |  |
| Association of Public Health Laboratories Informatics Messaging Services (APHL AIMS) |  |  |  |  |
| IZ Gateway |  |  |  |  |
| Other (please list): |  |  |  |  |

2a. If not using any general-purpose networks in prior question: Please select reason(s) for not using any of the general purpose networks: (Select all that apply)

Do not see the value in what they provide (i.e., services not useful or data limited)

Perceive them as competitors

Participation costs too high

Not a priority

Other. Please list:

1. Is your HIE participating in the Trusted Exchange Framework and Common Agreement (TEFCA)?

Yes

No, but we plan to participate as a QHIN

No, but we plan to participate as a participant or sub-participant

No, and we do not plan to participate

No, and we don’t know if we will participate

3a. If any no: Why are you not currently participating, or not planning to participate, in TEFCA? (Select all that apply)

Didn’t/Don’t have enough information

Didn’t/Don’t have time/resources to prepare

Had/Have concerns about the terms of the Common Agreement (please briefly describe):         
 Had/Have concerns over privacy and/or security of the network

Risk of inappropriate use of the data

Concerns about the burden associated with participation (e.g., financial, reporting, technical/infrastructure) (please briefly describe):

Did/Do not perceive sufficient value in participating (please briefly describe why):       .

Lessens competitive advantage

Did/Do not support the technical requirements, including standards, required to participate in TEFCA or within a QHIN.

Were/Are waiting to see if and how requirements for exchange and participation change (e.g., requirements related to FHIR based transactions) (please briefly describe):

Had/Have concerns about the volume of queries we would receive through TEFCA.

Had/have not yet developed a strategic plan to participate

Other (please list):

3b. If Yes or No, but we plan to participate as a participant or sub-participant: Which TEFCA QHIN(s) or Candidate QHIN(s) are you participating or planning to participate in? *Check all that apply.*

|  |  |
| --- | --- |
|  |  |
| Epic Nexus |  |
| eHealth Exchange |  |
| Health Gorilla |  |
| KONZA |  |
| MedAllies |  |
| CommonWell Health Alliance |  |
| Kno2 |  |
| Other (please list): |  |
| Don’t Know |  |

3c. If Yes or No, but we plan to participate as a QHIN/participant or sub-participant: What changes has your HIE made, or is your HIE planning to make, to its operations in order to participate in TEFCA:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Yes** | **No** | **Don’t know** | **Not Applicable** |
| Changing types of services offered |  |  |  |  |
| Selling/providing your services to other HIEs |  |  |  |  |
| Buying/using services from another HIE |  |  |  |  |
| Changing technical infrastructure |  |  |  |  |
| Changing legal agreements and/or policies |  |  |  |  |
| Changing other infrastructure (e.g., creating new training, supporting or making process redesigns (e.g., new workflows)) |  |  |  |  |
| New Partnerships with other HIEs |  |  |  |  |
| New Partnerships with an entity that is not an HIE (e.g., health IT developer) |  |  |  |  |
| Other (please list): |  |  |  |  |

3d. If Yes, how would you rate the benefit of participating in TEFCA to your HIE and members:

Substantial

Moderate

Minimal/Not at all (please explain):

Don’t know

3e. If Yes or No, but we plan to participate as a participant or sub-participant, how satisfied are you with your HIE’s QHIN?

Very satisfied

Satisfied

Neither satisfied nor dissatisfied

Dissatisfied (please explain):

Very dissatisfied (please explain):

N/A (e.g., we are the QHIN)

3f. If any response to Q3, how satisfied are you with the TEFCA Recognized Coordinating Entity’s response to issues identified by your HIE or your HIE’s QHIN?

Very satisfied

Satisfied

Neither satisfied nor dissatisfied

Dissatisfied (please explain):

Very dissatisfied (please explain):

My HIE or my HIE’s QHIN has not, to my knowledge, reported issues to the RCE.

3g. If Yes, what proportion of your members participate in TEFCA through your HIE?

All/Most

Some

Few (Please explain):

None (please explain):

Don’t know

**Information Blocking**

Information blocking practices have been defined in rules that went into effect on April 5, 2021. The following set of questions ask about practices that may constitute information blocking based on your understanding of the rules. Please respond based on your experience since the rules went into effect (April 5, 2021).

1. To what extent are you familiar with the information blocking rules, applicable actors, exceptions, and enforcement timeline?

Very Familiar

Moderately Familiar

Somewhat Familiar

Not Familiar

1a. To what extent are you familiar with ASTP/ONC’s process for reporting violations of the information blocking rules?

Very Familiar

Moderately Familiar

Somewhat Familiar

Not Familiar

1. How often have you encountered **each of the following form(s)** of information blocking by **EHR vendors** (and other Developer(s) of Certified Health IT)?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Rarely/Never** | **Sometimes** | **Often/ Routinely** | **Don’t Know** |
| **PRICE**  Examples:  using high fees to avoid granting third-parties access to data stored in the developer’s EHR system  charging unreasonable fees to export data at a provider’s request (such as when switching developers) |  |  |  |  |
| **CONTRACT LANGUAGE**  Examples:  using contract terms, warranty terms, or intellectual property rights to discourage exchange or connectivity with third-party  changing material contract terms related to health information exchange after customer has licensed and installed the vendor’s technology |  |  |  |  |
| **ARTIFICIAL TECHNICAL, PROCESS, OR RESOURCE BARRIERS**  Examples:  using artificial technical barriers to avoid granting third-parties access to data stored in the vendor’s EHR system  using artificial reasons to limit the types of information that can be sent/shared or received |  |  |  |  |
| **REFUSAL**  Examples:  refusing to exchange information or establish connectivity with certain vendors or HIOs  refusing to export data at a provider’s request (such as when switching vendors) |  |  |  |  |
| **OTHER** (please list): |  |  |  |  |

1. What proportion of **EHR vendors** have you encountered engaging in information blocking?

All/Most

Some

Few

None (skip to 6)

Don’t know or N/A (Don’t interact with developers) (skip to 6)

3a. Among **EHR Vendors** that engage in information blocking, how often do they do it?

