

How could health information exchange better meet the needs of care practitioners?

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Keywords

Health information exchange, consent model, evaluation studies, community, information systems

Summary

Background: Health information exchange (HIE) has the potential to improve the quality of health-care by enabling providers with better access to patient information from multiple sources at the point of care. However, HIE efforts have historically been difficult to establish in the US and the failure rates of organizations created to foster HIE have been high.

Objectives: We sought to better understand how RHIO-based HIE systems were used in practice and the challenges care practitioners face using them. The objective of our study were to so investigate how HIE can better meet the needs of care practitioners.

Methods: We performed a multiple-case study using qualitative methods in three communities in New York State. We conducted interviews onsite and by telephone with HIE users and non-users and observed the workflows of healthcare professionals at multiple healthcare organizations participating in a local HIE effort in New York State.

Results: The empirical data analysis suggests that challenges still remain in increasing provider usage, optimizing HIE implementations and connecting HIE systems across geographic regions. Important determinants of system usage and perceived value includes users experienced level of available information and the fit of use for physician workflows.

Conclusions: Challenges still remain in increasing provider adoption, optimizing HIE implementations, and demonstrating value. The inability to find information reduced usage of HIE. Healthcare organizations, HIE facilitating organizations, and states can help support HIE adoption by ensuring patient information is accessible to providers through increasing patient consents, fostering broader participation, and by ensuring systems are usable.

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1. Introduction

The US faces the challenge of improving the quality of healthcare in the midst of a fragmented system while at the same time controlling the rising costs of healthcare. A major component of the federal Health information technology (HIT) policy, as well for many of the states, is the widespread adoption of health information exchange (HIE). HIE systems enable providers electronic access to patient information from several different healthcare organizations [1]. Better access to patient information from multiple sources at the point of care has the potential to improve healthcare: comprehensive patient information can support optimal decision making [2]; the availability or recent diagnostic tests can decrease duplicative testing [3]; better medication information can improve patient safety [4]; complete pictures of patients' patterns of care can improve care coordination; and HIE systems can potentially save money and support public health [5-7].

In hope of realizing these benefits, the federal government has awarded grants totaling \$548 million to help states develop and advance state-wide HIE. This funding for state-level HIE is part of a broader federal government investment of \$19.2 billion towards the modernization of healthcare services through the implementation of interoperable HIT [8]. State HIE funding was awarded to a state government agency, or a non-profit entity designated by the state, to lead the exchange of information between providers within their state and also to work on exchange between states [9, 10]. These state designated entities set state-wide policies, recruit provider participation, and implement exchange technologies. Some states separated the policy-making and actual technical implementation roles between state agencies and their state designated entities [11]. While this funding introduced state-level HIE efforts for the first time in some locations, many states were already home to regional or local HIE efforts operating on a sub-state level. Local HIE efforts included Regional Health Information Organizations (RHIOs), which are non-profit collaborative organizations tasked with the responsibility of establishing information exchange between health care stakeholders in the local community in order to improve cost and quality [12, 13], and other exchange models like enterprise HIE efforts [14] or vendor-mediated exchange [15]. The approaches to HIE vary across states, but often it is the network of networks approach: providers and organizations join a local HIE effort for exchange purposes and the state designated entities serves to connect local HIE efforts to achieve state-wide exchange.

While HIE systems have the potential to improve care and save costs, historically HIE efforts have been difficult to establish in the US [13] and the failure rates of organizations created to foster HIE have been high [16]. The development of interorganizational relationships necessary to create HIE can face organizational, financial and attitudinal barriers [17]. Additionally, when HIE systems are in place for providers to use in practice, technical, usability, and workflow barriers can discourage usage [18-20]. Generally, HIE system usage tends to be infrequent [21-24], suggesting challenges in integrating HIE into the organization's workflow and practice.

Given the historic difficulty with HIE in the US, we sought to better understand how RHIO-based HIE systems were used in practice and the challenges care practitioners face using them. Specifically, the objective of our study was to so investigate how HIE can better meet the needs of care practitioners by:

1. assessing if the HIE system supports its users information needs;
2. investigating workflow-fit;
3. evaluating the systems usability; and
4. using our findings to offer recommendations to those organizations facilitating HIE and to healthcare organizations seeking to use HIE to ensure that HIE is better integrated into patient care services.

With the significant government and local investment in HIE infrastructure, the effective application of those investments within healthcare organizations becomes a critical area of inquiry.

