2018 Health Information Organization (HIO) Survey

The nationwide survey of HIOs is being led by Dr. Julia Adler-Milstein at the University of California, San Francisco and is sponsored by the Office of the National Coordinator for Health IT (ONC). Over the past eight years our research team has conducted five nationwide surveys of organizations working to promote Health Information Exchange (HIE) to determine the state of current efforts, scope of activities, and financing. Our most recent findings were published in the March 2016 issue of Health Affairs and offered an independent, comprehensive evaluation of HIE progress.

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 HIE efforts. We request a brief amount of your time to complete our survey. Participation is completely voluntary and will contribute to a research study. We realize that you receive many such requests and thank you in advance for your time.

The survey includes questions in three broad areas:

- (1) Organizational Demographics
- (2) Information Blocking
- (3) Implementation/Use of Standards

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. We will create a de-identified dataset to share with ONC.

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).

If you are involved with multiple efforts, 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 effort. We also ask that you respond to survey questions only <u>from the perspective of your organization</u>. 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 <u>do not</u> respond on behalf of local HIOs with whom you work.)

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0990-0379. The time required to complete this information collection is estimated to average 10 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, to review and complete the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

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

Screening Questions

1. As of January 1, 2019 was your organization (select one):

Building (or planning for) the infrastructure or services to support*, or pilot testing, electronic health information exchange across your network (End of survey)
 Supporting* "live" electronic health information exchange across your network
 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 (i.e., between or among those that are not affiliated with one another)**?



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

**Independent entities are defined as institutions with no financial relationship or shared, central governance; HIE between independent entities requires that *at least one* entity is independent of the other(s).

From this point forward, **required** questions are marked with an asterisk.

Organizational Demographics

- 1. Please indicate if your organization is (select all that apply):
 - State HIE or State-designated Entity (SDE)
 - Regional or Local HIE
 - Private, Enterprise HIE
 - Network-of-Networks (i.e., facilitating exchange between networks)
 - Public Health Department or Public Health Agency
 - State Medicaid agency
 - State Government (other than state Medicaid or Public Health)
 - Healthcare Delivery Organization (e.g., hospital, IDN, IPA, ambulatory practice)
 - Health Information Service Provider (HISP)
 - Technology Vendor (End of survey if only this option is selected)
 - Other (please list):

2. *Please report whether **each type of stakeholder is involved** in your HIE in the following ways:

Answer Options	Provides Data	Views or Receives Data	Pays to Participate in HIE
INPATIENT SETTINGS			
Veterans Affairs (VA) Hospital			
Publicly-Owned Hospital (e.g., state, county)			
Private Medical/Surgical Acute Care Hospital			
Private Psychiatric, Rehabilitation, or Long-Term Acute Care Hospital			
Long-Term Care Provider (e.g., nursing home, skilled nursing facility)			
AMBULATORY SETTINGS			
Community Health Center or Federally Qualified Health Center			
Independent Physician Practice or Practice Groups (e.g., IPAs)			
Hospital-Owned or Health System-Owned Physician Practice			
Behavioral Health Provider (e.g., community mental health, SUD/OUD)			
OTHER SETTINGS			
Independent Laboratory			
Independent Radiology/Imaging Center			
Pharmacy			
Public Health Department			
Emergency Medical Service			
Private Payer (e.g., Blue Cross)			
Public Payer (e.g., Medicare, Medicaid)			

Federal Agency (e.g., SSA, VA/DOD)		
Social Service Agency (e.g., housing, transportation, food, financial services)		
FEMA or Other Disaster Relief Organization		
Other (please specify):		

(If in #2 one or more hospital types selected as providing or receiving data):

3. *Within the past year, please estimate the **number of acute care hospitals** (individual institutions, not systems; including VA, public, and private) that are directly connected to your HIE and:

Provide data	Do not know
Receive or view data	Do not know

4. Please ESTIMATE the number of licensed healthcare professionals with prescribing privileges (e.g., MD, DO, NP) who are:

Eligible to participate (e.g., have an "account")	Do not know
Participate (i.e., are active users)	Do not know

5. If you have a **Master Patient Index (MPI)**, please ESTIMATE how many patients are in your MPI and, if known, ESTIMATE what percent have at least one CCDA associated with them?

Estimated Number of Patients in MPI	Estimated Percent of Patients in MPI with CCDA(s)	
Do not know	Do not know	

6a. Please ESTIMATE the **number of EHR vendors** to which you have built interfaces:

6b. Please list **the top 5 EHR vendors** to which you have built interfaces that **represent the largest volume of participants in your HIE**:

Do not know

7. *In which state(s) does your HIE facilitate health information exchange?



