

**Patient Preferences in Controlling Access to their Electronic Health Records:  
a Prospective Cohort Study in Primary Care**

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## **Abstract**

Introduction: Previous studies have measured individuals' willingness to share personal information stored in an electronic health record (EHR) with healthcare providers. But none have measured preferences when patients' choices determine access by healthcare providers.

Methods: Patients were given the ability to control the access of doctors, nurses or other staff in a primary care clinic to personal information stored in an EHR. Patients could restrict access to all personal data or to specific types of sensitive information, and could restrict access for a specific time period. Patients also completed a survey regarding their understanding and opinions regarding the process.

Results: Of 139 eligible patients who were approached, 105 (75.5%) were enrolled and preferences were collected from 105 of them (100%). Sixty patients (57%) did not restrict access by any providers. Of the 45 patients (43%) who chose to limit the access of at least 1 provider, 36 restricted access only to all personal information in the EHR, while 9 restricted access of some providers to a subset of their personal information. Thirty-four (32.3%) patients blocked access to all personal information by all doctors, nurses, and/or other staff; 26 (24.8%) blocked access by all doctors and/or nurses, and 5 (4.8%) denied access to all doctors, nurses, and staff.

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Conclusions: A significant minority of patients chose to restrict access by their primary care providers to personal information contained in an EHR, and few chose to restrict access to specific types of information. More research is needed to identify patient goals and understanding when facing decisions of this sort, and to identify the impact of educating patients regarding information contained in the EHR and its use in clinical care.

Abstract = 276 words

Keywords: fair information practices, electronic health records, patient preferences

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## **Introduction:**

Some experts have suggested that patients should be allowed to exercise control over access by healthcare providers and others to specific types of personal health information in the electronic health record (EHR).<sup>1</sup> Fair information practices (FIPs) adopted by the Office of the National Coordinator for Health Information Technology and the US Department of Health and Human Services, for instance, support this sort of “granular control” of EHR information. A key justification of granular control is to respect the autonomy and privacy interests of patients who may not wish to share specific types of information with certain providers, especially socially sensitive information that may be embarrassing or stigmatizing, for example regarding sexuality and reproduction, sexually transmitted diseases, drug or alcohol use, and mental illness. Increasing patient control of the EHR may further the goal of encouraging greater patient trust of<sup>2</sup> and participation in the health care system.<sup>1,3</sup>

Efforts to design and implement a system of granular control, however, raise a number of key medical and ethical questions

- From a medical and ethical perspective, how can a system that provides granular control educate patients and help them make decisions that take into account their interest in privacy and confidentiality but also possible negative impacts on their care? Looking more broadly, how can a system take into account public health goals and providers’ desire and responsibility to deliver informed care? Are there situations (e.g. during life-

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threatening emergencies), where the providers should be allowed to override the patient's data sharing preferences?<sup>4</sup>

- From a technical perspective, how should EHR designers classify types of information in the EHR? How can programmers deal with information contained in narrative text such as provider notes?<sup>5</sup>
- From a human factors perspective, how can a system efficiently help patients meet their needs and expectations? At what level of granularity should patients control access to their EHRs: the level of the stored data points, classes of data, clinical conditions, or by dates, etc.?<sup>4,6</sup>

To address these questions designers of EHRs need a better understanding of patients' perspectives about control of personal information. Previous research has investigated patients' preferences regarding sharing EHR data with both healthcare providers (e.g., physicians) and non-provider recipients (e.g., family members).<sup>6-8</sup> However, none of these studies have investigated patients' choices in a health care setting where these preferences were implemented, thereby affecting the actual sharing of their EHR data. This paper presents findings about patients' choices for access to personal health information in an EHR in a clinical setting for the first time.

A recent study conducted by one of us (KC) showed that patients have varying degrees of comfort about sharing a range of types of information that might be stored in an EHR.<sup>6</sup> This

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study found that while patients were generally willing to share personal health information with clinicians providing them clinical care, especially their primary care physicians, they were more hesitant to share at least some personal health information with providers who were not treating them, or with other potential recipients such as health researchers or family members. Similarly, a survey of patients in Australia and New Zealand found them to be overwhelmingly willing to share information with providers who were treating them, but less willing for that information to be shared with other potential recipients such as administrative personnel, government officials and health researchers.<sup>8</sup>

Notably, in each of these earlier studies, participants' preferences for sharing health information did not affect how their health information was actually shared. Therefore a key question that remains to be answered is: when preferences about sharing actually affect what data is shared with providers, what will patients share and with whom?

