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Sociotechnical Analysis of Health Information Exchange Consent Processes in an HIV Clinic

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Abstract

Federal regulations have encouraged the electronic sharing of protected health information (PHI). As an opt-in state, New York abides by an affirmative consent model where PHI is electronically shared only after written consent is obtained. The purpose of our study was to describe sociotechnical factors that influence health information exchange (HIE) consent for persons living with HIV (PLWH) at 1 clinic in New York City. We employed mixed methods to gather perceptions of facilitators and barriers to HIE consent. Study participants included PLWH, staff and clinicians. The mixed methods approach revealed multiple interruptions in clinical workflow, staff and providers' time constraints and lack of dedicated personnel focused on HIE consent as the major barriers to HIE consent. Although there is no one strategy to resolve barriers to HIE consent, having a dedicated person was identified as the most salient factor for facilitating HIE consent.

Keywords

health information exchange; informed consent; persons living with HIV; sociotechnical analysis

HIV is an epidemic that currently affects 1.2 million persons residing in the United States (Centers for Disease Control and Prevention [CDC], 2013). Ethnic and racial minorities and

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those from disadvantage backgrounds are disproportionately affected (CDC, 2012). Continuity of care is essential for persons living with HIV (PLWH) and past work has supported linkage and retention in care as fundamental to assuring positive health outcomes, namely, viral suppression (Cheever, 2007). A key component of continuity of care and its resultant positive outcomes is the ability of health care providers to electronically access protected health information (PHI), such as patient medical records (Gordon et al., 2012; Schnall, Gordon, Camhi, & Bakken, 2011; Shade, Steward, Koester, Chakravarty, & Myers, 2015).

Federal initiatives have encouraged the electronic sharing of PHI to improve health care delivery and patient outcomes (Blumenthal & Tavenner, 2010; Kern, Barron, Abramson, Patel, & Kaushal, 2009; Tripathi, Delano, Lund, & Rudolph, 2009; Williams, Mostashari, Mertz, Hogin, & Atwal, 2012). Health information exchange (HIE), can facilitate important improvements in health care quality and efficiency by enabling the interoperability of patient health information (Kuperman, 2011). For example, in one study in the Emergency Department, access to additional clinical data through the HIE significantly reduced the number of laboratory tests and radiology examinations performed (Yaraghi, 2015).

Regulations related to HIE and meaningful use were designed to encourage implementation of technologies to provide clinicians, health care organizations, and public health entities with electronic information needed to enhance patient care (Furukawa et al., 2014). Currently, no standardized processes mandate how PHI is electronically shared in HIE and each state has its own jurisdiction over the sharing of PHI between patients and providers (Goldstein & Rein, 2010; Gray, 2011). At the same time, research has shown that limited consent requirements improve HIE and, ultimately, the information available to providers to support optimal care (Downing et al., 2016).

As an opt-in state, New York abides by an affirmative consent model where PHI is electronically shared only after written consent is obtained (Goldstein & Rein, 2010), and PLWH have additional protections in regard to disclosure of an HIV diagnosis through New York State (NYS) Public Health Law Article 27-F (Klein, Karchner, & O'Connell, 2002). The opt-in model in NYS places barriers to sharing PHI, which may be seen as beneficial given the history of fear and discrimination that PLWH have encountered, such as the additional protection of a required written consent to share. Yet these barriers may also discourage the sharing of PHI between providers and patients, which may negatively affect health outcomes. Given the current opt-in model in NYS, it is important to understand the sociotechnical factors that influence the decisions of PLWH to provide written consent to electronically share PHI via HIE. As a step to address this knowledge gap and provide a foundation for the design interventions that promote PLWH consent for HIE, the purpose of our paper was to explicate the factors that have influenced HIE consent for PLWH through a mixed methods study.

Conceptual Framework

The sociotechnical model that guided the study had eight domains and was premised on safe and effective health information technology (HIT) usage and the understanding of HIT-

related interventions, work processes, and the interdependent relationships between the domains (Sittig & Singh, 2010). These domains were: (a) hardware and software; (b) clinical content; (c) human-computer interaction; (d) people; (e) workflow and communication; (f) internal organizational policies; (g) external rules, regulations, and pressures; and (h) system measurement and monitoring (Sittig & Singh, 2010). The model dimensions, definitions, and operationalization of the dimensions for our study are summarized in Table 1.