8. *For the state(s) selected in the prior question, please select the specific hospital service $area(s)^{\dagger}$ in which your HIE facilitates exchange.

[†] 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]

9. Which of the following services do you offer that are used by participants in your HIE? Select all that apply:

GENERAL SERVICES	
Provider Directory	
Consent Management	
Community Health Record: Aggregation of health information from across the community served by the HIE]
Record Locator Service	
Messaging using the Direct Protocol	
Receive CCDAs	
Parse and store data elements from a CCDA	
Transform other document types or repositories into CCDAs (e.g., MDS, OASIS, Community Health Record)]
Alerting services (e.g., gaps in care) and/or event notification (e.g., Admit- Discharge-Transfer)]
Connection to prescription drug monitoring program (PDMP)	
Prescription fill status and/or medication fill history	
Provide data to third party disease registries (e.g., Wellcentive, Crimson)	
Advanced care planning (i.e., POLST/MOLST)	
Integrating claims data	
Other (please list):	

Services related to VALUE-BASED PAYMENT MODELS	
Providing data to allow analysis by networks/providers	
Generating quality measures	
Validating quality measures	
Reporting quality measures to payers/programs on behalf of participants	
Operating as a clinical registry including a qualified clinical data registry (QCDR)	
Analytics (e.g., risk stratification)	
Other (please list):	

10. Does your HIE: (check all that apply)

Sell/provide your infrastructure to other HIEs	
Buy/use infrastructure from another HIE	
Connect to other HIEs in SAME state	
Connect to other HIEs in DIFFERENT state(s)	

11. *Is your HIE currently using the following national networks to exchange data?

	Operational (i.e., using to sychonyce data)
	Operational (i.e., using to exchange data)
CareinAlliance	

CommonWell	
Digital Bridge	
DirectTrust	
Surescripts	
Strategic Health Information Exchange Collaborative (SHIEC)/Patient Centered Data Home (PCDH)	
e-Health Exchange	
Carequality	
Other (please list):	

12. (If none selected in prior question) Please select reason(s) why your HIE is not operational with any of the national networks listed above? Select all that apply:

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

- Perceive them as competitors
- Participation costs too high
- Not a priority

Other (please list):

No

13. Is your HIE planning to participate in the Trusted Exchange Framework and Common Agreement?

Yes

L

Don't know

14. How is your HIE planning to respond to the proposed Trusted Exchange Framework and Common Agreement:

	Increase	No change	Decrease	Not Applicable
Types of services offered				
Selling/providing your infrastructure to other HIEs				
Buying/using infrastructure from another HIE				
Partnering with HIEs in SAME region/state				
Partnering with HIEs in DIFFERENT regions/states				
Other (please list):				

15. How long has your HIE been operational (i.e., from completion of initial pilot to present):

Less than one year
1-2 years
3-5 years
6-10 years
11 or more years

16. Do you receive funding from a state innovation model (SIM) grant?

Yes No 17. *Do entities participating in your HIE cover 100% of your operating expenses?

Yes No

17a. (If no) Do you expect to earn sufficient revenue from participating entities to cover 100% of your operating expenses in the future?

Definitely not Probably not Maybe Probably will; how long do you expect that it will take? Years Definitely will; how long do you expect that it will take? Years Don't know

18. To what extent does each of the following factors pose a **moderate or substantial challenge** to your development? Select all that apply:

Answer Options	Moderate or Substantial
Competition from other health information exchange efforts	
Competition from health IT system vendors offering HIE solutions (e.g., EPIC's CareEverywhere)	
Stakeholder concerns about their competitive position in the market	
Addressing federal government regulations	
Addressing state government regulations	
Addressing governance issues	
Stakeholder concerns about privacy and confidentiality issues (e.g., HIPAA, consent)	
Stakeholder concerns about cybersecurity issues (e.g., breaches)	
Managing complexity of consent models	
Developing a sustainable business model	
Addressing technical barriers (e.g., procurement architecture, applications)	
Limitations of current interface standards	
Lack of resources to implement interface standards	
Accurately linking patient data/patient matching	
Ability to hire/retain staff	
Integration of HIE into provider workflow	
Other (please list):	

Information Blocking

Section 3022(a) of the Public Health Service Act (PHSA) defines information blocking as a practice that