We investigated this question as part of a larger demonstration project where patients exerted granular control of information in an EHR.<sup>5,9</sup> In an urban public teaching hospital, we asked patients to record their preferences for sharing or restricting data in their EHR with certain recipients (e.g., doctors, nurses, staff) and then implemented these choices to control healthcare provider access to information stored in each patient's EHR. Finally, we surveyed patients after their preferences had been made and assessed their understanding of the process and desires for having their preferences implemented.

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## **Methods:**

### **Setting and Participants:**

This study was approved by the Indiana University Institutional Review Board and was conducted in a hospital-based primary care adult medicine practice in an urban teaching health system. Patients were eligible if they had at least two visits to their primary care physicians in the prior year. When eligible patients presented for care, a research assistant approached the patient in the waiting room, described the study, and assessed their interest. Interested patients were taken to a private room where the study was described in detail. Risks of the study were described, including the danger that restricting access to data in the EHR might lead to a situation where a “healthcare provider might not see information that might be important to their care.” In addition, patients were instructed that providers would have the option of viewing all information in the record, including information that was chosen to be restricted, “if they feel that it is important to do so.” Patients desiring to participate signed informed consent forms. At the completion of the patient’s involvement in the study, each was compensated with a \$50 gift card.

The research assistant then read a script that again identified the purpose of the study, provided a general description of the types of information that are included in the EHR, and explained how to use the computer-based program to state preferences for sharing EHR information.

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The patient was first shown a heading asking, “Whose access would you like to restrict?” This was followed by a list of participating clinic providers by name and category (doctors, nurses, and “other staff” which included physicians’ assistants, nurse practitioners, clinical nurse assistants, and medical assistants). The patient could select individual persons or multiple people by category. This was followed by a section with the heading, “What information would you like to restrict?” Responses included no information, all information, and five categories of information deemed to be sensitive and desirable to be restricted: sexually transmitted infections, HIV or AIDS, sexual health and pregnancy, drug or alcohol use or abuse, and mental health. The final section asked, “For what ages would you like to restrict information?” Patients could provide a range of ages and the system then calculated the relevant dates by using the patient’s birthdate (a required registration field). Screenshots of the patient preference platform are provided in Leventhal et al. (this issue).<sup>5</sup>

Patients then filled out a survey that assessed their understanding of the EHR and the personal health information it contains, as well as the process of stating their preferences and controlling access to that information. The questions were drafted, edited, and discussed among co-investigators, a group that included clinicians (PHS, AEC, WMT), experts in health information technology (KC, SAA, AEC, WMT), human factors (KC), privacy (KC, SAA), survey methodology (AEC), and bioethics (PHS, SAA, EMM). Questions were selected for face validity and were not pilot tested. There were 10 Likert-style questions, each with possible

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answers: “Strongly agree”, “Somewhat agree”, “Neutral”, “Somewhat disagree”, and “Strongly disagree”.

Once accepted, the information was implemented in the data viewing program called Careweb,<sup>®</sup> which providers have been using at this hospital since 1977 to access all diagnoses, test results, medications dispensed, vital signs, and other data. During a five-month observation period the patient’s preferences for sharing of or restricting access to their EHR data were implemented. . Providers were not notified of the presence of any information that was redacted, unless they hit a button on the Careweb<sup>®</sup> screen labeled, “Break Glass (Pt Preferences)”, at which time any redacted information would be displayed.

## **Results:**

### *Demographics:*

This study was conducted from August through December of 2013. During the study period 139 eligible patients were approached and 105 (75.5%) were enrolled and their preferences were collected from 105 of them (100%). The demographics of enrolled patients are displayed in Table 1. Of the 105 patients, 104 (99%) had sensitive information in their EHR, i.e. that was judged to fall in at least one of the five categories identified in advance. Fifty-two (49.5%) had data related to HIV or an HIV test.