2. Research Methods

2.1 Study Design

In order to understand the myriad of challenges, issues, and applications of HIE in various settings, we undertook a multiple-case study using qualitative methods. We conducted interviews onsite and by telephone with HIE users and non-users and observed the workflows of healthcare professionals at multiple healthcare organizations participating in a local HIE effort in New York State. The state provides a suitable setting for the evaluation of HIE efforts in healthcare organizations and has already invested nearly over \$440 million into the modernization of their healthcare through the HEAL NY program [25-27]. At the time this study took place (May 2013), 11 RHIOs existed in within the state [28] in addition to the state designated entities charged with state-wide HIE.

2.2 Setting & Sites

With the assistance of the New York eHealth Collaborative, the private-public non-profit organization charged with facilitating state-wide HIE, we identified and secured the cooperation of three RHIOs. Our selection criteria the RHIOs inclusion in the study was that they serve three distinctly diverse communities in order to allow maximize variation and comparison [29]. All three of the RHIOs had received public start up and implementation funding through the HEAL NY program and have been in existence for 7 or more years. As indicated in ►Table 1, the three communities provided varying perspectives in relation to the geographic area served, population size, population distributions, provider participation, number of users, year the RHIO HIE system was implemented, and technology offerings. For example, Community A consists of large city in the western portion of the state surrounded by adjacent rural counties, Community B consists of a mostly rural area with small cities area, and Community C includes large portions of the New York City metropolitan area. In all three communities, healthcare organizations are able to engage in HIE activities through the RHIOs HIE service. At the time of the study, all three RHIOs used different commercial HIE platforms to facilitate data exchange. Additionally, the HIE exchange architectures varied between communities, where Community A and C used a federated model and Community B used a centralized model. In a federated model, participating organization locally store and retain control over the patient information and responds to queries when information is requested from other organizations subscribing to the local RHIO effort. In a centralized model, patient data is collected from participating organizations but is stored in a central repository maintained by RHIO. Participating organizations are able to retrieve data through external delivery methods [30]. Also, each RHIO operated a stand-alone query-based HIE web portal where authorized users could search for patients and access their information. In addition to this, the RHIOs also facilitated the automatic delivery of Continuity of Care Documents (CCDs) or other defined sets of electronic message standards designed to facilitate the data exchange of a clinical document between EHRs from different vendors. The three communities also used other services and methods to engage in information exchange activities.

General policies around patient consent for HIE inclusion are set at the state level; in all three communities the rules for how patients are included in, and their data area accessible from, each RHIO were uniform. New York is an opt-in state meaning patients must provide written consent to have their patient information accessible to authorized users. Providers and organizations agree to participate in a RHIO, but those organizations may only view their patients' data after those patients have provided written consent allowing access. Each participating healthcare organization is able to electronically document in their respective HIE system patient consent status, thereby enabling data to be accessed. For this study, the single consent policy provides a specific advantage. Because all three sites operated under the same rules, differences between consent rates likely reflect at least in part the implementation of consent processes within organizations participating in the RHIOs.

2.3 Data collection

Data were collected during two-day site visits to each of the communities served by the three RHIOs. Prior to the site visits, a staff member from each RHIO provided us with an overview of the

HIE effort and an interactive demonstration of their HIE system's interface, data sources, and functionalities. In this way, we were familiarized with the capabilities and objectives of each effort prior to data collection. We also reviewed instruction manuals, recruitment materials, and technical documents from each RHIO.

In each community, we specifically sought informants in primary care and emergency care settings as these settings can face significant challenges in obtaining information about care delivered by other providers. We asked RHIO staff to help identify and secure the cooperation of current, former and non-users of their system users in each of these settings. Informants were eligible to participate in the study if they had knowledge of the RHIO and the HIE system. To ensure that the different point-of-views would be considered, we used a snowball sampling procedure in which we asked each informant to recommend other potential interviewees at that site who could provide additional insight about their experiences with the HIE system. Snowball sampling is beneficial when representation from diverse communities is needed and when identifying participants where there are multiple eligibility requirements [31].

Interviews were conducted at the informant's place of work, using a semi-structured protocol with questions aimed at investigating users experiences of interaction with the different attributes of the HIE system (see appendix 1). Pilot interviews with healthcare service researchers guided the refinement of the original interview guide. The interviews lasted an average of 30 minutes and were audio recorded. Additionally, we observed in-person the processes of obtaining patient consent and how users accessed the HIE system [32]. All observations were documented through the use of field notes.

The data collection process at each site ended when the point of data saturation was reached, that is when the interviews and observations did not produce any new information [33]. From the interviews and field observations, it was possible to create a narrative of how the HIE system was integrated into the daily workflow and user-experience at each site. All data collection began in May 2013 and ended in June 2013.