- is likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information;
- is not required by law and is not otherwise reasonable and necessary; and
- is committed by
 - o a **health information technology developer, exchange, or network** who knows, or should know that the practice is likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information; or
 - o a **health care provider** who knows that the practice is unreasonable and likely to interfere with prevent, or materially discourage access, exchange, or use of electronic health information

	Never/ Rarely	Sometimes	Often/ Routinely	Don't Know
PRICE e.g., using high fees to avoid granting third-parties access to data stored in the vendor's EHR system charging unreasonable fees to export data at a provider's request (such as when switching vendors)				
CONTRACT LANGUAGE e.g., 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 e.g., using artificial technical barriers to to avoid granting third-parties access to data stored in the vendor's EHR system				
REFUSAL e.g., 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):				

19. In what form(s) have you experienced information blocking by EHR vendor(s)?

20. Overall, to what extent have you encountered **EHR vendors** engaging in information blocking?

What proportion of vendors?	Among vendors that engage in information blocking, how often do they do it?
All	Often/Routinely Sometimes

Some Few Don't know or N/A (Don't interact with EHR vendors)	Rarely/Never Varies by vendor Don't know
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- 21. When information blocking by **EHR vendors** occurs, does it vary by vendor marketshare?
 - Yes predominantly by vendors with **large marketshare**
 - Yes predominantly by vendors with **moderate marketshare**
 - Yes predominantly by vendors with small marketshare
 - No does not vary by marketshare
 - Don't know
- 22. In what form(s) have you experienced information blocking by **hospitals and health delivery systems**?

	Never/Rarely	Sometimes	Often/Routinely	Don't Know
ARTIFICIAL TECHNICAL, PROCESS, OR RESOURCE BARRIERS e.g., requiring a written authorization when neither state nor federal law requires it				
requiring a patient to repeatedly opt in to exchange for TPO				
REFUSAL e.g., refusing to exchange sharing of information with competing providers, hospitals, or health systems				
Other (please list):				

23. To what extent have you encountered **hospitals and health delivery systems** engaging in information blocking?

What proportion of hospitals and health systems?	Among hospitals and health systems that engage in information blocking, how often do they do it?
	Often/Routinely
Most	Sometimes
Some	Rarely/Never
Few	Varies by hospital/health system
Don't know or N/A (Don't interact with	Don't know
hospitals and health systems)	

Implementation and Use of Standards

24. Which of the following technical standard(s) does your organization regularly use to access and/or exchange **provider data associated with a provider directory**? Select all that apply:

Exchange standards based on IHE IT Infrastructure Technical Framework Supplement, Healthcare Provider Directory (HPD) Trial Implementation

HL7 v2 MFN interface

Exchange standards based on HL7 Fast Healthcare Interoperability Resources (FHIR)

Exchange based on ASC X12 274

Other (please list):

Don't know

25a. To what extent does your HIE electronically exchange care summaries among providers in a structured format (e.g., CDA, CCR, C32)?

		,	. ,
To	o a great exter	nt (ao to) 25b)

To a moderate extent (go to 25b)

To a small extent or not at all (skip to 26)

25b. To what extent do EHR installations you integrate with use the following templates for C-CDA?

C-CDA Template	All or most EHR installations	Some EHR installations	Few or no EHR installations	Don't know
Continuity of Care Document (CCD)				
Discharge Summary				
Referral Note				
Care Plan				
Other C-CDA templates (please list):				

26. Which types of clinical and other health-related information are made available by/through your HIE (as part of a clinical document or as a discrete field)? Select all that apply: *NOTE: CCDA and CCDS (2015) data types included for reference*

	Included in your HIE	Included in CCDA	Included in CCDS (2015)
Smoking Status		✓	\checkmark
Problems		✓	\checkmark
Medications		✓	\checkmark
Filled Medications		✓	
Medication Allergies		✓	\checkmark
Laboratory Test(s)		✓	✓
Laboratory Value(s)/Result(s)		✓	✓
Vital Signs		\checkmark	\checkmark
Care Plan Field(s), including Goals and		\checkmark	