### *Patient Preferences for sharing EHR data with doctors, nurses and other clinical staff:*

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Sixty patients (57%) chose to provide all listed providers with access to all personal health information in their EHR. Forty-five patients (43%) chose to limit the access of at least 1 provider to information stored in the EHR.

36 patients (34.2%) restricted access to at least one provider to ALL the information included about them in the EHR and did not limit access of any provider to just part of their data (i.e. sensitive information in the five categories, and/or information during a specific time period). That is, these patients only controlled access to their EHR data as a block. .

Table 2 provides information about preferences for sharing data in the EHR by patients who provided or restricted access to all their data, not to part of their data. Thirty-four (32.3%) denied access to all listed individuals of at least one provider/employee type (i.e. doctors, nurses, or other staff), 26 (24.8%) blocked access by all doctors and/or nurses, and five patients (4.8%) denied access to all doctors, nurses, and other staff to view any of the information in their EHRs.

Nine patients (8.6%) restricted access of at least some providers to a subset of the information about them in the EHR (Table 3). That is, these patients took advantage of the opportunity to exercise granular control over personal information in the EHR. Six patients (5.7%) restricted access of at least some providers to at least one sensitive type of information, and four patients (3.8%) restricted access to at least some information based on time period

All 105 enrolled patients responded to the survey, administered after accepting their preferences, about their opinions regarding the preference process and controlling access to the EHR. As shown in Table 4, a vast majority of participants agreed or strongly agreed with the

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statements that they understood “what an electronic health record is” (90.4%), “what information is in my electronic health record” (96.2%), and “who can view my electronic health record” (96.2%). A vast majority also agreed or strongly agreed that the process of stating their preferences was easy to do (95.2%), that undergoing this process made them feel more comfortable with providers viewing the record (97.1%), that it was acceptable for them to prevent some providers from seeing parts of their EHR (93.3%), and that it was a good thing for patient to have control over who sees specific electronic health information (94.3%). Of note, patients’ had varied levels of agreement with the statement “Preventing some providers from seeing parts of my electronic health record could affect my relationship with them”: 48.6% agreed or strongly agreed, 14.3% were neutral and 34.2% disagreed or disagreed strongly.

### **Discussion:**

When given the opportunity to limit access to some portions of the personal information in their EHR by at least some health professionals, a significant minority of patients (43%) chose to do this, and 4.8% restricted all providers’ access to all EHR information. This result is particularly important because it is the first study of patients’ granular EHR data-sharing preferences in a clinical setting where their choices actually affected the ability of their primary care providers to access information in their EHR. Since patients received limited education regarding the content and use of the EHR, their choices can be understood as a “baseline” that

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may indicate the starting point for educational efforts necessary for future implementations of granular control.

Our finding that a majority of patients (57.1%) chose not to impose any limitations on access for any listed healthcare providers is in line with previous findings. Whiddett et al. (2006) found that more than 75% of patients would be willing to share general non-sensitive information, about themselves in the EHR with a doctor or practice nurse. When it was specified that the information could include potentially sensitive data (e.g. about sexually transmitted diseases or mental health), 70% agreed to allow access to a doctor or practice nurse.<sup>7</sup> In another study, 86% of HIV patients said they would be willing to share personal health information through an electronic record with their primary HIV care provider; 78% agreed to share that information with other clinicians in the same clinic, and 78% agreed to sharing that information with other health care providers, such as emergency or hospital personnel.<sup>8</sup> In a third study, of patients without sensitive information in their EHR, 100% said they would share less sensitive items with their primary care physician, while 78% would share highly sensitive items. For patients whose EHR contained sensitive information, 95% would share non-sensitive items and 76% would share highly-sensitive items.<sup>6</sup>

These results, like ours, suggest that many patients believe that their providers have good reason to see such electronically stored health information and can be trusted to responsibly use it, even when it contains potentially sensitive information. Interpretation of our results is limited since we do not have information about patient understanding or reasons for choices, and thus it

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may be that allowing providers to view the record could have been a “default” choice that reflected avoidance of making an active choice. It is important to consider, in addition, that a majority of our patients might not have restricted access to any providers because the patients may have known them for some time (an inclusion criterion was that the patient had made at least two visits to the clinic in the previous year). This personal experience may have increased patients’ comfort level with allowing the employees and providers to view all EHR information. A recent Cochrane review has shown that such trust has far-reaching effects, since it is associated with increased patient satisfaction, adherence to treatment, and continuity of care.<sup>10</sup>