2.4 Data Analysis

All interviews were transcribed and coded using QSR NVivo 10. The coding process was iterative, using both an initial coding scheme and open codes [34, 35]. We first used categories and codes based on the study objectives and interview protocol. A second cycle of coding took place in which the authors remained open to new codes and categories when appropriate. Using an axial coding strategy, we related the group codes with the same content and meaning into categories. Selective coding was used to analyze patterns and identify emerging themes [36]. The analysis was carried out until theoretical saturation had been achieved, that is when the data analysis ceased to generate any new or distinctive categories, high level concepts, or substantive codes. Two of the authors (PK and JV) coded transcripts independently and frequently reflected on their coding decisions to support 'researcher reflexivity' in order to increase the trustworthiness and credibility of the results [37]. The authors resolved differences through team meetings and discussions to reach consensus. The most revealing quotes were selected to illustrate the results of our analysis.

3. Results

We interviewed a total of 38 healthcare professionals (► Table 2). Overall, we visited 3 EDs and 7 primary care practices. The primary care practices included a federally qualified health center, a community health center, solo practices, and large group practices. Three distinct groups of participants were identified as the users of the RHIOs HIE system: physicians, other clinical users and administrative staff. To preserve individual confidentiality, we only identify the respondents quoted in this study as clinical or administrative users located in either the emergency department (ED) or in any other outpatient setting (i.e. office practice). During our site visits, we observed that all care organizations were equipped with Electronic Health Records (EHRs). The majority of private practices also had access to external systems, such as the local hospitals Picture archiving and communication system (PACS) and EHRs, via physician portals. All care organizations have access to their RHIO's HIE

system through a web portal. However, some primary care providers did not use this feature frequently, but instead relied on the RHIO to automatically “push” clinical data to their EHR through Continuity of Care Documents (CCDs) or other standards of electronic data interchange such as HL7 formatted messages [38]. ► Table 4 summarizes the 8 major themes identified during our analysis that directly addressed the research objectives of this study.

The themes *Availability of information* and *Search confidence* describes user’s perceptions and level of confidence in relation to finding relevant information in the system. *Purpose of usage* and *Frequency of usage* are descriptions of users’ activities and goals for using the HIE system. Informants’ experiences with and perceptions of the HIE systems *Usability* are captured by system performance and information management. Lastly, the themes of *Patient consent*, *Healthcare organization participation* and *non-RHIO related exchange mechanisms* can be loosely considered as contextual factors impacting information exchange.

Although other categories and themes were discovered during the analysis phase, we have chosen not to include them in the manuscript as they were not directly related the research objectives of this study. Additionally, during the interviews we learned of instances where HIE supported users work or helped improve care. Although these “success stories” are not part of the objectives of this study, we felt it was important to document good outcomes from the efforts of these communities. These are not all the examples of efficiency or improvements to care, but these quotes demonstrate the active good work occurring in the communities included in our study. We have provided examples in ► Table 3.

3.1 Supporting the information needs of users

In the case of query-based exchange like the RHIOs’ web portals, it is not sufficient to simply have the technology available. Users must be able to actually employ the system and find the data that they need. The *Availability of information* was critical for continued use and adoption. In all three cases we noted that the perceived availability of information influenced whether practitioners would choose to utilize the HIE system or *non-RHIO related exchange mechanisms*. Among *Community A* and *Community B* users, practitioners are able to retrieve the objective clinical data the majority of the time. However, users *Search confidence* in being able to find information varied as the majority of data they were looking for was nearly always unavailable – even with their respectively high provider participation rates. Users in *Community C* reportedly experienced less available information in the system.

There’s still a lot of patients that have nothing on there, thoughI’d say at least 30% of the time, there’s nothing in the system... (Clinical, outpatient, Community B)
 I would say I get the information I’m looking for like, maybe 70% of the time.... (Clinical, ED, Community A)
 The hit rate for the data I need is very small. It’s less than 5%, which is the biggest reason I think why people aren’t using it and I think why I don’t use it more often. (Clinical, ED, Community C)

Physicians at all three communities reported a low tolerance for failures to find information: if information searching was not success in the first three or four attempts, physicians would abandon usage all together.

The amount of data available in the HIE system was dependent on two key factors: patient consent and healthcare organization participation.

Patient consent is necessary for information to be available to HIE users and one avenue to improve the usefulness of HIE to users would be to increase the number of consented patients. Consent is obviously an individual choice, but healthcare organizations can establish processes to obtain consent and encourage patient consent by being a source of information about the positives of the local RHIO. The sites that we visited indicated that success in obtaining patient consent varied dramatically between Community C and the two other communities. Neither the primary care practice nor the ED participating in Community C had established and implemented regular workflows for securing patient consents. The ED was in a busy, urban hospital, and observation and interviews revealed the registration staff did not prioritize obtaining RHIO consents. The clerks did not possess the skills or knowledge to effectively educate patients, so after experiencing several refusals to con-

sent, the clerks quit trying. In the primary care clinic, after the initial push to obtain consents by RHIO staff stationed in the clinic ended, widespread attempts to get consents dropped off. Eventually, it was primarily case managers who were collecting consents, but that accounted for only a fraction of the clinics total patient population.

