

## Final Progress Report

**Project Title: Privacy in Practice: The Role of EHRs in Pediatrician Interactions with Patients**

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## **STRUCTURED ABSTRACT**

### ***Purpose***

This study explored perceptions and practices of privacy as they related to electronic health record (EHR) use among pediatric care providers and their patients.

### ***Scope***

Little is known about how the use of EHRs will affect the doctor-patient interaction, privacy, and disclosure among pediatric providers and their adolescent patients and if EHRs affect the delivery of care to adolescents or the recording and dissemination of personal health information.

### ***Methods***

This was an exploratory in-depth interview study of adolescents and pediatric providers. This design offered an opportunity to understand how EHRs shape expectations, interactions, communication, information exchanges, documentation, and work flow. Ninety interviews were conducted (26 pediatric care providers and 64 adolescents between the ages of 12 and 21).

### ***Results***

Adolescents expressed mixed praise and concern for the role of EHRs within clinical settings and for the utility of EHRs as a way to store health information and to communicate with their health care providers. Common themes from interviews also emerged among health care providers and centered on discussions about how the EHR affected patient confidentiality and information control. EHRs provide a safe and secure repository for health information and also had the potential to enhance quality of care and communication. However, limitations particularly resonated among pediatric providers as this medium posed new challenges which tasked them to alter work flow, routines, and privacy practices and to re-conceptualize how confidentiality, privacy, and disclosure is managed via the EHR.

### ***Keywords***

Electronic Health Records, Privacy, Disclosure, Adolescents

## **PURPOSE**

The purpose of this study was to examine perceptions and practices of privacy as they related to disclosure, personal health information, and use of electronic health records (EHRs) among pediatric care providers and their patients. The goal was to examine the role that EHRs play in shaping privacy perceptions and interactions among adolescents and their health care providers. The specific aims of the research were to:

- Explore how the use of EHRs affected privacy perceptions and disclosure among adolescent populations.
- Explore the extent to which perceptions of privacy surrounding EHRs affected the way adolescents communicate health information to their health care providers.
- Explore how perceptions of privacy and the use of EHRs affected the way pediatric health care providers communicate with their patients.
- Explore how perceptions of privacy and the use of EHRs affected the way pediatric health care providers use health information technology to record and disseminate patient information.

Uncertainty about how adolescents perceive the privacy of EHRs and how these perceptions shape interactions and pediatricians' use of health information technology (HIT) present a critical barrier to progress in the field. By exploring these questions and aims, the goal of this project was to inform future development of HIT applications, strategies for HIT implementation in real world settings, and the conduct of future HIT implementation. We also evaluated the role of HIT to support patient-centered care and discuss the implications of findings for the growing use of EHRs and their potential for facilitating information sharing in health care. Exploring each of these topics and questions produced a greater understanding of how privacy perceptions affect doctor-patient interactions and the exchange of information among adolescents seeking health services.

The qualitative interview design offered an opportunity to explore and understand how the expectations, perceptions, and interactions which occur among health care providers and patients shape communication, information exchanges, and management of emergent information technology to recorded health information. Findings from interviews identify gaps between patients' and providers' privacy perceptions and how these perceptions affect the use of technology to share and disseminate health information.

## **SCOPE**

Though the potential for electronic health records to improve the quality of health care is generally understood (1-4), concerns about the confidentiality and privacy of EHRs present significant barriers to their effective use (5, 6). Adolescents, in particular, have a variety of privacy concerns when using information technology, in general (7), and when seeking health care and confiding in their health care providers, in particular (8-10). In one survey of American high school students, Cheng et al (9) found that 58% of adolescents have health information or concerns they desire to keep confidential from parents. Likewise, 69% of adolescents reported a desire to keep certain health information private from friends or classmates. Importantly, Cheng et al (9) suggest that these privacy concerns impact how adolescents receive their care: 25% reported that if concern for privacy was present they would not access care if there was a potential their parents would find out. This finding is supported by Sankar et al (11, 12), who find that a significant minority of patients forego necessary medical care due to the threat of deficient confidentiality. Therefore, it is imperative that EHR systems are

designed to preserve confidentiality as these privacy concerns directly affect how adolescent patients access health services (9). However, to date, there have been few studies which explore the role that EHRs and subsequent privacy perceptions play in pediatrician/patient interactions (13).

Recent discussions surrounding the use of EHRs in pediatric settings have identified a number of barriers posed by their use with adolescent patients (13). For example, some uncertainty is noted about how privacy should be maintained for adolescents when using patient portals via the EHR that parents may have access to (13-16). Parents and adolescents are beginning to use online portals as they become available by their health care providers as a way to follow their health care and also communicate with providers (17). Yet, currently there are few available standards and functionality incorporated into existing EHRs to limit parental access or provide granular control to some or all information that adolescents may want to keep private from parents that is contained in the EHR and/or through the use patient portals (15, 18, 19). Adolescent patient confidentiality may have been more easily maintained via paper records where conversations about confidential information was more often and effectively parsed out or could be separated from a paper record when/if they were released to parents or transferred to other providers (14). How the pediatric health care provider should go about maintaining patient confidentiality within this new platform has become critical to its value as a tool to aid rather than inhibit quality care to patients, yet to date pediatric providers are often tasked to work around these issues in creative ways in an effort to innovate or utilize this technology despite its current limitations (14).

