

Public Health Practice within a Health Information Exchange: Information Needs and Barriers to Disease Surveillance

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Abstract

Introduction: Public health professionals engage in frequent exchange of health information while pursuing the objectives of protecting and improving population health. Yet, there has been little study of the information work of public health workers with regard to information exchange. Our objective was to gain a better understanding of information work at a local health jurisdiction before and during the early stages of participation in a regional Health Information Exchange.

Methods: We investigated the information work of public health workers engaged in disease surveillance activities at a medium-sized local health jurisdiction by conducting semi-structured interviews and thematically analyzing interview transcripts.

Results: Analysis of the information work of public health workers revealed barriers in the following areas: information system usability; data timeliness, accuracy and completeness; and social interaction with clients. We illustrate these barriers by focusing on the work of epidemiologists.

Conclusion: Characterizing information work and barriers to information exchange for public health workers should be part of early system design efforts. A comprehensive understanding of the information practice of public health workers will inform the design of systems that better support public health work.

MeSH Keywords: Public Health Informatics, Public Health Practice, Disease Notification, Communication Barriers, Information Services, Health Information Technology

Introduction

Public health professionals work with numerous stakeholders to fulfill requirements for notifiable conditions reporting, disease surveillance and immunizations to safeguard and improve population health (1). However, many local health jurisdictions (LHJs) lack the information and communications infrastructure to effectively engage with technologies and systems that can support access to and/or use of population-level health data (2). A Health Information Exchange (HIE) provides a secure, interoperable infrastructure for electronically moving clinical data between heterogeneous health information systems and its stakeholders, including public health.

Participation in a HIE presents the opportunity to support public health workers engaged in disease surveillance (3-6); however, it is unclear how the public health practice need for HIE data can best be understood and expressed to HIE organizations and stakeholders.

By providing a framework for integrated care management and coordination across the health care setting, HIE efforts are a means for overcoming a fragmented healthcare system in the U.S. HIEs hold great promise for addressing many of the barriers to effective care management by providing complete clinical information at the point of care. By including public health, the information exchange is broadened to population-level oversight, collaboration and coordination, facilitating the real-time ability of local, state, regional, and federal entities to share clinical and facility-based resource utilization information to enhance rapid response to, and management of, potentially catastrophic infectious disease outbreaks and other public health emergencies. In their 2010 annual survey of HIEs initiative in the United States, the eHealth Initiative reported continued increases in the number of initiatives and a significant increase in the number of public health organizations involved in these initiatives (7).

There is a recognized need to better understand health information exchange at the individual, group, organization, and network levels to facilitate system design improvements and successful adoption by stakeholders (8). While the information needs and work of public health practitioners have been the subject of several studies (9-12), existing studies of HIEs are primarily physician- and hospital-focused (13-17). Little work has been done to characterize the information practice of public health workers with regard to the exchange of health information within public health organizations or with external stakeholders. In particular, a comprehensive view of epidemiologists' information practice and communication is important and warranted given the epidemiologist's central role in disease investigation and community health assessment (18, 19). This study explores the public health practice need for HIE data in the context of a LHJ in the early stages of interactions with a HIE organization.

Methods

Semi-structured interviews were conducted in February 2009 with 9 participants at a medium-sized LHJ in Washington State. The LHJ has approximately 250 employees and serves a population of more than 400,000. Participants were drawn from a convenience sample of LHJ employees with a range of job titles and disease surveillance responsibilities. Study participation was voluntary; all participants were consented into the study. Interview questions solicited descriptions of information uses, information needs and exchange of health information related to outbreak investigation and disease surveillance. Study procedures were approved by the University of Washington Institutional Review Board.

Interviews were recorded using a digital audio-recorder. Recordings were transcribed verbatim and imported into QSR NVivo 8 qualitative data analysis software that facilitates coding, analysis, and text searches of documents (20). Three coders (BR, RH, DR) thematically coded the transcripts (21, 22) to describe the characteristics of information exchange between external stakeholders and public health practitioners at a LHJ in the early stages of participation in a HIE.