So most of the clerks don't push the effort, because they're like, the patients hate the form, they hate the idea of sharing their medical information.....so there's no real training for the clerks to say what it is.... (Administrative, ED, Community C)

As with Community C, after a facility joined the RHIO, both Community A and Community B would station staff members at the location to consent patients and train staff. Unlike, Community C however, Community A and Community B experienced more success due to front staff members explaining the purpose of the HIE to the patients even though many front line staff had not been directly trained by RHIO staff or had only learned about HIE on the job. All cases showed that patients are generally receptive if the care organizations willingly guide and educate the patients on the benefits of having their data made available for sharing on the HIE system.

Once you know you explain to them or even give them that question answer sheet, if they have it, they're usually opt to change their mind, so it is very little percentage of the patients that say no.(Administrative, outpatient, Community B)

I've had a couple that I've had to talk to about it, and once they understand that it's not that everybody can go out there and get their info, and if they want to know who's looking at it, they can get that information. (Clinical, outpatient, Community A)

While these two RHIOs appeared more successful in obtaining consent and responding to patient concerns, they still reported some patients did not understand why consent forms had to be signed at multiple locations and why the extra paper work was needed.

All sites wanted more **Health organization participation** from providers, different types of organizations, and even other RHIOs in order to increase the volume of information available in each RHIO's HIE system.

The other thing that would be ideal would be if [other providers] would link up with [the HIE]. We have a lot of patients that go to [other provider]...they're reluctant to share with any RHIO. (Clinical, outpatient, Community B)

[the HIE] incorporates most of the nursing homes, which is a large amount of our population, especially the population who cannot provide history and the population.. I do believe having more primary physicians would also be helpful...Obviously the more facilities, the better, the higher the hit rate will be. (Clinical, outpatient, Community C)

We have a couple sites [other providers] that are very close to Buffalo. (Administrative, outpatient, Community A)

Additionally, respondents from all three RHIOs noted the inherent challenge with geographically-based exchange: patients saw providers served by other exchanges.

We see a ton of students from downstate. It would be great to have their information. They say, "I saw my cardiologist on LI, but I can't remember what he said." That information would be great. (Clinical, outpatient, Community B)

We have a lot of patients who use Manhattan facilities, as I'm sure every outer borough has and Long Island probably has. So I think that that would be the biggest help. They may not live there, but their data is there. (Clinical, ED, Community C)

We do need to hook up with Buffalo's RHIO. (Clinical, outpatient, Community A)

Even among users that were supportive of the RHIOs' efforts to foster exchange saw this as a limitation that needed to be addressed. One private practice physician noted the need for nationwide exchange given their large "snow bird population" that traveled annually to Florida.

3.2 Workflow Fit

Interviewees reported that the **Purpose of usage** for their interaction with the HIE system was to overcome information sharing and gathering challenges. These included all types of clinical information: medications, radiology reports & imaging, and prior laboratory test results. In Community A and Community B, the HIE systems enables the access of actual radiology imaging in addition to reports and that feature was very popular with users.

It's a wonderful resource because we can't always access the information through the computers for other practices. So if they're signed up with [the RHIOs] through the other practices, then we can utilize the information from one resource, which is very nice. (Clinical, outpatient, Community B)

An emergency physician using the system in Community C reported that the HIE is accessed to help identify potential drug seekers and another physician participating in Community A described how historical laboratory data can help make more informed decisions around care.

I've used it occasionally when I question a patient's use of medications. And try to promote it in house, which it's a big topic and I don't think it's been adopted fully yet. (Clinical, ED, Community C)
Just looking for a historical data, patient's creatinine values. Typically, is this a new anemia? Is this a chronic anemia? [Does] the patient have a creatinine of 2.5? Is it always 2.5? Is it up from normal? And that kind of stuff. (Clinical, ED, Community A)

Each of the EDs and primary care sites observed had "active" users. However, the **Frequency of usage** varied between the RHIOs, the settings of care, and professional types. In general, physicians rarely accessed the HIE web portals due to workflow disruptions and their own EHR systems providing the necessary information. However, most facilities had at least one physician "champion" who was an active user of the HIE web portal, but usage was most common among other professional types.