Nowhere is the expectation of privacy more salient than in the doctor-patient relationship. Teen-aged adolescents, in particular, present a precariously situated population who must contend with their own private health concerns, while lacking many of the rights to privacy that are afforded to their adult counterparts (20). As they approach young adulthood, teen-aged adolescents have a variety of new health concerns, such as pregnancy, sexually transmitted diseases, and drug use, which they may wish to keep confidential and private from parents, caregivers, friends, classmates, teachers, and authority figures (9). Thus, the interaction that pediatricians have with older adolescent populations becomes one of careful consideration. In order to receive effective care and treatment, adolescents must be willing to share personal health information and trust that their providers will keep information confidential. However, Carlisle, et al. (8) suggests, “young people who are concerned that consultations may not remain confidential are reluctant to consult their doctors, especially about sensitive issues” (p. 133). Subsequently, pediatricians must respect these privacy concerns and build trust in patient confidentiality, while conforming to federal and state mandatory reporting and privacy laws.

The negotiation process, which underlies these interactions, has the potential to compromise the effective delivery of health care to adolescents who are concerned about the privacy of their health information. Yet, to date we know little about how the use of EHRs will affect the doctor-patient interaction among pediatric health care providers and their adolescent patients and the consequences that HIT may have for privacy perceptions and the delivery of quality care to adolescents concerned about the privacy of their health information. Though Weisleder (20) identifies doctor-patient confidentiality, in particular, as a precept of adolescent medicine, the emergence and proliferation of new HITs in current medical practice offers even greater challenges to assuring and maintaining patient privacy. For example, uncertainty about privacy protections and confidentiality, such as who has access to and use of electronic health data may lead adolescents to withhold information, thus compromising a provider’s ability to adequately and effectively deliver care and treatment. The added uncertainty of privacy protections offered through the use of EHRs raises questions about how pediatrician/patient interactions will be affected. Chiefly, does the way that

adolescents and providers think about privacy and use HITs affect the way they interact and communicate? Secondly, will these privacy concerns affect the way pediatricians record information into EHRs?

Electronic health records hold the potential to vastly improve healthcare integration by making patient health information more readily collected, aggregated, and disseminated to the various actors involved in care delivery (21-24). This marks a significant change from paper records, whereby health information is easily reproduced and transmitted (25). Moreover, compiled patient information can be utilized in data mining for research-based analyses. However, this inherent increase in the availability of health information raises unaccounted for questions pertaining to patient privacy and confidentiality (23).

Findings from recent qualitative research have explored the privacy and security implications of various forms of HIT, and the role that EHRs, in particular, play in stakeholder group interactions (between doctors, nurses, administrators, and adult patients)(26, 27). Analyses of these data revealed two notable findings applicable to the present study. First, patients who felt that they had stigmatizing medical conditions were more likely to be concerned about the privacy and security of health information stored in EHRs (27). These patients also raised concerns that stigmatizing medical information could more easily “travel” with them through the multiple health care settings that they navigated. Since entire records could be accessed via a computer system, these patients worried that sensitive information present in their record could negatively influence their interactions with providers. Subsequently, these patients reported greater apprehensions about volunteering personal and potentially stigmatizing health information to their health care providers because of perceptions surrounding the privacy of EHRs. Second, given privacy concerns reported by patients, some clinicians reported that they now altered how they entered information into the EHR (26). For example, some clinicians reported that they adopted less stigmatizing language or ambiguous notes that could otherwise reveal personal health information to outsiders and to auxiliary care providers, or which could be construed as insults or inaccuracies. In each of these cases, the potential of open and immediate access increased the perception that electronic records were more vulnerable to privacy breeches than paper records.

While the above studies revealed how perceptions of privacy and EHRs influenced interactions among adult patients and their health care providers, pediatricians and adolescent patients were not included in these studies. Added concerns arise among adolescents when seeking health care, such as whether or not parents or guardians will have access to their records, and what kinds of information will be recorded in the EHR by their pediatricians. Spooner (28) suggests that the EHR may not adequately be designed to facilitate and manage the privacy needs and concerns of special pediatric populations. However, other research suggest that EHR use by pediatric clinicians may improve communication and the amount of preventative counseling discussed during patient visits then those that still use paper based records (29). Still, there is a need to understand the processes that shape pediatrician/patient interactions and which occur via the EHR. This current study explores how the use of EHRs affect privacy perceptions among adolescent populations and, thus, the extent to which adolescents communicated health information to pediatrician providers. Moreover, we sought to explore how perceptions of privacy and the use of EHRs affected the way pediatricians communicated with patients and use EHRs to record and disseminate patient information.

## **METHODS**

We sought to examine perceptions and practices of privacy as they related to disclosure, personal health information, and use of electronic health records (EHRs) among pediatric care providers and their patients. Accordingly, we interviewed the aforementioned stakeholder groups to understand how EHRs affected their experience, practice, and concern. This design offered an opportunity to explore and understand how the expectations, perceptions, and interactions which occur among health care providers and patients shape communication, information exchanges, and management of this emergent information technology to recorded health information.

### ***Theoretical Framework***

A symbolic interactionist perspective (30) was applied to understand the negotiated order which underlie and shaped pediatrician and patient interactions and the role which EHR and privacy perceptions played in facilitating, or not, the flow of clinical information in the delivery of health care. This perspective places emphasis on understanding small group interactions and the shifting social processes which shape actor's interpretations of themselves and others, and the structural forces in which they are embedded.