Instructions		
Procedures	✓	✓
Care Team Member(s)	✓	✓
Immunizations	✓	✓
Unique Device Identifier(s) (UDIs) for a	✓	✓
Patient's Implantable Device(s)		
Assessment and Plan of Treatment	✓	✓
Goals	\checkmark	\checkmark
Health Concerns	\checkmark	\checkmark
Radiology Result(s)	✓ (Diagnostic Image Reports)	
Clinical Notes	 ✓ (Note Section/Note Activity – C-CDA 2.1 Companion Guide 	
Discharge Disposition	✓	
Substance Use Disorder (as defined in 42 CFR Part 2)		
Social Determinants of Health (e.g., housing, food insecurity)	✓ (Veteran's Status/Military History not included)	
Admission and Discharge Dates and Locations	1	
Encounters	✓	
Referrals	\checkmark	
Discharge Instructions	✓	
Family Health History	\checkmark	
Functional Status	\checkmark	
Cognitiive Status	\checkmark	
Gender Identity		
Pediatric Vital Signs	✓	
Pregnancy Status	✓	
Reason for Hospitalization	✓	
Provenance	✓	
Other (please list):		

27a. Does your HIE **engage in delivery of results or other information ("push") to share data with your participants**? Note: delivery of results of other information refers to a one-directional transmission, e.g. through an interface into an EHR or clinical registry.

Yes (go to 27b/c)

Don't Know (skip to 28)

27b. Please ESTIMATE your monthly average volume of outgoing transactions (with or without attachments):

No (skip to 28)

Don't Know

27c. To what extent do EHR installations you integrate with receive what you send using each of the following standards?

	All or most EHR installations		Some EHR installations		Few or no EHR installations		Don't know					
HL7 v2 messages												
HL7 CCDA documents												
HL7 Fast Healthcare Interoperability]									

Resources (FHIR) messages DSTU2 or later)		
Some other open standard managed by HL7 or some other standards development organization		
Some other proprietary standard published by the EHR vendor		

28a. Does your HIE **make data available via participant query to your HIE?** Note: query refers to a query-and-response exchange, e.g. a request from one participant through an interface that results in a response delivered into an EHR.

Yes (go to 28b/c/d/e)

No (skip to 29)

Don't Know (skip to 29)

28b. Please ESTIMATE your **monthly average volume of queries** placed (regardless of whether data available):

Don't Know

28c. Please ESTIMATE the average percent of queries with data returned:

Don't Know

28d. To what extent do EHR installations you integrate with use the following standards to query your HIE?

	Some or most EHR installations	Few or no EHR installations	Don't know
IHE XDS (Cross-Enterprise Document Sharing)			
IHE MHD (Mobile Access to Health Documents)			
IHE XCA (Cross-Community Access)			
NwHIN Specifications for Query for Documents and Retrieve Documents			
HL7 Fast Healthcare Interoperability Specifications (FHIR) DSTU2 or later for data element query			
HL7 Fast Healthcare Interoperability Specifications (FHIR) DSTU2 or later for document query			

28e. What type(s) of responses do you return when you receive queries from your participants? Select all that apply:

Existing documents: respond with documents created by other systems such as EHRs and stored or accessible by the HIE

Dynamic documents: respond with a document produced upon demand from a community health record or other repository of clinical data

Other (please list):

Don't know

29a. Does your HIE exchange health information with other HIEs or private enterprise networks (e.g. integrated delivery systems) that are NOT part of your HIE (e.g., your HIE queries them or they query your HIE)?

Yes (go to 29b/c/d)

No (end of survey)

Don't Know (end of survey)

29b. Which of the following standards do you use to exchange health information with these external entities? Check all that apply

IHE XDS (Cross-Enterprise Document Sharing)		
IHE MHD (Mobile Access to Health Documents)		
IHE XCA (Cross-Community Access)		
NwHIN Specifications for Query for Documents and Retrieve		
Documents		
HL7 Fast Healthcare Interoperability Specifications (FHIR) DSTU2 or		
later for data element query		
HL7 Fast Healthcare Interoperability Specifications (FHIR) DSTU2 or		
later for document query		
Other (please list):		
Don't know		

29c. What **type(s) of query do you place** to HIEs or private enterprise networks outside your HIE? Select all that apply:

Directed to one entity: a query to a single system known or believed to be the source of the information

Directed to many entities: a single query to multiple, named systems that may have information that is returned as multiple documents or single, consolidated document Broadcast: a query to all or a geographic subset of systems where the source of information is unknown, returning multiple documents or single, consolidated document Other (please list):

Don't know

NA—do not place queries

29d. What **type(s) of responses do you return** when you receive external queries from HIEs or private enterprise networks outside your HIE? Select all that apply:

Existing documents: respond with documents created by other systems such as EHRs and stored or accessible by the HIE

Dynamic documents: respond with a document produced upon demand from a community health record or other repository of clinical data

Other (please list):

NA—do not return queries

Don't know