It is notable that in our survey, most of the patients agreed that it is acceptable to prevent some providers from seeing parts of the EHR, that it is a good thing for patients to have control over who sees specific electronic health information, and that the process of making choices regarding access by providers made the patient more comfortable with others viewing the EHR. On the other hand, almost half of patients also agreed or strongly agreed that preventing a provider from seeing parts of the EHR could affect the patient’s relationship with the provider. This may suggest that patients are concerned about the possible impact of restricting access to the EHR could have, and it may have been an additional reason why at least some patients did not impose limits on any providers or employees. Managing and addressing such concerns will be an important goal of any initiative to make granular control of the EHR more widespread.

A large majority of the patients who choose to limit access to their medical record, a large majority (36 or 45, or 80%) limited access to the entire EHR, rather than parts of it. There

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are multiple possible reasons for this choice, including that the patient preference program interface made it relatively easy for patients to limit access in this way, since they could do so by checking a single box. If a patient was concerned about sharing one particular type of information and was unsure about how to characterize that type of information, they might simply choose to restrict access to all information. Compared to restricting access to just a single type of data, such as sexual history, for instance, a global restriction on access to data in the EHR could carry a much higher chance of causing significant negative consequences for the individual's healthcare.<sup>11</sup> These potential dangers of restricting access to providers or employees at the clinic may not have been apparent to patients given the relatively limited training they received regarding the information in their EHR and its use. In addition, our finding that 15.2% of patients blocked all access to the EHR for all physicians participating in the study stands in tension with the finding in a previous study that 100% of patients, many from the same health system as we studied, would share nonsensitive data with their primary care physician.<sup>6</sup> Future research should study the impact of additional education, and of the design of the user interface, on patient choices to restrict access to all or part of their information.

Of the 36 patients who blocked access to the entire EHR to at least some providers, 34 of them (94.4%) restricted access to *all* members of at least one group of providers/employees (i.e. doctors, nurses, or staff). Five denied access for all listed doctors, nurses, and staff to view any of the patient's information in the EHR, while 26 blocked access to all doctors and/or nurses. Such choices raise important questions that should be studied in future research. Did patients

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who blocked access to all providers/employees actually intend to do this (e.g. did any who chose to block access believe they were granting access?)? Do patients who block access to all doctors envision that adequate care will be provided without their referring to any previous information stored in the EHR? Do patients who block access to all nurses or staff have an adequate understanding of the use of the EHR by these members of the clinic staff? For instance, are patients aware that nurses access the EHR to issue new prescriptions for medications the doctor has previously prescribed? It is possible that patients would be willing to accept the risk they take on by restricting access to some of their information, particularly if that access is restricted from non-clinicians working in a medical practice. Such questions about patient understanding and intent must be addressed in future research.

Patients' privacy needs must be respected, but there would be significant risks to implementing a system that simply empowers what might be uninformed or unreflective choices regarding restricting access to EHR data. Our findings thus re-emphasize the need for any system of granular control to be coupled with an efficient and meaningful system for educating patients regarding the information included in the EHR, who uses it and why, and how, and the potential impacts of restricting access to data.<sup>4</sup>

Like all studies, our work has limitations that warrant consideration. First, we utilized a simple patient interface for stating choices, and there was no educational intervention about the content and use of data in the EHR, beyond simply listing types of information that the EHR contains. Any more widely implemented system of granular control must involve a more

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carefully designed interface and educational program, along with access to their own EHR content, to help patients make informed decisions that can protect their privacy interests while also assuring that they receive excellent healthcare. Second, the study was conducted at a single clinic that serves a population with low socioeconomic status, and thus our results cannot necessarily be generalized to other populations of patients. Future work should investigate the opinions and responses of patients in other practices and with different demographic characteristics. Third, this project only studied patient desires regarding access to information by providers and employees of a primary care clinic, not in other settings, such as hospitals, emergency rooms, insurance companies, or other myriad secondary users of clinical information. Fourth, this study did not assess patient desires regarding granular control of their EHR data for research uses, rather than clinical care.