Rooted in symbolic interactionism, proponents of the negotiated order perspective suggest that the task-specific nature of hospital routines inhibit the uniform application of many rules and standards (31). Rather than a system of fixed rules handed down and universally followed, adherents of the negotiated order perspective suggest that order must be maintained through a negotiation process, which continually shapes and re-shapes the organizational culture as new imperatives, demands, and task specific applications emerge. Thus, communication in health care settings must happen through both formal and informal channels, and by way of both inter- and intra-professional and clinical interactions (32-34).

The negotiated order which underlies and shapes pediatrician and patient interactions and the role which EHRs and privacy perceptions play in facilitating, or not, the flow of clinical information in the delivery of health care, are governed by norms and expectations surrounding the role and security of HIT in contemporary health care settings. Though the provision of confidential medical services to adolescents is preferred by most pediatricians (35, 36), to date, there have been no systematic observations of the role that EHRs play in privacy perceptions and clinical interactions among adolescents and their pediatrician providers and the negotiation process which shape these interactions.

Though privacy rules and standards, as well as HIT, continually shape and reshape work life in contemporary healthcare settings, much of the negotiation process, which underlie the effective use of HIT and the adherence to privacy laws, standards, and expectations occur through both formal and informal routines developed through patient and clinical interactions within discreet hospital work settings (26, 37). Therefore, in order to understand how these practices emerge, and the norms that govern patient perceptions and the exchange of clinical information, we must explore both the context in which adolescent and pediatrician perceptions of privacy and HIT are embedded, as well as the role that new forms of HIT, such as EHRs, play in interactions among them.

### ***Research Sites***

There were two research sites from which a non-probability convenience sample of pediatric care providers (physicians, nurse practitioners, and nurses) and adolescents with health care experience (N=90) were recruited for this study. The first site was a nationally ranked tertiary-care hospital, closely coupled with a school of medicine, serving the Northeastern United States. At this site,

pediatric care providers (n=26) and adolescent patients (ambulatory clinic patients and one in-patient) (n=20) between the ages of 12 and 17 were recruited and interviewed. Other U.S. born adolescents (n=44) between the ages of 18 and 21 were recruited from a small liberal arts college in the northeastern United States. Institutional review boards at both sites approved the study and the recruitment of interview participants at their respective, governing research sites.

### ***Sample and Procedure***

The research design involved gathering qualitative in-person interview data, using in-depth, semi-structured, and open-ended questionnaires constructed for respondents in each group. Each interview lasted approximately thirty minutes to one hour. With verbal permission from respondents, interviews were digitally voice recorded and transcribed. Working with a departmental liaison at the hospital, potential provider participant volunteers were recruited through announcements at pediatric department section meetings and through email solicitations. Prior to being interviewed, pediatric provider volunteers were provided with written and verbal information about the study and were then asked to give verbal consent to be interviewed and recorded.

Adolescents volunteers were solicited at the hospital through recruitment flyers posted in each of the participating ambulatory clinics. Interested participants (or caregivers on their behalf) contacted the principal investigator directly to learn more about the study and to schedule an interview. Permission by parents for adolescents under the age of 18 to participate in interviews was required and established via a signed parental consent form prior to an adolescent patient interview. Parents or guardians of interested adolescents received information about the study so that they could learn about the rights of their children as research participants. After parental consent was granted, adolescents underwent a similar consent/assent procedure in person, prior to being interviewed. At this time adolescent participants were asked for their signed consent to be interviewed and recorded.

In an effort to gain a greater understanding of cumulative teen age and adolescent health care experiences beyond sampling early adolescents themselves, an additional subsample of late adolescents between the ages of 18 and 21 were recruited from a liberal arts college in the northeastern United States. This effort produced a larger sub-sample of late adolescents who were able to speak retrospectively about their cumulative health care experiences and interactions during their early teenage years as well as their later adolescent experience when they gained greater experience navigating health care interactions independent of parents, but that were still recent in their lives. Recruitment flyers were posted throughout the campus. Interested participants contacted the principal investigator directly to learn more about the study and to schedule an interview. Permission to be a participant in the study was established via a signed informed consent form prior to the interview. Prior to being interviewed, student volunteers were given written and verbal information about the study and were asked to provide signed consent to be interviewed and recorded.

All patient/adolescent participants recruited from the hospital as well as the college were given with a \$20.00 gift card for their participation redeemable at a major retail website. All interviews were confidential. Interviews took place in a private setting, such as an office or private conference room, provided by the hospital or college. Names were not attached to recordings of interviews. Respondents were assigned a study identification number. Only limited identifying information (gender, age, race/ethnicity) was collected and all data collected were kept confidential. Only researchers working on this project had access to interview data. All unidentified data was stored on password-protected computers of members of the research team, and hard copies and data-recordings were stored in locked filing cabinets.

### ***Inclusion of Children***

In accordance with the Code of Federal Regulation (45 CFR 46) there was no greater than a minimal risk to adolescent participants in this study. In addition, adequate provisions were made for soliciting their assent and the permission of their parents or guardians (see above). No interview participants were asked to give health information about themselves or to comment on the health status of patients. Thus, the study did not pose any psychological or privacy risks to participants.

### ***Interview***

Adolescent interview participants were asked to give their opinions about the use of EHRs in healthcare, the implications they had for protecting privacy, and their perceptions of the EHR's impact on their own care and interactions with healthcare providers. Participants were asked to share experiences when EHRs were used during health care interactions and then asked to evaluate those experiences and whether or not this shaped privacy expectation or disclosure. Participants were also asked to share any praise or concerns they had about the positive and negative effects of EHRs and the implications for the privacy of health information.