Codes were created for work activities related to programs and services. The terms “information practice” and “information work” were used interchangeably to refer to routine and impromptu activities and processes involving some form of information and information processing (23, 24) in an organizational setting or community of practice (25). Given that there are numerous conflicting definitions of communication (26), for simplicity’s sake, we used a conventional definition of “communication”: transmission of information from a sender to a receiver (27).

Two coders (BR and RH) independently coded and reconciled three transcripts by discussing discrepancies to ensure consistency in the application of codes (21). Both coders met to compare results and differences were resolved through discussion until agreement was reached. The codebook was reviewed by a third coder (DR) for face validity and consistency. Two coders (RH and DR) partially coded and reconciled a fourth transcript as an additional test of inter-rater reliability. One coder (BR) coded the remaining interviews.

Results

Nine individuals with the following job roles participated in the study: epidemiologist (4), program manager (2), public health nurse (1), health program specialist (1) and administrative assistant (1). See Table 1 for participant job roles and responsibilities.

Table 1. Participant job roles and responsibilities

Participant	Job Role	Responsibilities
Participant 1	Public Health Nurse	Track and manage cases of tuberculosis through interaction with internal and external stakeholders
Participant 2	Health Program Specialist	Conduct surveillance and partner notification for sexually transmitted illness (STIs)
Participant 3	Program Manager	Coordinate community health assessments based on hospital data and other data sources
Participant 4	Program Manager	Manage communicable disease epidemiology and disaster preparedness efforts
Participant 5	Epidemiologist	Conduct communicable disease surveillance and investigation
Participant 6	Epidemiologist	Conduct communicable disease surveillance and investigation
Participant 7	Epidemiologist	Conduct communicable disease surveillance and investigation
Participant 8	Epidemiologist	Conduct chronic disease surveillance and community health assessments
Participant 9	Administrative Assistant	Receive, verify and route STI reports from health care providers to internal or external investigators

All participants reported exchanging information with a number of external stakeholders. Table 2 shows references to unique external information exchange partners made during interviews, grouped by role and exchange partner type. External information exchange partners were

Public Health Practice within a Health Information Exchange: Information Needs and Barriers to Disease Surveillance

grouped into three types based on their characteristics: Healthcare system partners, community and government partners and public stakeholders. Epidemiologists referenced the greatest numbers of unique external information exchange partners. We note that epidemiologists were represented in the greatest numbers in the participant sample.

Table 2. Number of external information exchange partners grouped by role and type

Participant Role	Healthcare System Partners*	Community and Government Partners**	Public Stakeholders***
Epidemiologist	19	5	8
Public Health Nurse	10	2	1
Health Program Specialist	8	1	2
Program Manager	8	1	1
Administrative Assistant	5	1	2

**Healthcare system partners include: local health jurisdictions, the local Board of Health, the U.S. Centers for Disease Control and Prevention (CDC), private laboratories, Medicaid, Medicare, local plasma centers, providers (hospital, non-hospital and unspecified), Washington State Department of Health (DOH) and the U.S. Department of Veterans Affairs (VA)*

***Community and government stakeholders include: other states, community and non-profit organizations, municipal courts and universities*

****Public stakeholders include: clients, their partners and family members, the media, private citizens (“the public”) and local schools*

Public health work is complex, non-linear and dependent on information exchange and data that must be interpreted in context. Documenting public health information practice is important to the design of future information systems that will interoperate to exchange health information. Common characteristics and barriers to the information work of public health workers are described below, with a focus on epidemiologists as frequent exchangers of information. The four epidemiologists who participated in this study all worked in the disease prevention division of the LHJ with different responsibilities related to communicable disease investigation and community health assessment. They were frequent exchangers of health information with external stakeholders in their work of responding to communicable disease reports and requests for population health information from the public and community partners.

Data require context

Public health workers must trust the source, provenance, collection methods and processing of the data they use. The visualization of these data and relationships among them must be clear and understood.