I don't use it that often. I've probably used it once a month, once every other month in the last year. (Clinical, ED, Community C)
I don't actively go on the portal itself, because for my electronic medical record it's one other step that I'd need to do that I haven't found that helpful yet, mainly because I use it so infrequently I forget the password since it's [HIE portal] not connected with our EMR. (Clinical, outpatient, Community A)

Often, we noticed that some physicians delegated the task of interacting with the HIE systems to obtain information to proxy users. While physicians were the ultimate consumers of the information, it was the responsibility of medical scribes, clerks, case managers, and assistants to actually use the HIE system. For example, in the ED, use-by-proxy was exclusively for the web-based portal HIE system. After retrieving the data, the proxy users would relay the information to the physician during the point of care. In the ED, proxy use varied from the ad-hoc to the codified. As an example of the latter, the ED participating in Community B provided dedicated medical scribes to physicians whose role was to retrieve clinical information and relay it to the physician. This setting had a high frequency of usage as a result.

"We're using this all the time." (Clinical, ED, Community B)

In primary care settings, physicians would not only rely on proxy users to access the web portal, but left the task of reviewing and parsing the data delivered via CCD for inclusion in the EHR to other staff members. Again, proxy usage could be fairly informal (asking an available staff member to retrieve information), or it could be much more structured. One large practice gave the job of parsing CCDs to assistants who were trained on the respective physician's preferences for existing information and historical labs. Because of the availability of both "pull" (the web portals) and "push" (CCD delivery), overall usage or reliance on HIE for data tended to be much higher in primary care settings than in the emergency departments.

3.3 Usability

In addition to having data in the system and being able to locate it, the design, functionality, and performance of the system must not create barriers to usage. In the case of each RHIO's portal, **Usability** was a concern for physicians who saw the login process as disruptive care processes and a significant barrier given the limited time available to treat patients. Other concerns raised involved the systems slow response time.

It's been a struggle to get people to use [the HIE] because of that extra login and the learning curve, which I think is not much of a learning curve, but others do. I think it's that extra login and having to go to yet another site... (Clinical, ED, Community B)

Changing screens, definitely goes past the point where you want to shut it off. I mean, for most people in outside a second. So it's not slow - it's barely even moving, but it's slow enough that's noticeable, that using it is slow. (Clinical, ED, Community C)

A clunky system, and by no means are [physicians] going to accept it with open arms... [physicians] don't want anything to do with it, let alone remembering a second log in or tenth log in, and then having to deal with fumbling around a system when we already have a bad EMR to begin with... (Clinical, ED, Community A)

Because proxy users were often delegated the task of interacting with the HIE system and not engaging in the dual task of providing care to patients, they did not perceive the portals as particularly slow or the step of logging into another system as that onerous in comparison to physicians.

Informants in primary care settings raised additional concerns about the automatic delivery of CCDs and HL7 messages. In their case it was not that HIE was too slow, it was that HIE was too efficient in delivering large quantities of information. The volume of information was too much for the practice to handle.

[Automatic delivery of information] is a little inundating, because we get that every single time. It's not since their last visit or since the beginning of the year, it's all their information that [the HIE] has (Administrative, outpatient, Community B)

We've turned [automatic information delivery] off because of course I don't want to see the labs every single day that a person is in the hospital (Clinical, outpatient, Community A)

So that's been the biggest problem for us as physicians in trying to handle the volume and the flow in such a rapid succession. The problem with having structured data without human or physician or practitioner evaluation is that when I get labs back, three quarters of them are considered or flagged abnormal, but it might be because of a small thing ... not clinically relevant to what we need. So often, you can't sift the wheat from the chaff. (Clinical, outpatient, Community A)

4. Discussion

Our investigation of three communities served by three operational RHIOs revealed differing approaches to system utilization, different user experiences, and contextual factors that were integral to workflow fit and user perceptions. Our findings indicate that HIE can be successfully used to meet the needs of healthcare practitioners and support their workflow. However, HIE still faces several hindrances that are preventing it from reaching its full potential and demonstrating value to physicians (e.g. usage of HIE supports patient care). The important determinants of system usage and perceived value include users experienced level of available information and the fit of use for physician workflows. Fortunately, these issues of workflow-fit and information availability are amenable to both policy-based and technological solutions. There are opportunities for all concerned (healthcare organizations, RHIOs, and the state policy makers) to implement improvements around patient consent, provider participation, and interconnectivity to help HIE better meet the needs of care practitioners.

In line with the first objective of this study, our results reveal that HIE systems can better support the information needs of care practitioners if there is an increase in the number of patients consented into the system and more access to comprehensive patient data is made available through the

expansion of patient data sources through an increase in provider participation and interconnectivity between HIE systems. Addressing these problem first would help minimize the challenges associated with the poor availability of information in the system and users low levels of search confidence. Such problems often leads to reduced usage of HIE [20]. We propose the following recommendations as to how these challenges can be addressed.