Pediatric care providers were asked to give their opinions about using EHRs for delivering patient care, the implications they had for protecting privacy, and their perceptions and experience of the EHRs impact on patient interactions and on other aspects of their work. Pediatric care providers were also asked to share experience and any praise or concerns they had about the positive and negative effects of EHRs on patient privacy and communication, their use during clinical interactions, and how they used EHRs to record and communicate patient health information. Finally, they were asked about what they thought could be done with the EHR to reduce privacy concerns and/or to protect the privacy of health information.

### ***Analysis***

Following an exploratory and grounded interview approach (38, 39), interviews with participants evolved iteratively as the investigator learned more about the subject and experience of participants through preliminary and ongoing analysis throughout the data collection phase of the project (40). This process allowed interviews to develop over time by building on prior conversations with other participants and allowing for digressions from planned questions to capitalize on interviewees experience, knowledge, and concern (40, 41). To explore these research questions, interview transcriptions were thematically coded. The coding and analysis of interview data identified a broad spectrum of privacy expectations, concerns, and practices among both patient and pediatrician providers to understand how these expectations guided information exchanges, clinical interactions, EHR use, and the implications this had for the delivery and quality of care.

## **RESULTS**

### ***Participant Characteristics***

Sixty four adolescents were interviewed across the two research sites (31 male, 33 female). Adolescent participants ranged in age from 12 to 21. The average age of this group was 18. All participants were currently enrolled in school or college appropriate to their age level. Adolescent participants reported a variety of health care and specialty health care experiences, and generally participants self-reported health as very good or excellent. All but four reported that they had seen a

doctor in the last 12 months. Three reported that they had been admitted to a hospital within the last 12 months. All participants were asked to rate their health care experiences within the last year. On a scale of one to ten, where one was the worst health care possible and ten was the best health care possible, they generally rated their health care experience as positive with an average of 8.4.

Pediatric health care providers (physicians, nurse practitioners, and registered nurses) ( $n=26$ ) interviewed ranged in age from 29 to 66, with an average age of 41. All but two were female. Among this group, twelve were physicians, four were nurse practitioners, and ten were registered nurses. Twenty participants in this group came from general pediatric departments and six were from specialty departments (including pediatric urology, pediatric pulmonology, ears, nose, and throat (ENT), and pediatric intensive care)

The race distribution of all study participants is presented in the inclusion enrollment report (appendix A). As this was an exploratory research study based on a non-probability convenience sample, the aim was not to generalize findings to the wider U.S. patient or pediatric provider population. Participant income and family income for the adolescent sample or family member's occupation was not recorded.

### ***Principal Findings***

Adolescents expressed mixed praise and concern for the role of EHRs and technology within clinical settings and during clinical interactions, and for the utility of EHRs as both a way to store personal health information and as a way to communicate with their health care providers. Consistent with previous research findings (noted above), adolescents came to health care encounters with a variety of experiences and these tended to shape discourse and disclosure, perceptions of privacy, and subsequently the role of parental involvement in their health care. These factors shaped interactions with health care providers in predictable ways and were often external to the use of EHRs in particular.

Some adolescents felt fearful to disclose potentially stigmatizing information to their health care providers for fear that it might inadvertently be communicated back to parents through parent discussions with health care providers or through parental access to information stored in records. For example, one participant was reluctant to disclose her sexuality to her health care providers, as she believed this would be a point of contention between her and her parents if that information was somehow revealed to them. During these interactions she chose not to disclose that information to her providers, and persisted with this practice beyond her teenage years. Others noted similar concern when discussing sexual activity, drug use, and health risk behaviors with health care providers during their adolescence.

Much of these anxieties, however, were tempered through greater autonomy within health care interactions as adolescents gained independence from parents. As adolescents aged, eventually they began to talk with health care providers privately, usually at the request or encouragement of providers themselves. However, this had the potential to cause additional anxiety with some as they did not want to alienate parents or make an issue about their need for private conversations with their health care providers. For example, one adolescent participant noted:

When I got a little older and they started asking questions about puberty, sex education, or drinking or drugs, then it became a little uncomfortable for my mom to still be in the room, but it also would have been uncomfortable to say, "mom, I don't want you to hear this", because then it's like, "oh, what are you hiding from me."

Ultimately, however, these parent-free private consultations were a way that providers could talk to teens, free from evaluations of adolescent behavior by on-looking parents. However, some participants noted that they also appreciated that their parents were there during their health care interactions, particularly during situations where they needed help with decision making and were comfortable with parents having access to their health records.

Technology did play a role in shaping some concerns about disclosure during these interactions in a variety of ways, both positively and negatively. For example, the clinics from which patients and providers were recruited attempted to resolve historical concerns about disclosure in the adolescent-provider relationship through the use of use hand-held tablets that were given to adolescent patients in waiting rooms when they visited the clinic. On the tablet, they could respond to general and sensitive questions about their health when prompted to do so. Interview participants noted this as a benefit which allowed them to avoid awkward conversations with providers, potentially in the presence of parents. Providers now having this information at their disposal could use it to guide interactions and conversations appropriately. However, by allowing the adolescent to freely volunteer sensitive information on their own, and permanently into the EHR, one consequence is that this method, while satiating anxiety about in person conversations and disclosure, eliminated the filter enabled when providers used discretion during in-person conversations with patients to enter or not sensitive information permanently into a record (see below). In fact, in an effort to maintain confidentiality and privacy, many providers utilized these in-person interactions and conversation as a way to determine *what* information ought to be recorded in the EHR and how to record it to maintain confidentiality. This topic is returned to below.