Materials and Methods

Study Design

The observational study employed mixed methods. These included: (a) ecological scan (internal and external; Graham, Evitts, & Thomas-MacLean, 2008) for local, state, and national context; (b) registration database query to determine HIE consent rates; (c) observations using contextual inquiry (Beyer & Holtzblatt, 1997; Ho, Aridor, & Parwani, 2012) to describe workflow processes; and (d) focus group and individual interviews to gather perceptions of facilitators and barriers to HIE consent.

Sample and Setting

The study was conducted at an outpatient HIV clinic of a large urban academic medical center. The clinic population consisted of 1,661 PLWH with the predominant payer sources of Medicare and Medicaid. The average age of the clinic population was 52 years; 45% were women and 65% Latino. The HIV clinic had a comprehensive staff of 18 full-time and 21 part-time staff consisting of primary care physicians, a gynecologist, a neurologist, psychiatrists, nurse practitioners, medical fellows, registered nurses, social workers, a nutritionist, and a medication adherence educator. Of the clinic population, a sample of 12 PLWH patients participated in the focus group sessions and 4 clinicians participated in interviews. All registration clerks ($N = 4$) and patient navigators ($N = 3$) from the clinic participated in the study.

Procedures

The study protocol was approved by the Columbia University Medical Center Institutional Review Board prior to the initiation of any study procedures. Data collection and analysis methods and study samples are summarized in Table 2. The methods used to conduct our study included an ecological scan, queries of an existing database, observations, semi-structured interviews, and a focus group.

Ecological scan—An ecological scan (Graham et al., 2008) was used to assess external and internal influences on consent for HIE as an important context for understanding HIE consent in the study setting. Internal sources of information were organization documents such as the clinic HIE consent and operating policies and procedures that were retrieved from the organization's intranet. External sources of information included the current NYS HIE policies (Kern et al., 2009; New York eHealth Collaborative, 2012), the governing rules and regulations of Meaningful Use (Blumenthal & Tavenner, 2010; Steinbrook, 2009), and the Health Insurance Portability and Accountability Act (Steinbrook, 2009); these were retrieved from public Web sites.

Registration database query—Data regarding consent rates and the clinic population were obtained through a query of the patient registration database.

Observations—The technique of contextual inquiry (Beyer & Holtzblatt, 1997; Ho et al., 2012) was used during clinic observations to understand the workflow processes of the clinic's registration clerks. The four components of contextual inquiry are (a) gaining context by going where the work is being performed, (b) articulating the work experience through shared inquiry, (c) clarifying observational findings with participants, and (d) maintaining focus with the topic of interest (Beyer & Holtzblatt, 1997). Three observers (RR, SZ, HI) documented the workflow processes of the four registration clerks over a 2-day period for a total of 10 hours of clinic time (4 hours morning and 6 hours afternoon) using a pen-and-paper format. The observers then compared their field notes and discussed their observations. One observer (RR) transformed the field notes from the observations into a flow chart of the clinic registration process and a sequence diagram that described one PLWH registration process. These were reviewed with other observers to ensure that they were valid representations of the observations and with another member of the research team (SB) to assess the completeness and comprehensibility of the diagrams.

Semi-structured interviews and a focus group—A convenience sample of stakeholders (PLWH, clinic registration clerks, clinicians, and patient navigators) was recruited to elicit perceptions of facilitators and barriers that influenced consent to HIE at the HIV clinic. PLWH and patient navigator data were obtained via focus groups; other data were gathered via individual interviews. Focus groups and interviews were led by a member of the research team using a structured interview guide (RR), professionally transcribed, and analyzed thematically to describe the perceived facilitators and barriers to HIE consent. Data were initially coded by one author (RR) and then reviewed by a second (SB). Differences were discussed to achieve consensus on the final themes.

Results

The study results are presented by model dimension and synthesized across data collection methods when more than one method related to the model dimension.