“I think one of the things that’s really hard for people, sometimes, with data sets, is understanding kind of how the data is structured – So what are these variables? And what does this actually mean? And, you know, just really having a codebook

for people that are going to be using whatever sort of database or interface you have .” (Participant Eight, Epidemiologist)

Information practice is non-linear

Information work is non-linear in nature, as described in this narrative of note-taking during investigations.

“I take notes on paper, the reason I like that is because then I can organize my notes based on the conversation so I can see if I’m missing things I want to ask, but if all I’m doing is typing in a single straight line whatever’s coming in to me... they’re bouncing all over the place, so that way I can start here and then move over here because there’s something else, go back over there, come back here...that makes it easier. And then stuff that’s superfluous to the interview I don’t have to input, and – cause it’s not relative to the risk factors... I need a pad that just throws it in.” (Participant Seven, Epidemiologist)

Disease investigations vary

The variable nature of disease investigation is illustrated by this description of investigation details.

“Bare minimum for an interview is usually... 15 minutes, sometimes they go 10 if it’s very uncomplicated... Some of the enteric disease issues, vaccine preventable disease issues are usually a multi-stage interview... We let them know that they can expect a second interview... with the vaccine preventables we always try to contact within the next day... to identify more contacts. So, a lot of those are usually a couple of phone calls of direct contact. But, with the viral hepatitis... if you’re looking at an interview, you’re looking at probably 30-40 minutes by the time you’re doing all the calls.” (Participant Six, Epidemiologist)

Publicly available tools are useful

Web-based tools that have become available in recent years are sometimes used to enhance situational awareness through information exchange.

“It’s not really active surveillance, but we have employed Survey Monkey quite a few times over the last 3 or 4 years... We’re trying to collect some basic information for a large group, that kind of tool is great for us... People sitting at their desks at work can complete it the survey in 10 minutes... We don’t have to interview all [of] them, and so that’s been a great help to us”. (Participant Five, Epidemiologist)

Assessing community health is a complex endeavor

Assessing disease burden can be difficult even if data are available to public health workers through information exchange.

“You know the thing that is super hard for us to talk about is the disease burden in our community, because we look at things that are chronic conditions... for example, diabetes, ‘Oh, well, we’ve got deaths, and we’ve got in-patient hospitalizations, and recently we were able to access ER data’. But does that really tell us how many people have diabetes in our community?” (Participant Eight, Epidemiologist)

Quality improvement efforts rely on good data

Quality improvement efforts are informed by information exchange and involve complex processes based on available data.

“We go by disease and by investigator looking at time from when we received the report to time the investigation starts, so we want to see how timely we are in terms of beginning an investigation, then we look at time from beginning an investigation to the time of completing and investigation... What are the percentage of cases by disease that are completed...? It’s interesting to kind of see, by disease, the difference in terms of how easy it is to complete an investigation, and how long it takes.” (Participant Six, Epidemiologist)

Barriers to Information Exchange

Public health workers experience barriers specific to their work processes with regard to usability, data timeliness, data accuracy, data completeness, and social interactions while collecting data during case investigations (Table 3). These barriers were common to all participant roles.

Table 3. Barriers to Information Exchange for Public Health Workers

Type	Barrier
Usability	Information systems do not match work processes
Usability	Data streams may not be in a usable format
Timeliness	Lag in time for reports to reach public health workers
Accuracy	Information from clients and medical workers may vary
Completeness	Lack of information exchange with other states
Completeness	Client demographic information from labs is often insufficient for investigations
Completeness	Poor denominator data
Completeness	Incomplete vaccination records in the state immunization registry
Social Interaction	Clients may not want to talk to public health workers during investigations
Social Interaction	Investigation questions may be sensitive to clients and public health workers
Social Interaction	Clients may not speak the same language as public health workers

Barrier Type: Usability

Usability: Information systems do not match work processes

Given the non-linear, complex and variable nature of their work, information systems often are not congruent with or supportive of public health work processes. Participants identified issues such as the following: data errors resulting from faulty system logic; inability to record necessary data, such as complete information about food-borne illnesses during investigations, in the information system; inability to track information from phone calls; and information systems that do not capture and show information that is available in other formats, such as vital statistics data from death and birth certificates that are available in hard copy formats. Usability issues related to information systems that do not match work processes can influence overall data timeliness, accuracy and completeness as well as impact the information systems of external stakeholders during case investigations.