It is also important to note that most of the adolescents interviewed did not know the granular detail of information accessible to parents or to themselves within their EHR and/or through patient portals. As a communication tool, few reported utilizing online portals to access information in their EHR, but if they did, noted that routine physical and immunization information was sought for the purpose of the forwarding that information to other doctors or schools. This lack of understanding about access, privacy, what kind of information was recorded, and parental rights to access, colored interpretations of privacy and confidentiality and were often overshadowed by aforementioned concerns about the dialectics of disclosure (42). With regard to the EHR itself, adolescents expressed little concern about the privacy and security of HIT in general and EHRs in particular and this technology did not serve as an inhibiting force determining disclosure. Adolescents did however note that EHR use during clinical interactions had the potential to inhibit the flow of information, and sensitive questions were often impersonalized when EHRs and laptop computer use during clinical encounters de-personalized conversation. One participant noted this when discussing her physician's use of a laptop during her visit.

“It’s easier to talk to someone when they’re not typing it in. ...there was more focus when she used a clip board because we would have a conversation then she writes it down, rather than typing it down when we are speaking, if that makes sense...”

Any negative role that EHR use may have had on the way adolescents communicated with their health care providers may have been tempered by a prevailing trust in technology and offset by the way that EHRs could potentially improve communication and the interoperability of health records across multiple providers and institutions. This was particularly salient when adolescents discussed the role that parents played in their health care and the benefit of allowing them access to health record information or their portals. In the case of adolescents who experienced health problems, parental involvement was important as a means of decision making and support. Some

more practical motivations for adolescents were the accessibility of EHRs to make transferring information simpler. Parents played an integral role in helping to manage their children's health care and information in these cases, and the EHR was seen as a benefit in this regard. This is not to say that these same adolescents were not concerned about the privacy of their health information especially if they discussed sensitive health or personal issues with their providers that they did not want their parents to know about. However, these fears were often managed by non-disclosure, or mitigated by trusting relationships with health care providers, parents, or both.

Common themes from interviews also emerged among health care providers and most notably centered around discussions about how the EHR affected patient confidentiality and the way they entered information into records. Concerns over the use of EHRs were particularly salient among health care providers. For health care providers, EHRs provided a safe and secure repository for health information and also had the potential to enhance quality of care and communication. This finding is also supported by other research (17). However, limitations particularly resonated among pediatric providers as this medium posed new challenges that many adolescents often overlooked when discussing how EHRs affected perceptions of privacy, confidentiality, and disclosure. This is noted here, as the advent of EHRs did not necessarily change the way adolescent participants disclosed information or the way they had conversations with their health care providers (though in some cases it did, see above), but rather tasked providers to further alter work flow, routines, and privacy practices and to conceptualize how confidentiality was managed via the EHR.

While pediatric providers have always afforded confidentiality to adolescents seeking care, and also limit parental access to confidential information in records, during interviews health care providers often noted the permanency of EHR data which prompted them to think differently about how they should enter such information *into* a health record. First, some providers were concerned about the "legacy" of information in the EHR, and the technical possibility that EHR could now serve as a lifelong health record that is carried with a person forever. One physician noted:

I would love for the questionnaires to be there for eighteen months and then self-destruct, so they can't be found anymore. So, if a kid did something stupid, and they disclose something stupid, that has no impact on their future ... those things never really go away, so would that have an impact on a potential job ten years from now if someone went back and found that they did something stupid when they were sixteen? They have sealed criminal records that are juvenile records, but with an EHR ... nothing gets sealed.

Others were concerned that the functionality of the EHR allowed it to do too many things, and this compromised the EHR as a tool for patient health information and as a repository for confidential patient information. Another physician noted:

The problem with the EHR is that it is intended to serve too many different purposes. So it's meant to be a note to me and other providers who will see this patient in the future. ... It's meant to be a tool for billing. ... And it's intended to be a way to communicate with family. So there are 3 different uses. And we're using the same platform of information to serve all of these purposes. And that's great for multitasking.... But that's the problem: it's not that it's electronic. It's that we've tried to have this tool multitask but we haven't been clear about what parts are multitasking and what parts need to stay discrete. And that's where the problem comes in.

This motivated some to change the way they recorded information in the record, especially if the information pertained to potential stigma, deviant behavior, and information an adolescent wanted to remain private from parents. For example, some providers noted that they excluded selected

potentially stigmatizing information from macro-fields that they were prompted to enter through automatic templates in the EHR, such as drug, alcohol, and tobacco reporting, if that reporting did not indicate what they considered to be a problem for the patient. Rather, in these instances, the provider would make a note in the EHR that they “discussed” these issues with patients. However, this language was coded to mean something else to the individual entering that information, so that they could follow up with a patient about an issue while concealing the stigma potentially produced by detailing it.

There are some patients for whom I will not document accurately in the EHR to be sure that no one else can see the information. Which is an extreme, but I do that if I feel it needs to be kept sensitive or private. -*Nurse Practitioner*.