First, the low number of patients consented into the system is an issue that originates with the patients first point of contact – the front desk staff. Universally, the front desk staff, such as registration clerks, were responsible for obtaining patient consents and therefore could either enable or limit the extent of availability of information inside the shared through the HIE services. Other investigations have noted issues around obtaining patient consent [39], but our findings highlight the important role of these non-clinical members of the healthcare organization. More than often, our study revealed that the lack of formal training of front desk staff in interpersonal skills and presentation methods presented a stumbling block in obtaining consent due to their inexperience on how to educate patients concerning the value of HIE and how it would benefit the quality of their care. Organizations seeking to increase the usefulness of HIE for their users and providers should consider providing additional training and support for front desk staff in terms of their interacting with patients in order to obtain their consent. The implications of our study reveals that building the internal capacity to provide persuasive justifications for consent and a culture of being pro-active in obtaining patient consent are critical. While the front desk staff work consists of established verbal routines with patients [40], they are unlikely trained in handling relationships with patients [41], as their role primarily responsibilities involves administrative and clerical tasks such as “checking-in, booking appointments, filing, coding and directing” [42]. More skills in interpersonal relationships with patients and persuasion may be very productive in obtaining patient consent. At a minimum, better integration of consent processes into work routines should help consent rates [43]. Without additional support or formal training of new staff, staff turnover could erode even successful organization’s ability to obtain patient consents. An emphasis on front desk staff’s acceptance of information exchange would be a relatively new area of focus for organizations as usually most attention regarding HIE and information technology acceptance is focused on physicians and clinical staff.

Second, care practitioners access to the range and comprehensiveness of patient data was often due to low provider participation in HIE and non-RHIO related exchange mechanisms. For health information exchange to better support the information needs of care practitioners, providers must have access to a wide, and nearly comprehensive, range of data sources. Historically, increasing provider participation in HIE has been a RHIO responsibility. However, that approach may have reached its limits of effectiveness, or at least may be in a period of diminishing returns. Users in this study wanted more providers participating, but that is within the context of numerous forces that should increase participation: providers generally wanting the information made available by HIE systems [44], extensive state and federal funding for practices to implement EHRs [9, 45], Meaningful Use criteria that require exchange capabilities [46], and (at least in New York) RHIOs that have been operational for multiple years. Currently, providers have multiple options to meet Meaningful Use requirements that do not require the on-going exchange of data with a wide-variety of community providers as in the RHIO model. Exchange models like vendor-mediated exchange or enterprise HIE efforts may be limiting participation in RHIO and therefore limiting data available to RHIO users [47]. To address this option, the state could require providers to participate in a RHIO. An alternative solution would be to require all non-RHIO health information organizations (like enterprise HIE, vendor-mediated exchanges, integrated delivery systems, or even accountable care organizations) to make patient data accessible to individual RHIOs via the state-level exchange network. This would leave individual providers free to engage in exchange relationships that meet their business needs, but would prevent the further development of information silos. As needed for patient care, users would be able to query patient information regardless of source and it would treat other types of HIE organizations in the same manner as other RHIOs in the area of interconnectivity. RHIOs and those implementing HIE systems have roles in addressing the above challenges. However, they are more directly responsible for the technological concerns of system usability and handling the volume of information. State policy interventions could also address all three of these factors (patient consent, provider participation, and interconnectivity) that are limiting the information available to providers through HIE. While individual organizations can strengthen the HIE consent

process, as we recommend above, this is really a piecemeal approach. State policy could uniformly remove the limitations of consent processes by shifting from an opt-in policy to an opt-out model. As the name implies, under this approach patients are assumed to have consented to have their information made available to providers unless they specifically rescind that access. New York selected an opt-in model after a state-wide collaborative process, but that policy could be revisited. A large proportion of states have selected opt-out approaches or even more nuanced levels surrounding specific types of data and health conditions [10]. The wide variation is again reflective of the US' historical approach of letting states and even localities tailor HIE efforts to their own political and social environments [13, 48]. Opt-out models address the logistical challenges of obtaining consent and increase patient participation [10, 11], it is already in use for public health's immunization information systems [49], and would allow individual RHIOs and organizations to redirect resources away from obtaining signatures to other areas of operation. Additionally, studies have revealed that patients are generally supportive of HIE and comfortable with their information being made available to providers [50-52]. However, opt-out models are not without challenges in terms of ensuring patient comprehension and choice [53]. States choosing an opt-in consent policies need to be ready for wide variation in consent rates [43] and their potential consequences on HIE usage with alternative means of public education and provider support.