“The hassle... when you call a provider is the demographic information. You know they may have the name and date of birth right there, but getting their phone number and name of parents or guardians and the address, and occupation... They’re having to wait... to go to a different screen... to the billing screen to get the address and phone number because it’s not in the medical screen. It seems very strange that it’s so dislocated.” (Participant Seven, Epidemiologist)

Usability: Data streams may not be in a usable format

Clinical data that come to public health workers through the regional HIE may not arrive in a usable format.

“There’s no algorithms applied to it, it’s just raw...You can see diagnosis and ICD9 data without anything applied to it to tell you whether the data is usable or not and some of the numbers are so small that it wouldn’t really matter anyhow.” (Participant Seven, Epidemiologist)

Barrier Type: Data Timeliness

Timeliness: Reporting lags

Participants reported receiving case reports more quickly when they are reported through Public Health Reporting of Electronic Data (PHRED), the Washington State laboratory reporting system (28). However, since PHRED is not consistently used across all labs required to report to the LHJ, this timeliness benefit is not universal. In addition, the local lab does not report through PHRED which delays receipt of notifiable conditions lab reports to public health workers. For those labs that do report through PHRED, not all cases are reported through the system. Cases reported in a less timely fashion are less useful to investigations.

“Just going back to giardia, for some reason, we will get, at the end of the month, every month... a listing off of cases that came in through [the local lab], and some were reported and some were not, so I’m not sure why that happens, and at that point, it’s maybe moot? You know, if we get the report on February 2nd, and the case was diagnosed on January 2nd, well that’s not that helpful.” (Participant Five, Epidemiologist)

Barrier Type: Data Accuracy

Accuracy: Information from clients and medical workers may vary

Public health workers receive information from a variety of sources that must be verified because of conflicts. For example, onset dates as reported by clinicians and clients during investigations may differ by several days.

Barrier Type: Data Completeness

Completeness: Lack of information exchange with other states

Participants reported that the lack of formal information exchange agreements and technology between other states and regions presents a barrier to the information exchange that would support interstate and international collaboration for disease investigations and population health assessments.

Completeness: Client demographic information from labs is insufficient for investigations

Patient name and age are usually provided on lab reports; patient date-of-birth, provider’s name, patient phone number, patient address, patient occupation and parent/guardian information are often missing. When an investigation is warranted and patient demographic data is missing from lab reports, public health workers must contact the provider before calling the client.

Completeness: Poor denominator data

Incomplete data with regard to the number of tests ordered and the number of positive tests results is a barrier to understanding the complete picture of disease in the community.

“We don’t have the number of tests ordered for a particular issue, as a result we have no denominator, so we have no idea...So what we have 10 of this...? It doesn’t tell us anything. It doesn’t tell us that there are... physicians who are ordering this like crazy, because then we could do a provider thing saying... ‘If you have a positivity rate of 1 out of 1000 tests that are done, why are you doing all those tests? Why are you thinking this, when you’re never getting a positive test?’” (Participant Seven, Epidemiologist)

Completeness: Incomplete vaccination records in the state immunization registry

Incomplete immunization data can be a barrier to disease investigations and limit comprehensiveness of community health assessments.

“What’s our immunization rate? Well, we know how many kids exempt when they’re in kindergarten. OK, well, that doesn’t really tell us if the 2 ½ year olds are up-to-date on their immunizations. So, I think that’s one other piece that’s really lacking.” (Participant Eight, Epidemiologist)

Barrier Type: Social Interaction

Social Interaction: Clients may not want to talk to public health workers during investigations

The nature of the disease under investigation may dictate the willingness of clients to interact with public health workers.