I have a line, a sort of standard line, in the template that says “GC Chlamydia is done if applicable”. I delete that for patients where that is not applicable. So, if the parents read the note it basically says if applicable. Where kids who aren’t having sex, I take that out completely. That’s sort of my signal to myself if they are sexually active. ...And I think that kids who have a high concern about bad things happening if their parents know they’re having sex. Then, I encourage them to go to Planned Parenthood instead of doing it with us because of the insurance. -*Physician*

I’ll write something like “discussed.” I won’t write what behaviors, but I’ll write “discussed behaviors.” After that, I’ll write something. So if they’re like “I use a lot of pot and it’s cool,” I’ll write, “discussed behaviors – free contemplative.” So that’s my clue to go back and think about what we talked about last time and what we should talk about this time. Sometimes I’ll write “free contemplative, provide education” or something so I know that’s where my starting point is. -*Physician*

Some of these codes were created by individual providers to cue themselves in when seeing the same patient again.

It’s completely subjective. We’ll say things like, “making excellent choices,” which means that they’re not doing anything they shouldn’t be doing. Or, “making good choice, discussed healthy options,” which would be the code for, well they are doing something, so we discussed how they should do that in a better way, like don’t smoke. I: Does everybody know that “code”? R: I don’t think [everybody knows the code], but it’s the only way that I really know how to [do so]. I’ll be specific and do a sexuality reminder or bullet point and say, “making good choices, discussed safe options,” which will cue me for next time, that that kid is having sex and it [the language I use] is very grey because I want to protect the kids. -*Physician*

Others, had agreed upon sets of codes within a practice or clinic, so that other providers collectively would be provided with the same cues if they so happened to see the same adolescent at their next visit.

My whole clinic uses it. If we discuss, say, drug and alcohol use with an adolescent, we have a code of ... “denies” means they don’t do it, “discussed” means they do it, and “discussed in detail” means we have concerns. We all agree how we’re going to document it because it is something that a child will often do, and then be fine, and it doesn’t need to be a legacy on their chart forever and ever, so we try to only use that information if it’s important to their healthcare. ... [There are] so many reasons [to do this]. One, is so that they can redesign themselves and not be left with any stigma of prior health decisions that they have done. So, I like the clean slate so someone who is just checking them in the

ER doesn't have to see that they smoked pot two years ago. Second, is so that people who don't need to know, don't have to see -*Nurse Practitioner*

In this case above, other providers in the same practice who see this patient and who are privileged to knowing the meaning of the word "discussed", may then be alerted that the adolescent had experimented with substances, but did not report habitual use. This personal and group practice of utilizing coded language in the EHR had two purposes. By knowing the meaning of the word "discussed" (in this example) other providers who come into contact with the patient may again probe them about their drug use history. However, by not indicating use patterns within pre-defined templates, citations of substance use effectively remained concealed in the record, so that other health care providers outside of the practice, perhaps later in life, would not be privileged to knowing this information. These practices are a kind of "low-tech workaround" (14), designed to protect the privacy of patient information and confidentiality in the doctor-patient relationship. They function to preserve knowledge about health, events, or potential stigma in the record, but coded so only the two parties (or a clinic and patient) know about them.

However, a number of inadvertent consequences were also identified through these examples and practices. For example, some providers *do* utilize these templates to cite even potentially stigmatizing information as they are prompted to do so and this creates inconsistencies across records as some report and others conceal. One registered nurse noted:

I'm not judgmental. Like, if you smoked pot at some point in time, that's what you did, that's part of your life. It isn't going to affect every decision. It has no effect on my opinion of you as a person, so I don't think about things like that because it is what it is. ...I wouldn't hesitate to put different things like that into a patient's chart because it's the truth and ...that's part of who they are, and that's part of their history. ...If someone thinks that it's going to affect them for the rest of their lives, then it's kind of their problem and not mine, if that's fair to say.

If non-uniform and inconsistent practices for entering personal or private information into EHRs persist, collectively a review of patient data becomes incomplete or inaccurate. The EHR, as a potential tool to aggregate patient data to understand population level trends and public health may become inconsistent as some feel (and others do not) that these fields compromise the confidentiality of patient information or narratives that might otherwise be better concealed or obscured in notes. This impacts the meaningful use expectation of EHRs. Second, when that adolescent sees another physician who is not knowledgeable about the word "discussed" (in the above example) or any given "code" and their meanings, that provider will not be privileged to details of a patient's health history. Although this practice has the potential to preserve the privacy of what may otherwise be trivial but stigmatizing information, it also may compromise the care of a patient. For example, one physician noted:

I will put in something very vague, so it will hopefully trigger me, but unfortunately it is not a good enough communication tool for others that might see the family. We have a lot of families [where someone is] in drug treatment and that is in the chart and I think that's very appropriate because those in particular are kids who are at risk for significant issues with attachment and everything else, but at what point do you let that go? How many years clean, how many years sober before that shouldn't be there anymore?

Aside from locking notes and incorporating “break the glass” features that allow only privileged access to sensitive information (14) there are few other ways to preserve confidentiality within the EHR. For example, a nurse practitioner said:

[Sometimes] I’ll label the note that I’ve written and lock it so that it says it can only be opened or released with express consent of the patient. We can lock our notes, so you can lock it if I have to, or I’ll simply just write at the top “can’t be released without express consent from John Doe”.

Thus, providers recounted privacy practices and fixes to limitations posed by the EHR, namely how to communicate information, but be selective about who sees what. Much of this concern centered around how to remove confidential information from problem lists which appear when opening EHRs. As has been cited in recent literature (13, 14) problem lists as a functionality of the EHR pose some challenges to maintaining confidential information when others review a record. Similarly, one registered nurse in this study noted this as a potential impasse to preserving confidentiality:

I know there have been some situations where like, you go through a health history, you’ll enter information, and if someone sticks something on the chart, like something that you kind of picked up from the mother, it forever is potentially labeled on a problem list.