In relation to the second and third objective of this study, our findings suggest the need for technology based improvements to better the usability of systems and their workflow-fit. In our study, physicians reported workflow challenges due to several factors that have caused disruptions to their workflow such as a slow system response time and multiple logins. Single sign-on or more context-aware system integration are necessary to increase usage of the RHIOs' web-based portals, especially for physicians [20, 54]. Interestingly, our interviews also indicated that the more information presented to the users may not always be better. Previously, the amount the impact of information shared on patient perceptions of HIE has been discussed, however, with this study we were able to get some insights of the impact on HIE users [55]. Given the efficiency of technology, the amount of patient information that can be shared may outpace any individual's or organization's ability to effectively use it. The automatic delivery of recent patient information through CCDs or HL7 messages may provide many conveniences, but the information needs to be filtered to provide better overview of meaningful information for clinicians. For example, providers were uninterested in discontinued prescriptions, tired of clinically irrelevant labs, or did not want to deal with every lab result generated during long hospital stays when they only wanted the relevant information from the discharge summary. To minimize usability challenges, RHIOs could benefit from increasing physician involvement during the HIE systems design process using participatory design techniques [56], and conduct pilot implementations prior to exposing their system to a larger number of providers [57].

This study also raises the discussion that the idea of a "user" of HIE requires clarification. Previous evaluations of query-based exchanged portals have found that providers can obtain HIE generated information indirectly, such as having frontline office staff print records [20, 58]. In the settings of this analyses, the practice of use-by-proxy was more extensive and often was more formalized. The more extensive proxy usage was a result of multiple forms of information exchange technologies in use at the sites. Whether it was query-based or point-to-point transmission approaches to HIE, providers relied on other users to access the information on their behalf. While this practice of proxy usage could remain ad-hoc, in some settings it was highly formalized with specific job titles and responsibilities. The use of proxies effectively places a filter between the ultimate consumer of the information and the information system delivering patient information. This is not necessarily bad, as some proxy users were clinically trained and had close working relationships with their providers that refined information sharing techniques, but the practice can pose challenges for, user acceptance, design, and evaluation. For one, the presence of proxy users indicates the system, either in terms of functionality or workflow fit, is not meeting the needs of providers. Also for those implementing HIE, the frequent reliance on proxy users really raises the question, for whom are these systems designed? If systems are designed in anticipation of physician users, then the technology may not actually be a good fit for the workflow and cognitive practices of non-clinicians who are retrieving data. Lastly, quantitative studies attempting to examine the relationship between HIE usage and patient or organizational outcomes should take into account that use-by-proxy as an important method of system usage.

Although based on experiences in New York, several of the suggestions above are relevant to other states and the international communities. For example, ensuring ease of use and workflow fit are critical for healthcare professionals engaging in HIE worldwide [18, 59, 60]. Likewise, inadequate organizational support can lead to technology implementations failures [61]. Finally, many other states are like New York and have selected an opt-in policy [62], which will make an effective patient consent process paramount [39].

Study limitations

First, this is based on three communities and would benefit from additional comparative analysis of other exchange efforts in New York and elsewhere. New York has invested heavily in technology and the users' tended to be very knowledgeable about HIE and RHIOs. Other RHIOs or HIE efforts with more recent histories may have other user experiences. Likewise, while each RHIO facilitated exchange, in effect it provided multiple technological interventions. Our respondents clearly distinguished between query-based and point-to-point transmission exchange and many of the contextual factors were pertinent to both. Nonetheless, the multi-modal HIE environment with generally voluntary usage of the query-based HIE may not be reflective of all RHIO efforts and user experiences. Also, we were only able to interview one private clinic associated with Community C, which happened to be a relative new adopter. Both factors may have limited the range of experiences we documented. Also, the processes involved in our data collection has some disadvantages as snowball sampling can lead to selection bias [63] and observations can result in participants modifying their natural behavior [64].

5. Conclusion

Making patient information more available to providers at the point of care is a critical piece of US health information technology policy. Our findings indicate that HIE can be successfully used to support the information accessibility needs of healthcare professionals. However, challenges still remain in increasing provider adoption, optimizing HIE implementations, connecting HIE systems across geographic regions, and demonstrating value. Healthcare organizations, HIE facilitating organizations, and states can help support HIE adoption by ensuring patient information is accessible to providers through increasing patient consents, fostering broader participation, establishing connections between HIE networks, and by ensuring systems are usable.

Clinical Relevance Statement

Healthcare organizations can benefit from the use of health information exchange (HIE) systems. However, several difficulties exist in integrating HIE into the organization's workflow and practice and the failure rates of organizations created to foster HIE have been high. Findings from this study suggest policy-based and technological solutions that can be implemented by individual healthcare organizations, RHIOs, and the state to address these challenges.