Hardware and Software, Clinical Content, and Human-Computer Interface

The hardware used for the clinic registration included a hospital desktop computer with a single monitor. The process of registration was triggered by the registration clerks having to logon to three different registration software systems. Software applications included: (a) Eagle 2000, (b) Allscripts/Eclipsys, and (c) Sorian. Eagle 2000 was used for patient registration and real-time insurance eligibility verification through the Department of Health. The second software program, Allscripts/Eclipsys, was used by the registration clerk to enter data into the patient's medical chart and alerted the health care provider that the patient was ready to be seen. The third software program, Sorian, was used to schedule follow-up visits after completion of a health care encounter. Eagle 2000 and Allscripts/Eclipsys were used consecutively at the beginning of patient registration. Sorian was used by the registration clerk following the patient's clinic visit. Clinicians accessed patient data, documented

clinical encounters, and managed PLWH needs using Allscripts/Eclipsys. Consent for HIE was documented in Eagle 2000.

People

Demographics—Study participants comprised the entire clinic population including: key stakeholders (PLWH, registration clerks, clinicians) or potential stakeholders (patient navigators) in the HIE consent process and their demographics are summarized in Table 3. Patient navigators were added as study participants based on PLWH suggestions during a focus group discussion about potential navigator roles in HIE. PLWH were predominantly male and African American. Most registration clerks, clinicians, and patient navigators were female. All registration clerks and patient navigators were Hispanic.

Clinic roles—Registration clerks were the initial point of contact for patients at the clinic. They had multiple responsibilities, of which the most important was patient registration. They were also responsible for distributing the HIE consent form to PLWH as part of the registration process and for entering the consent decision into the registration system.

Clinicians were responsible for diagnosis and management based on PLWH needs. They did not have a formal role in the HIE consent process, although some clinicians were involved in HIE initiative committees at the organizational level, and they might answer questions related to HIE consent.

Patient navigators helped PLWH become more independent and adherent to their HIV care. This included working with patients to improve medication adherence and also accompanying them to other non-HIV clinic appointments. At the time of the study, patient navigators had no formal role in obtaining HIE consent.

Perceptions of Barriers and Facilitators for PLWH HIE Consent

The thematic analysis of focus group and interview data revealed two principal barriers (time and lack of knowledge) and one facilitator for PLWH HIE consent (dedicated person for all aspects of consent process).

Barrier: Time—PLWH, registration clerks, and clinicians reported time as a barrier to patients consenting to HIE. PLWH were concerned about time from two perspectives: (a) clinician time, because they wanted to discuss their CD4+ T cell counts and current health status during clinical encounters and did not want their limited time with the clinician to be taken up with a discussion about HIE consent; and (b) registration clerk time, stating that ... “they have so much else going on that they may not be able to give you the individualized attention that you need, to help you with your questions.” To address this concern, one PLWH suggested that the patient navigator might play a role in HIE consent. Registration clerks reported that their competing demands with patient registration, answering phones, and other responsibilities prevented discussions about HIE consent. For instance, one stated,

Mainly time constraints, due to the fact that we have a large volume of patients coming in at one time, sometimes. Some patients get overlooked as far as offering the exchange forms. But most of the time we do try to play catch-up to it, like

backlogging it and making sure that it's done, maybe after the visit. We ask not before, but after the visit. We ask them if they could sign it.

A clinician noted that an option would be to have clinicians obtain consent, but that ... "it would take up time that you're trying to use for other things with the patients."

Barrier: Limited knowledge—PLWH and patient navigators reported that limited knowledge was a barrier to consent. Although a number of PLWH who participated in the focus groups had consented to HIE, when handed the clinic's HIE consent and asked to review it, they were unable to distinguish HIE from the Health Insurance Portability and Accountability Act (HIPAA). Representative comments included: "Is it a HIPAA form?", "What is this form for? You sign this for what?", "Just like a HIPAA form almost, no?" Focus group data revealed that patient navigators were not very familiar with the concept of HIE or the HIE consent process. For example, HIE was described as "medical providers accessing patient data" but the patient navigators could not articulate the steps to obtaining consent or where the information was accessed.