“If someone has an acute diarrheal illness, they are usually pretty eager to talk to you. If someone has chronic Hepatitis C, you know, they figure they’ve had that for years, maybe they had a period of time where they were or are using intravenous drugs...it’s: ‘What are you telling me, you’re not telling me anything new.’ ...Some people will hang up on you with those or don’t really want to talk about specific issues about their disease.” (Participant Six, Epidemiologist)

Social Interaction: Investigation questions may be sensitive to clients and public health workers

Questions regarding race and ethnicity can be sensitive issues for both clients and public health workers during investigations.

“The two most important pieces of information that you have to ask a client, which I don’t want to ask the client, is what is your race, and what is your ethnicity, and your ethnicity is either ‘Unknown’, ‘Hispanic’, or ‘Not Hispanic or Latino’... [the client says:] ‘What do you think? I have an accent.’... I can’t do that, you know, I have to ask you the question...” (Participant Seven, Epidemiologist)

Social Interaction: Clients may not speak the same language as public health workers

Lack of common language between clients and public health workers can be a social interaction barrier during investigations.

Limitations

This is an exploratory study and does not capture an all-inclusive view of information practice in the study setting. Although all LHJs provide variations of the same services, results may not

generalize to other health agencies nationally or internationally due to local differences related to organization, culture and population.

Discussion

Our objective was to better understand information practice at one LHJ before and during the early stages of participation in a regional HIE. We conducted and qualitatively analyzed interviews to identify themes that describe information exchange and information work. Information practice within a medium-sized LHJ is a complex endeavor that is characterized by multiple, non-linear information processes. Public health information work is data-intensive and requires data from a variety of sources. Disease investigations vary but follow a basic set of steps, the order of which is determined by specific disease instance, circumstances of the investigation and the work load of individual public health workers. Community health assessments require context and effort even when data are readily available and, as a result, are difficult to automate. Public health workers do not rely on a single, well-designed information system to get their data but employ a wide variety of technologies, including in-house and state information systems, free web-based survey tools and, often, the telephone.

Public health workers face usability barriers when information systems do not match their information work, data are delivered in formats that are not ready to use and data are of poor quality. Data quality barriers of timeliness, accuracy and completeness are common in data originating outside the LHJ. At times, data that are needed to assess community health or conduct investigations are simply unavailable. In addition, lack of data sharing agreements block the exchange of information with external stakeholders. While public health workers have much to gain from better support of their information practice through well-designed technology, other barriers are independent of information systems. However, although public health workers rely on technology tools to support their information practice, much of their work is accomplished through interactions with people. It is unlikely that social interaction barriers will ever be overcome by technology.

Transforming workflows is challenging in the face of disparate information systems, cultures, organizational structures and budget constraints within and external to public health agencies. Building or transitioning to better designs that overcome the usability barriers we identified in this exploratory study may appear daunting but, even in the face of limited funding and short delivery timeframes, these challenges must be met. Human-centered design and methods to improve the usability of information systems are an integral part of public health informatics that have yet to be fully utilized in organizational contexts. Identifying the barriers and facilitators of the information work of public health practitioners would help ensure that public health workers do not reject new systems, duplicate work or develop work-arounds that cause preventable delays and inefficiencies in disease surveillance, outbreak investigation, community health assessment, and other public health work. Although public health processes and work are often characterized as unique to each LHJ context, understanding public health workers' information needs and workflow will not only provide a clearly defined roadmap for improved system design but participatory design of new systems can increase the possibility that these systems will be widely adopted and championed.

Conclusion

Characterizing public health information practice is essential for the design of systems that minimize the investigation of low risk alerts for infectious disease outbreaks and improve targeted and timely surveillance for seasonal outbreaks and other disease events. Public health workers must trust the data they use to make decisions during investigations and assessments of population health. HIEs, as formal organizations, have the potential to improve population health by linking public health practitioners and other stakeholders through information access. Though additional studies are required to describe the full range of information work for all roles in different types of public health organizations, this study has characterized the information practice of one group of public health workers to inform design of information systems that support health information exchange for public health practitioners. As part of future HIE design efforts, we advocate the engagement of public health workers early in the design process.

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Conflicts of Interest

None.

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