However, another physician noted how she could tailor the problem list to hide some information from the general view of others, such as parents.

This content within the problem list, you can put subcategories in there that won’t be visualized. But the problem list will be visualized. Where I just came from, there was a button you could unclick, so that a problem wouldn’t go into the problem list, so patients couldn’t see it. In other words, there was a complete “parents saw nothing” trend, then a “parents see everything” trend. I could uncheck some things in the patient’s problem list so that it doesn’t infiltrate their after visit summary. It’s more concerning if it’s a teenager. Like, let’s say a teenager has a pregnancy. I might want to have a pregnancy in the problem list. [But] if parents were unaware of that, I want to be able to uncheck that.

Still this was unclear to others who noted that all such information in a record could not be parsed out in such a way to protect some information and not the other information in situations when parents would need to be involved in an adolescent’s care and/or in situations when adolescents sought care from other specialists. For example, one physician noted that this function could falter when seeking care from multiple providers or specialists.

It’s not clear to someone else what information is protected if the patient chose to keep it private from their parents, versus what information their parent needs to know. My opinion is that parents need to know all of it, but I recognize the fact that it’s not how all families work. And so they don’t – the neurologist doesn’t know what information was put in there that was meant to be shared with parents versus what information isn’t. There’s not like a separate place in the medical record that says, “physician information that patient chose they keep quiet from their parents.”

As noted above, the accompanying patient portal, which provides secure online access to portions of a patient’s medical record also became the focus of conversations with health care providers. This too has been noted in recent literature which has outlined limitations of EHRs in pediatric care (13-16). The utility of patient portals became the focus of some of the interviews as providers thought this to be a potentially useful tool to solve some longstanding difficulties to

preserve privacy. At the time of the interview, however, the functionality of patient portals for the purpose of securely communicating with patients was limited as it could not sufficiently preserve the confidentiality of communications and messaging via the portal as these communications ultimately became part of the patient's records. Thus, the workaround was to dismantle or limit the communication function of the EHR and go back to traditional methods of communication, such as phone calls, emails, and in-person visits. Emails, in particular, were one, albeit discouraged way to communicate with patients and parents, but these transmissions were not secure as they did take place through the portal. Moreover, since there was no one secure online communication portal, the provider was tasked with determining which part(s) of these communications should be added to the EHR and how to preserve privacy given the variety of ways to communicate. Ultimately, these workarounds tasked the provider to determine, not only how to communicate, but what was the best course of documentation as well as what methods of communication were appropriate to maintain privacy given the need to effectively manage workflow and follow institutional rules and demands. At times, providers could not meet each of these expectations simultaneously.

[The EHR] changes things because we document everything or nearly everything. Am I doing it correctly? Am I saying too much? Even in this quick note? ... Many of our patients like to use email and we constantly get these emails from the administration saying don't email patients. That can be 50% of what I do in a day. ... I was told that I can receive an email from a patient. I can respond to that email and click reply, so it is going directly back to whoever sent it. But, I should never start an email to a patient myself. ... [In the EHR] I will then copy the entire email. ... I have a templated note that says I received this specific email from blank. I copy and paste the entire email and then I copy and paste my reply to it so I can cover myself and the patient's privacy. ... It's rare that I've had one that's like "Woah. There's no way I can copy and paste this." But if there is, [for example] I've had parental, spousal issues. ... In that case I pick up the phone and say, "you sent me this email, I'm a little uncomfortable [documenting] that given what's in the email." So I will specifically ask ... the person who has emailed me. Now that's tricky. [Sometimes] they can't take calls from home, someone's at work. I leave at 5. It happens over and over again, where the communication is really difficult. Parents email me on a regular basis. And I don't even think they think about it. You know, it's convenient, it's fast. They know I'm sitting in front of my computer if I'm not in clinic. It's easier to try and get through if there's one secretary at the desk and the phones are ringing off the hook. So I don't even really think they think about it for the most part. ... And every time you get an email from the administration saying don't do this or don't do that and you shouldn't be talking about this or emailing a parent. I mean sometimes I just email a parent back to say, "how is he?" I try very hard not to use names in emails. I never use a full name in the bar for the subject bar. Even with colleagues I don't do that. I use initials or a first name with a last initial. But I try to decrease the identifiers as much as possible. That's the conundrum – there's more and more and more and more and more communication that people expect you to do, want you to do, the parents want, and then, you know, then you're getting it from all ends. I'm getting things in my [in-box], emails directly from patients, phone calls up the wazoo. And I'm trying to communicate back with everybody. And how do I do it and still make sure that I maintain everyone's privacy? I try. I'm desperate to try. But there have been times when I go home thinking, "Did I do that right?" "Did I put the name in the subject bar?" I've had moments of nausea. –*Nurse Practitioner*

Alternatively, communicating through portals was cited as a potential benefit to a fully functional EHR, which would resolve some of these multifaceted and overlapping dilemmas, but had yet to be resolved in the clinics from which interviews were solicited.