Routinely

Sometimes

Rarely

Don’t know

1. When you have experienced practices that you believed constituted information blocking by **EHR vendors** in the past year, how often did you report the information blocking to ASTP/ONC/HHS?

Always

Most of the time

Sometimes

Rarely

Never

4a. If Rarely or Never: Why have you not reported information blocking by **EHR vendors** when you have experienced it?

1. To what extent does information blocking by **EHR vendors** make it more difficult for you to provide HIE services to your participants?

Greatly

Moderately

Minimally/Not at all

Don’t know

1. In what form(s) have you experienced information blocking by **hospitals and health systems**?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Rarely/Never** | **Sometimes** | **Often/ Routinely** | **Don’t Know** |
| **ARTIFICIAL TECHNICAL, PROCESS, OR RESOURCE BARRIERS**  Examples:  requiring a written authorization when neither state nor federal law requires it  requiring a patient to repeatedly opt in to exchange for TPO |  |  |  |  |
| **REFUSAL**  Examples:  refusing to exchange information with competing providers, hospitals, or health systems  refusing to share data with other entities, such as payers or independent labs |  |  |  |  |
| **CLOSED NETWORK EXCHANGE**  Examples:  promoting alternative, proprietary approaches to HIE  exchanging only within referral network or with preferred referral partners |  |  |  |  |
| **OTHER** (please list): |  |  |  |  |

1. What proportion of **hospitals and health systems** have you encountered engaging in information blocking?

All/Most

Some

Few

None (skip to 10)

Don’t know or N/A (skip to 10)

7a. Among **hospitals and health systems** that engage in information blocking, how often do they do it?

Routinely

Sometimes

Rarely

Don’t know

1. When you have experienced practices that you believed constituted information blocking by **hospitals and health systems** in the past year, how often did you report the information blocking to ASTP/ONC/HHS?

Always

Most of the time

Sometimes

Rarely

Never

8a. If Rarely or Never: Why have you not reported information blocking by **hospitals and health systems** when you have experienced it?

1. To what extent does information blocking by **hospitals and health systems** lead to missing patient health information?

Greatly

Moderately

Minimally/Not at all

Don’t know

1. Among other types of entities, to what extent have you observed information blocking behaviors?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Rarely/Never** | **Sometimes** | **Often/ Routinely** | **Don’t Know** |
| **Commercial Payers** |  |  |  |  |
| **Laboratories** |  |  |  |  |
| **Commercial Pharmacies** |  |  |  |  |
| **Public Health Agencies**  **Healthcare Providers other than Hospitals and Health Systems (e.g., independent practices)** |  |  |  |  |
| **National Networks (e.g. CommonWell, eHealth Exchange)** |  |  |  |  |
| **State, Regional, and/or Local Health Information Exchanges** |  |  |  |  |
| **Other** (please list): |  |  |  |  |

12. If Laboratories selected in Q10 above: What types of laboratories have sought to limit or refused to provide access, exchange, or use of electronic health information? (Select all that apply)

Hospital-based labs

Commercial labs

Independent labs (not including commercial)

Physician office-based labs

Mobile labs (e.g., Point of Care Labs for COVID-19)

Public health labs

Other. Please list:

1. Which of the following reasons have laboratories used as the basis for limiting or refusing to provide electronic health information to your HIE? (Select all that apply)

Role of CLIA or other federal regulations in restricting them from sending additional data

Fees associated with HIE participation

Labs don’t derive value as a data contributor only

Concerns with HIE’s ability to do patient matching

Concerns with producing duplicate data

Exchanging data with HIEs is not considered related to treatment, payment, or operations and thus would require patient consent

Labs reporting obligation ends with returning result to ordering provider

Public health agencies (including emergency rules) do not mandate reporting to HIE

Labs need consent from each individual provider, resulting in your HIE having to execute multiple disclosure forms (e.g., for each participating health care provider)

Technological reasons/use of specific standards (convenient reason or wide spectrum of what labs are able to do)

Other. Please list:

1. To what extent have you been able to overcome these difficulties to access data from laboratories?

Not at all

To a small extent

Somewhat

To a great extent

Fully

**Additional Information**

1. Initiative or Organization Name:

2. We appreciate your participation. Would you like to receive a copy of our results that will enable you to compare your effort to others in the nation?

Yes

No

3. If you would like to receive a $50 amazon.com gift certificate, please complete the following fields:

Name:

Email:

1. A Qualified Clinical Data Registry (QCDR) is a Centers for Medicare & Medicaid Services (CMS) approved vendor that is in the business of improving health care quality. These organizations may include specialty societies, regional health collaboratives, large health systems or software vendors working in collaboration with one of these medical entities. [(CMS)](https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/A-Brief-Overview-of-Qualified-Clinical-Data-Registries.pdf) [↑](#footnote-ref-3)