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.)

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)**?
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 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))

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)			

	Fed	deral Agency (e.g., SSA, \	/A/DOD)					
	Social Service Age	ency (e.g., housing, transp food, financial s						
	FEMA or	Other Disaster Relief Orga	anization					
		Other (please speci	fy):					
3. ³	(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		o not kno	W				
	Receive or view of		o not kno					
	Please ESTIMATE th g., MD, DO, NP) who	ne number of licensed h	ealthcare	orofessional	s with prescribi	ng privileges		
	Eligible to partic	cipate (e.g., have an "ac	count")		Do not know			
	Participate (i.e.,	, are active users)			Do not know			
	PI and, if known, EST	IMATE what percent ha		ited Percen	associated with			
		Do not know	00271		Do no	t know		
6b.	☐ Do not kn Please list the top 5	5 EHR vendors to which icipants in your HIE:		·				
7. '	*In which state(s) doe	es <u>your HIE</u> facilitate he	alth inform	nation excha	nge?			
	All Alabama California Distr. of Columbia	Alaska Colorado Florida	_	necticut	Arkansa Delawa			
	Idaho Kansas Maryland Mississippi Nevada New York Oklahoma Rhode Island Texas	Illinois Kentucky Massachusetts Missouri New Hampshire North Carolina Oregon South Carolina Utah	India Louis Mich Mont New North	siana igan ana Jersey n Dakota asylvania n Dakota	Hawaii lowa Maine Minnes Nebras New Me Ohio Puerto Tennes Virginia	ka exico Rico see		

8. *For the state(s) selected in the prior question, please select the specific hospital service area(s) † in which your HIE facilitates exchange.

[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:

all that apply:	
GENERAL SERVICES	
Provider Directory	
Consent Management	
Community Health Record: Aggregation of health information from the community served by the HIE	across
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., OASIS, Community Health Record)	
Alerting services (e.g., gaps in care) and/or event notification (e.g., Discharge-Transfer)	Admit-
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, Cri	mson)
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	
Providing data to allow analysis by networks/providers Generating quality measures	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data reg (QCDR)	
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Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data reg (QCDR) Analytics (e.g., risk stratification) Other (please list): 10. Does your HIE: (check all that apply) Sell/provide your infrastructure to other HIEs	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data reg (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	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data regonomy (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	
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data reg (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	gistry
Providing data to allow analysis by networks/providers Generating quality measures Validating quality measures Reporting quality measures to payers/programs on behalf of partic Operating as a clinical registry including a qualified clinical data reg (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)	gistry

[†] Hospital Service Areas are geographic areas defined by the Dartmouth Atlas.

Digital Bridge					
DirectTrust					
Surescripts					
Strategic Health Information Exchange Collabor (SHIEC)/Patient Centered Data Home (PCDH)	ative				
e-Health Exchange					
Carequality					
Other (please list):					
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): 13. Is your HIE planning to participate in the Trusted Exchange Framework and Common Agreement? Yes No Don't know					
14. How is your HIE planning to respond Common Agreement:	I to the propose	ed Trusted Exch	nange Fram	ework and	
	Increase	No change	Decrease	Not Applicable	
Types of services offered					
Selling/providing your infrastructure to					
other HIEs Buying/using infrastructure from another HIE					
other HIEs Buying/using infrastructure from another HIE					
other HIEs Buying/using infrastructure from another HIE Partnering with HIEs in SAME region/state Partnering with HIEs in DIFFERENT					
other HIEs Buying/using infrastructure from another HIE Partnering with HIEs in SAME region/state					

*Do entities participating in your HIE <u>cover</u> 100% of your op Yes No	erating expenses?
17a. (If no) Do you expect to earn sufficient revenue from 100% of your operating expenses in the future? Definitely not Probably not Maybe Probably will; how long do you expect that it will take Definitely will; how long do you expect that it will take Don't know To what extent does each of the following factors pose a mode your development? Select all that apply:	e? Years e? Years
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
 - 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

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

	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)				
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				
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):				

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 Most	Often/Routinely Sometimes	