Facilitator: Dedicated person for all aspects of the HIE consent process—PLWH, registration clerks, and clinicians stated that having a dedicated person would be beneficial to address all aspects of the HIE consent process. For example: "I concur with them as far as someone specifically...that'd be someone's specific job responsibility as it relates to this health consent" (PLWH). "Dedicate a person to get this, you know get the patients to agree. And have time, enough time with the patient to explain" (Registration Clerk). "I think the highest priority is to actually find someone with the time to take the patients through the process" (Clinician). These quotes suggested that responsibility as well as time to fulfill the responsibility were needed.

Workflow and Communication

Observations revealed a high volume, busy environment, and competing demands for the registration clerk's time beyond HIE consent. Figure 1 displays the clinic registration process including the registration clerk interaction with three different systems requiring separate logins. The multiple responsibilities of the registration clerks were reflected in the sequence diagram of one PLWH registration encounter (Figure 2), which shows 17 interruptions during a brief period of time. Because the registration environment was very busy (i.e., multiple phone calls, appointment scheduling, patient and clinician needs) during the observation period, registration clerks initiated the registration process and then had patients go to the waiting area until they were able to fully complete registration. The registration clerks did not initiate HIE consent discussions during the observation period.

Internal Organization Policies

In terms of internal context, use of HIE was a part of the organizational initiative to electronically exchange PHI, which was in compliance with Meaningful Use stage two (Blumenthal & Tavenner, 2010). The organization also implemented, monitored, and enforced compliance with HIPAA.

External Rules, Regulations, and Pressures

External rules and regulations of relevance to PLWH consent for HIE in our study included activities specific to NYS as well as federal regulations. NYS governance required written informed consent to electronically share medical records with clinicians across HIE opt-in health care settings. One exception to this rule allowed a qualified entity or participant, such as a provider organization or a practitioner, to “break the glass” and access PHI in life threatening and emergency situations (Ancker, Edwards, Miller, & Kaushal, 2012; Kim, Joseph, & Ohno-Machado, 2015). The Statewide Collaboration Process, which included (Ancker et al., 2012; Kern et al., 2009) the New York eHealth Collaborative, and the NYS Department of Health, governed standardized statewide policies and procedures that ensured that New Yorkers would benefit from HIE (Kern et al., 2009). NYS Public Health Law Article 27-F (Klein et al., 2002), protected PLWH and the disclosure of confidential HIV serostatus information. The HIPAA rule protected an individual’s identifiable health information, such as HIV serostatus. NYS had more stringent standards with regard to protecting identifiable health information and would always supersede the general HIPAA privacy rule.

Established in 2012, Healthix was the regional health organization that served the New York metropolitan and Long Island areas (Garg et al., 2014). It provided HIE data for more than 10 million patients to health care providers, nursing homes, insurers, and other related entities at more than 500 locations, including the study setting (Healthix, 2015). Patient data was accessed through written informed consent and used to improve care coordination, medical treatment, and patient outcomes (Healthix, 2015). Three options for HIE consent were available in Healthix: (a) to consent only in a medical emergency, (b) to deny consent even in a medical emergency, and (c) to give consent for all PHI to be accessed by their health care providers (Healthix, 2015). Healthix was HIPAA compliant; all information was protected by federal and state privacy and confidentiality laws (Healthix, 2015).

At the federal level, the Center for Medicare and Medicaid through the Office of the National Coordinator created an incentive program to qualify providers and organizations to meaningfully use certified electronic health records (EHR; Blumenthal & Tavenner, 2010; Steinbrook, 2009) with the intention of improving patient experience, care, and outcomes. In complying with this initiative, HIE facilitated meaningful use, as it permitted the transfer and accessibility of patient health data between health care providers.

System Measurement and Monitoring

When patients consented to HIE they were required to sign a consent form. The registration clerks documented this in the EHR by marking a box indicating the patient had consented to share all personal information electronically via HIE. Once consent was documented, patient data were accessible via Healthix procedures and the hardcopy consent was scanned into the patient EHR. Clinic consent rate data demonstrated that 48.1% (799) of the patients had consented, 4.2% (70) had declined, and 47.7% (792) had neither consented nor denied consent.