In summary, this is the first study of what patients choose regarding restricting access of primary care providers to personal EHR data when those choices affect access in a real-life clinical setting. Many patients chose not to restrict access of any doctors, nurses, or staff, and most of the patients who did restrict access did so by blocking access to all of the personal information in the EHR rather than to just sensitive information or specific date ranges. More research is needed to identify patient goals and understanding when making decisions of this sort, and into the impact of educating patients in various ways regarding the information contained in the EHR and how it is used in clinical care and beyond. In addition, further

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research is needed into the impact of the design of the interface on the choices patients make regarding granular access to personal EHR data.

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**Table 1: Participant demographics**

	Overall N (%)
Gender	
Male	31 (30%)
Female	74 (70%)
Age (years old)	
18-30	2 (2%)
31-45	16 (15%)
46-64	62 (59%)
>= 65	25 (24%)
Race	
White	46 (44%)
Black	48 (45%)
Unknown	11 (10%)

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**Table 2: Choices by patients who granted or restricted access to ALL the information in the EHR, not to parts (i.e. did not exercise “granular control” over particular types or time periods of information in the EHR) (n=96):**

**2a. Number of patients who chose to grant access to specific numbers of doctors, nurses, or staff:**

Number of individuals provided access:			Number of patients making this choice
Doctors	Nurses	Staff	
0	0	0	5
0	1	0	1
0	1	1	1
0	2	1	1
0	0	1	4
0	0	4	1
1	0	0	2
1	0	1	1
1	1	1	1
2	0	0	1
0	All	1	1
1	All	0	1
0	All	0	1
0	All	All	1
All	0	0	3
All	2	0	1
All	0	1	2
All	1	All	1
All	0	All	1
All	All	0	6
All	All	All	60

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**2b. Number of patients who chose to grant access to All/ Some/ or No participating Doctors vs. Nurses and Staff**

		Access provided to		
		All Doctors	Some Doctors	No Doctors
Access Provided to:	All Nurses and Staff	60	0	1
	Some Nurses and Staff	11	3	10
	No Nurses and Staff	3	3	5

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**2c. Number of patients who chose to restrict access to doctors, nurses, or staff to ALL the personal information in the EHR:**

	Number (%)
Restricted access by doctors	
Restricted access by ALL doctors	16 (15.2%)
Allowed access by just 1 or 2 doctors	6 (5.7%)
Restricted access by nurses	
Restricted access by ALL nurses	20 (19.0%)
Allowed access by just 1 or 2 nurses	6 (5.7%)
Restricted access by staff members	
Restricted access by ALL staff members	21 (20%)
Allowed access by just 1 or 2 staff members	11 (10.5%)

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**Table 3: Choices by patients who restricted access by at least some doctors, nurses, or staff to PART OF the information about them in the EHR:**

Restricted access to	Number of patients (%)	Patient ID#s
Time period	4 (3.8%)	#s 4, 5, 6, 7
Mental health	4 (3.8%)	#s 1, 2, 3, 7
Drug/ Alcohol	3 (2.9%)	#s 1, 8, 9
Sexually transmitted infection	1 (1.0%)	#1
Sexual health/ pregnancy	1 (1.0%)	#1
HIV	0 (0%)	

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**Table 4: Patients' responses to the post-preference survey**

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree	Don't Know or Can't Say
I understand what an electronic health record is	72%	18%	3%	4%	3%	0%
I understand what information is in my electronic health record	80%	16%	1%	1%	2%	0%
I understand who can view my electronic health record	88%	9%	2%	0%	2%	0%
Today I underwent a process where I decided who could access my electronic health record	90%	9%	0%	0%	1%	0%
I found the process of making my preferences known easy to do	89%	7%	2%	2%	0%	1%
This process made me feel more comfortable about providers seeing my electronic health record	89%	9%	1%	1%	1%	0%
This process made me feel that only those who should have access to my electronic health record do have access	90%	6%	2%	1%	2%	0%
It is okay for me to prevent some providers from seeing parts of my electronic health record	82%	11%	4%	2%	1%	0%
Preventing some providers from seeing parts of my electronic health record could affect my relationship with them	34%	14%	14%	13%	21%	3%
It is a good thing for patients to have control over who sees specific electronic health information	85%	10%	3%	1%	2%	0%

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