	Few Don't know or N/A (Don't interact with vendors)	Var	rely/Never ries by vendor n't know				
	When information blocking by EHR vend marketshare? Yes – predominantly by vendors with large series of the year o	large markets n moderate m small markets	hare arketshare share				
۷۷.	In what form(s) have you experienced intelligence delivery systems?						
ļ		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						
	e.g., refusing to exchange sharing of information with competing providers, hospitals, or health systems						
Į	Other (please list):						
23.	23. To what extent have you encountered hospitals and health delivery systems engaging in information blocking?						
	What proportion of hospitals and hea systems?	engaq they o	ge in informat do it?	nd health system ion blocking, how			
	engage in information blocking, how often do they do it? All Most Some Few Don't know or N/A (Don't interact with hospitals and health systems) engage in information blocking, how often do they do it? Often/Routinely Sometimes Rarely/Never Varies by hospital/health system Don't know						

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							
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 a great extent (go 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?							
CDA?							
C-CDA Template	All or most EHR installations	Some EHR installations	Few or no EHR installations	Don't know			
-	EHR		EHR				
C-CDA Template Continuity of Care	EHR		EHR				
C-CDA Template Continuity of Care Document (CCD)	EHR		EHR				
C-CDA Template Continuity of Care Document (CCD) Discharge Summary	EHR		EHR				
C-CDA Template Continuity of Care Document (CCD) Discharge Summary Referral Note	EHR		EHR				

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

Instructions							
Procedures			√	√			
			√	✓			
Care Team Member(s)			√	✓			
Immunizations			▼	∨ ✓			
Unique Device Identifier(s) (UDIs) for a	³		•	•			
Patient's Implantable Device(s)							
Assessment and Plan of Treatment			✓	√			
Goals			•	√			
Health Concerns			✓ ✓	✓			
Radiology Result(s)			nostic Image Reports)				
Clinical Notes		(Note S	Section/Note - C-CDA 2.1 anion Guide				
Discharge Disposition			√				
Substance Use Disorder (as defined in 42 CFR Part 2)	1						
Social Determinants of Health (e.g., housing, food insecurity)		Stat	√ 'eteran's us/Military not included)				
Admission and Discharge Dates and Locations			√				
Encounters			✓				
Referrals			✓				
Discharge Instructions			✓				
Family Health History			✓				
Functional Status			√				
Cognitiive Status			√				
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) No (skip to 28) Don't Know (skip to 28)							
27b. Please ESTIMATE your monthly average volume of outgoing transactions (with or without attachments):							
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	Some EHR	Few or no	Don't			

	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 refers to a query-and-response exchange, interface that results in a response delivered	e.g. a reques	st from one parti						
Yes (go to 28b/c/d/e) No (ski	p to 29)	Dor	n't Know (skip to 2	29)				
28b. Please ESTIMATE your monthly ave whether data available):	rage volume	e of queries pla	ced (regardless o	f				
Don't Know								
28c. Please ESTIMATE the average percentage	ent of querie	s with data ret	urned:					
Don't Know								
28d. To what extent do EHR installations you integrate with use the following standards to query your HIE?								
		most EHR	Few or no EHI	R Doi	n't know			
	instal	lations	installations					
IHE XDS (Cross-Enterprise Document Sharing)	instal	lations	installations					
Sharing) IHE MHD (Mobile Access to Health	instal	lations	installations					
Sharing)	instal	lations	installations					
Sharing) IHE MHD (Mobile Access to Health Documents) IHE XCA (Cross-Community Access)	instal	lations	installations					
Sharing) IHE MHD (Mobile Access to Health Documents)	instal	lations	installations					
Sharing) IHE MHD (Mobile Access to Health Documents) IHE XCA (Cross-Community Access) NwHIN Specifications for Query for	instal	lations	installations					
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		lations						
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				pants?				

networks (e.g. integrated delivery systems) that are NOT part of 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 hea external entities? Check all that apply	lth information with these					
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 private enterprise networks outside your HIE? Select all that apply						
Existing documents: respond with documents created EHRs and stored or accessible by the HIE Dynamic documents: respond with a document product community health record or other repository of clinical data Other (please list): NA—do not return queries Don't know	ced upon demand from a					