Discussion

Of the total clinic population, almost half of the patients consented to HIE and were willing to consent to share their PHI through HIE. This was consistent with studies that have found that PLWH were willing to share PHI with essential need-to-know clinicians (Maiorana et al., 2012; Patel et al., 2011; Teixeira, Gordon, Camhi, & Bakken, 2011). On the other hand, the fact that almost 48% of PLWH in this HIV clinic had neither consented nor declined represented a missed opportunity to improve quality of care and quality of life for PLWH, given the evidence of the importance of sharing PHI across providers to support the HIV care continuum (Mugavero, Amico, Horn, & Thompson, 2013).

The mixed methods approach, informed by the eight dimensions of the sociotechnical model, revealed potential reasons for the missed opportunities and resulting suboptimal consent rate. Because the responsibility for HIE consent rested with the registration clerks, who had other competing primary responsibilities, the busy work environment, which was characterized by multiple interruptions, affected the ability to highlight HIE consent among the documents presented to PLWH or to answer questions about it. The PLWH noted this issue in the focus group and recommended considering another type of personnel, such as patient navigators, who had established relationships with the PLWH, to possibly serve as the dedicated person responsible for HIE consent. In past studies, non-clinical support persons, such as case managers, have consistently been useful in helping PLWH navigate medical care and social services (Schnall & Bakken, 2011; Schnall, Cimino, Currie, & Bakken, 2011). Likewise, in the case of the implementation of an electronic health system to support HIV care, clinicians have cited the need to include additional support staff to facilitate the implementation of new HIV care services (Schnall, Clark, Olender, & Sperling, 2013).

The critical concerns of time and dedicated personnel for HIE consent were reinforced by the lack of PLWH knowledge about HIE and confusion between HIPAA and HIE, as revealed in the focus group. The stated confusion raised the additional issue of whether those who signed the HIE consent form were truly informed about that to which they had consented. This suggested that not only those who performed HIE consent, but how they performed it were important. Although NYS was one of seven HIE opt-in states, there were no recommendations in place that asserted who would be the appropriate staff member to obtain HIE consent from patients. Having knowledge and skills about HIE was foundational for the HIE consent administrator to ensure an informed consent process. PLWH focus group data revealed that the patients felt that their clinicians were well-prepared to do this, but that a discussion about HIE was not a priority for patient time with their clinicians. Although the PLWH nominated patient navigators for the HIE consent role, the focus group data with patient navigators documented that the patient navigators were not prepared for such a role given limited knowledge about HIE. Findings suggested that, regardless of who performed HIE consent, having the time and knowledge to ensure informed consent was essential (Sage Bionetworks, 2015).

Our study had several limitations. It was conducted at one urban HIV clinic. Although reassurances were provided to protect the confidentiality, patient/provider relationships, and

the employment status of patient navigators and clinicians, it was unknown if those factors influenced participants' responses during interviews or the focus group session. Duration of patient HIV status and length of professional experience of clinicians and navigators were not studied but could have influenced interview responses. Generalizability was limited because the results were based on patients and employees of one HIV clinic in a single urban site and may not have been representative of all PLWH.

Conclusions

The purpose of our study was to conduct a sociotechnical analysis to better understand factors that affected PLWH consent to HIE. The patient population at our clinic may not have represented the larger population of PLWH in the United States in that they were nearly all covered by Medicare or Medicaid, an older segment of the HIV-affected population, and predominately from racial and ethnic minority backgrounds, and so might not inherently be willing to share PHI through an HIE. The study was relevant, as continuity of care shifts from fragmented silos to an accessible electronic patient continuum. By conducting a sociotechnical analysis, we were able to gain significant insights about the HIE-consent processes and also the barriers and facilitators that impacted consent. Our target population for this study was PLWH. However, our research could inform potential strategies about how consent procedures could be improved and may be applicable to other disadvantaged groups and/or chronic disease populations.