Author's contributions

Patrick Kierkegaard and Joshua R. Vest conceptualized the design of the study, guided data collection and analysis, and drafted the manuscript. Rainu Kaushal conceptualized the design of the study and provided critical manuscript feedback.

Conflicts of interest

The authors declare that they has no competing interests.

Protection of Human and Animal Subjects

The Institutional Review Board of Weil Cornell Medical College approved this study. The present study was conducted after receiving written and oral informed consent from each participant.

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Table 1 Organizational characteristics and exchange features of regional health information organizations included as case study sites.

| | Community A | Community B | Community C |
|---|--|--|---|
| Geographical area served | Western NY | Southern NY | New York City Area |
| Year RHIO established | 2006 | 2005 | 2005 |
| Year RHIO HIE system was implemented | 2007 | 2010 | 2008 |
| Total population of area | 1.4 million | 340,000 | 2.5 million |
| HIE Platform | Axolotl's OptumInsight | Info Cloverleaf Hosted HIE | InterSystems HealthShare |
| Total patients consented as of June 2013 | >800,000 | >150,000 | >250,000 |
| # of users | >2,900 | >2,400 | >1,800 |
| Exchange architecture | <ul style="list-style-type: none"> Federated model Users log into a standalone web portal to retrieve longitudinal patient information. Automated, electronic delivery of imaging and laboratory results to outpatient providers' EHRs. | <ul style="list-style-type: none"> Centralized model Users log into a standalone web portal to retrieve longitudinal patient information. Automated, electronic delivery of imaging studies, laboratory results, and Continuity of Care Document/Continuity of Care Record to EHRs. Results accessible to physicians via iPhone app. Patient portal. | <ul style="list-style-type: none"> Federated model Users log into a standalone web portal to retrieve longitudinal patient information. Secure clinical messaging. Event (e.g. admission) notification. |

Table 2 Number of organizations visited and individuals interviewed by regional health information organization.

| | Community A | Community B | Community C | Total |
|-----------------------------------|-------------|-------------|-------------|-------|
| Setting | | | | |
| ED | 1 | 1 | 1 | 3 |
| Outpatient office | 3 | 3 | 1 | 7 |
| Professional type | | | | |
| Physicians | 4 | 4 | 4 | 12 |
| Other clinical users ¹ | 2 | 5 | 1 | 8 |
| Administrative ² | 7 | 6 | 5 | 18 |
| Total interviews | 13 | 15 | 10 | 38 |

¹includes: nurses, pharmacists, medical / physician assistants, medical scribes.

²includes: receptionists, medical records, registrar, information technology specialist

Table 3 Quotes demonstrating HIE “success stories” in the communities included in our study

Last week, there was a stroke patient, and he was explicitly denying any sort of anticoagulation therapies or treatments. But when we were looking in [SYSTEM], we found that he was on anticoagulation therapy. So he had a thrombotic stroke, so they were deciding whether or not to give TPA, which if we hadn't had access to his information and we had given that drug he would have essentially died. (Clinical, ED)

I have a patient [with] some abnormal thyroid studies. I sent her to the specialist who then sent her to a surgeon. She had her thyroid removed. Apparently, per the patient, the surgeon told her that she didn't have cancer, and then somebody from the endocrinologist told her that she did have cancer. She called me and said, "What's going on?" I was able to look at the path report and see that she did in fact have cancer of the thyroid. That was definitely helpful to me because she's calling me, asking me for answers. (Clinical, outpatient)

So now, in real time, with the patient usually still there, we can get that information, so it's saving some duplication of effort on everybody when the information there. (Clinical, outpatient)

Where I found it the most useful is basically, in our setting, we get a lot of drug seekers. So they may have gone to another facility an hour before, a day before but I can actually get that information. (Clinical, ED)

Table 4 Description of major themes identified and criteria for categorization

| Theme | Definition |
|---------------------------------------|---|
| Purpose of usage | The reason of motivation for practitioners to use the HIE System |
| Frequency of usage | The amount of times practitioners chose to use the HIE system when providing patient care. |
| Availability of information | Determining whether the data inside the HIE provides practitioners with the clinical data that they are searching for. |
| Patient consent | The patients decision to sign the RHIOs consent forms to allow the care organizations to retrieve data through the HIE. |
| Healthcare Organization Participation | The choice of other organizations enabling the sharing of their data through the HIE. |
| non-RHIO related exchange mechanisms | Situations where data is unavailable because another system is being used for health information exchange purposes. |
| Search Confidence | The level of confidence that a patient can be located in the HIE. |
| Usability | The HIE user-interface and integration into the practitioners workflow. |

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