At some point it would be wonderful if the teen could securely message me to say, “I need birth control. I don’t know where to go or what to do about it; what should I do?” Because, right now, it takes the teenager to be able to tell the parent, “I need to come in to see the doctor. No, I am not going to tell you what it’s about, mom, but I really need to go see her.” Then they need to take time off from school, they need to get the ride from their mom to come here and if they were to be able to securely message myself or my nurse, they would be able to possibly ask some of those confidential health questions. –*Physician*

## **Discussion and Conclusion**

Following the aims of this study, interviews explored privacy perceptions among adolescents and pediatric health care providers to understand the role that EHRs played in pediatrician-patient interactions and the recording of personal health information. This exploratory study observed and identified key challenges to the utilization of EHRs in pediatric health care. Adolescents expressed mixed praise and concern for the role of EHRs within clinical settings and for the utility of EHRs as a way to store health information and to communicate with their health care providers. Common themes from interviews also emerged among health care providers and centered on discussions about how the EHR affected patient confidentiality and information control. Research finds that EHRs provided a safe and secure repository for health information and also has the potential enhance quality of care and communication (1-5) . However, findings from this present study suggest that limitations particularly resonated among pediatric providers as this new medium posed challenges which tasked them to alter work flow, routines, and privacy practices and to re-conceptualize how confidentiality, privacy, and disclosure were managed via the EHR.

Given concerns that health care providers have with the permanency of health information present in the adolescent EHR; parental access through patient portals; and the inability of EHRs and portals to effectively parse out selected confidential information from the view of others who access the record, providers reported a variety of strategies to further “practice privacy” when using EHRs. Practices included the selective or coded recording of certain kinds of health or personal patient information that may be brought up in the course of a visit, or through communications, in an effort to insure that otherwise confidential, potentially stigmatizing information will not be inadvertently revealed to others and/or carried with adolescents as part of their health record as they age into adulthood. Also, and perhaps more importantly, these privacy practices potentially neutralize some of the very benefits of EHRs and the role they play in achieving meaningful use goals.

Building on recent discussions in health care concerning the use of EHRs and EHR connected patient portals in pediatric health care settings (13-19), findings from this research provide empirical support for recent concerns and prospects for the effective innovation and use of pediatric designed EHRs in health care. Bayer, Santelli, and Klitzman (13) note that EHRs pose a threat to adolescents who may wish to keep information in their health records private from their parents as well as to parents themselves who may want to keep information in the record from an adolescent. Yet, Anoshiravani, Gaskin, Groshek, et al (18), note that “electronic medical record vendors nor many health care systems have adequately addressed the functionality and process design considerations needed to protect the confidentiality of adolescent patients in an electronic world” (P. 409). Findings from this study indicate that much of this may be tied to the inability of providers to effectively separate or parse out confidential information from the view of others who access the record and may also be due to problems or an inability to communicate confidentially via the EHR connected secure patient portal (see also 15, 16). In an effort to remedy these limitations health care providers were tasked to adopt their own practices and routines to protect adolescent privacy and confidentiality, which both helped and hindered work flow, interoperability, and the integrity of patient health

information. Each of these limitations may be remedied through the use of an EHR which addresses these needs and provides the appropriate functionality to protect the special privacy needs of adolescents (14, 19).

### ***Future research***

Findings from this study contribute to scientific knowledge to improve clinical practice by informing health practitioners and policy makers as they enact new standards and practices to ensure privacy in the use of EHRs. Specifically, this research provides a greater understanding of the role that EHRs play in privacy perceptions and interactions among the young who seek health care and the pediatric health care professionals who use EHRs in their day to day work. Findings from this study also help to inform researchers, HIT experts, clinicians, administrators, and policy makers as they develop and modify new HITs, which must cater to the needs of adolescent populations. Observing the experience of adolescents and their health care providers, the hope is that this exploratory study will inform larger, focused, and targeted studies of EHRs in the years to come.

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## **LIST OF PUBLICATIONS and PRODUCTS**

No publications to date have been produced.

# Appendix A

Program Director/Principal Investigator (Last, First, Middle): Timothy Stablein

## Inclusion Enrollment Report

**This report format should NOT be used for data collection from study participants.**

Study Title: The Role of Privacy in Practice: Electronic Health Records in Pediatrician Interactions with Patients  
 Total Enrollment: 90 Protocol Number: \_\_\_\_\_  
 Grant Number: R03 HS021537-02 REVISED

PART A. TOTAL ENROLLMENT REPORT: Number of Subjects Enrolled to Date (Cumulative) by Ethnicity and Race				
Ethnic Category	Females	Males	Sex/Gender Unknown or Not Reported	Total
Hispanic or Latino	4	0	0	4 **
Not Hispanic or Latino	53	33	0	86
Unknown (Individuals not reporting ethnicity)	0	0	0	0
<b>Ethnic Category: Total of All Subjects*</b>	<b>57</b>	<b>33</b>	<b>0</b>	<b>90 *</b>
Racial Categories				
American Indian/Alaska Native	0	0	0	0
Asian	4	2	0	6
Native Hawaiian or Other Pacific Islander	0	0	0	0
Black or African American	3	2	0	5
White	46	28	0	74
More Than One Race	4	1	0	5
Unknown or Not Reported	0	0	0	0
<b>Racial Categories: Total of All Subjects*</b>	<b>57</b>	<b>33</b>	<b>0</b>	<b>90 *</b>
PART B. HISPANIC ENROLLMENT REPORT: Number of Hispanics or Latinos Enrolled to Date (Cumulative)				
Racial Categories	Females	Males	Sex/Gender Unknown or Not Reported	Total
American Indian or Alaska Native	0	0	0	0
Asian	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0	0
Black or African American	1	0	0	1
White	2	0	0	2
More Than One Race	1	0	0	1
Unknown or Not Reported	0	0	0	0
<b>Racial Categories: Total of Hispanics or Latinos**</b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>4 **</b>

\* These totals must agree.  
 \*\* These totals must agree.