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Key Considerations

- Competing demands of providers and staff, and interruptions in the clinical workflow were identified as barriers to HIE consent.
- A key factor in ensuring continuity of care is the ability of health care providers to electronically access and share their patients' protected health information.
- Each state has its own jurisdiction over HIE consent with New York State mandating that patients opt-in to share their health information in an HIE.
- When introducing something new into a workflow that involves patient education it is prudent to have a staff member who becomes the expert and focuses on that aspect of the work until the new activity has been introduced to at least half of the patients and peer navigators.

Figure 1.

Flow chart diagram of the registration process.

Note: MD = medical doctor; EHR = electronic health record; ID = identification; MRN = medical record number

Intent: Patient Registration and HIE Consent **Figure 2. Sequence diagram of the clinic registration process**

HIE = health information exchange; EHR = electronic health record; MD = medical doctor;

Note: The registration clerk does not get through the entire patient registration process. The process is broken by many interruptions

Table 1
Definitions and Operationalization of the Eight Sociotechnical Dimensions

Sociotechnical Dimension	Definition	Operationalization
I. Hardware/Software	Physical and technological structures in place	Hardware and software used to support HIE
II. Clinical content	Textual and numeric data elements used in the clinical setting	Hardcopy and/or electronic data that identifies if a patient has consented to HIE in the clinic registration software
III. Human Computer Interface	Audio, tactile, and visual interaction with the system	Registration clerk's interaction with clinical hardware and software
IV. People	All stakeholders who interact with the system	Stakeholders involved in the HIE consent process
V. Workflow and communication	Processes involved in assuring patient care tasks are performed effectively	Registration clerks' workflow processes of obtaining HIE consent from patients
VI. Organizational policies and procedures	Internal structural policies and procedures that pertain to a specific organization	The hospital and clinic formal or informal processes of obtaining consent
VII. External rules and regulations	Guidelines set at the state and federal level that influence organizational priorities about electronic sharing, privacy rules/security, and incentives for certified EHR usage	HIE, HIPAA, and Meaningful Use federal and state regulations
VIII. System measurement and monitoring	Identifies intended and unintended consequences	HIE consent rates at the clinic

Note. HIE = health information exchange; EHR = electronic health record; HIPAA = Health Insurance Portability and Accountability Act.

Table 2
Summary of Data Collection and Analysis Methods and Study Samples

Data Collection Methods/ Model Dimensions	Analysis Method	Sample
Ecological scan (internal): Retrieval of organization policies and procedures from institutional intranet (VI)	Document review and narrative summary	Organization policies and procedures
Ecological scan (external): Retrieval of federal and state regulations and policies regarding electronic sharing of PHI, privacy rules/security, and incentives for certified EHR usage from public websites (VII)	Document review and narrative summary	HIE, HIPAA and Meaningful Use federal and state regulations
Registration database query (VIII)	Descriptive statistics	1 year of HIE consent-rate data, <i>N</i> = 1,661 clinic patients
Observation (I, II, III, IV, V)	Field notes/chronological mapping	<i>N</i> = 4 Registration clerks
Focus groups, semi-structured interviews (IV)	Thematic analysis	<i>N</i> =12 PLWH, <i>N</i> = 4 Registration Clerks, <i>N</i> = 4 Clinicians, <i>N</i> = 3 Patient Navigators

Note. HIE = health information exchange; EHR = electronic health record; HIPAA = Health Insurance Portability and Accountability Act.

Table 3
Demographics of Study Participants

<i>Variables</i>	Clinic Population N = 1661 PLWH N (%)	PLWH N = 12 Focus Group N (%)	Registration Clerks N = 4 In-Depth Interviews N (%)	Clinicians N = 4 Interviews N (%)	Patient Navigators N = 3 Focus Group N (%)
<i>Gender</i>					
Male	913 (55)	9 (75)	0	1 (25)	1 (33)
Female	748 (45)	3 (25)	4 (100)	3 (75)	2 (67)
<i>Race</i>					
African American	332 (30)	10 (83)			
White	831 (50)			4 (100)	
Other	498 (20)	2(17)			
<i>Ethnicity</i>					
Hispanic	1080 (65)	2 (17)	4 (100)	0	3 (100)
Non-Hispanic	581 (35)	10 (83)	0	4 (100)	0

Note. PLWH = persons living with HIV