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Authorized Access and the Challenges of Health Information Systems

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Authorized Access and the Challenges of Health Information

Systems

by

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Abstract

The need for an interconnected health network has reached its peak. Using electronic health records dramatically increases the quality of care for patients and the efficiency of the health care systems. With the rapid development and integration of health care technology, standardization and interoperability has become a paramount problem. Looking at electronic health systems independently presents an array of security related issues, which are then compounded as they are connected together. This paper focuses the issues surrounding authorized access systems used within these networks and solutions to bridge the gap that currently exists.

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Introduction

On a recent business trip across the country, you find yourself in a situation that no one should ever be in. You are laying, unconscious, in a hospital, with a team of doctors clamoring over you trying to find the cause of your recent illness. They know nothing about you including the long list of drug allergies that you have.

The above scenario, which is not that uncommon, could have been prevented if the presiding doctors had access to the patient's medical records. This type of scenario is just one of many where electronic health records (EHR) and electronic health systems (EHS)/networks could dramatically increase the efficiency and safety of the current health system. The following list (ordered least to most sensitive) shows the movement of personal data to a networked environment and how sensitive (severity of impact to user if data is compromised) that information is to the user: entertainment (online gaming, television shows and videos), communication (instant messaging, social networking, blogs, VoIP), productivity (work e-mail, teleconferencing, work documents), personal (contacts, calendars, photos), and financial (shopping, banking, billing, taxes). The movement of heath data to a "cloud" like networked environment is the next logical progression of the above list and resultantly would be the most sensitive. The inherit sensitivity of personal health information is the reason why the shift to a networked system has not yet happened and remains unpopular with public opinion.

There are many facets of electronic health and current academic research is focused on: electronic health records (EHR), personal health records (PHR), mobile health, consumer health informatics, health knowledge management and telemedicine. For the purpose of this paper, the scope will remain on only electronic health records and personal health portals, and how the two can be used together to provide a more secure and efficient health system. However, before the

main goals and objectives of this paper can be discussed an overview of the current health system and initiatives must be discussed.

Literature Review

Personal Health Records and Patient Portals

Personal Health Records (PHR) and Patient Portals are two separate and distinct entities that are often confused for the same thing. A personal health record is a tool that allows a patient to keep track of their medical history independent from any health information system that a medical institution uses. Patients are able to input and edit information like: allergies, family history, and a variety of other personal medical information. This area of electronic health is fairly new and is implemented in a very few instances. Doctors are hesitant to use information that a patient can edit because it is not verified by a medical professional. Currently the two major organizations that have launched research into personal health systems are Microsoft and Google, although Google's initiative has been discontinued due to privacy concerns and HIPAA compliance. Their products allow users to create and store their medical data in a system that is not in any way tethered to an existing health information system. Since these products have no association with a formal EHS they act more as a user generated repository. [7]

A Patient Portal is similar to PHR's in the regard that patients have access to their medical information except that a patient portal is tethered to an existing electronic medical record (EMR). This allows patients access to information maintained by their health providers and allows their healthcare providers to send information directly to their patients. In most cases, patient portals do not allow patients to edit the information they see in order to maintain data consistency and integrity. [7]

Some hospitals are utilizing the best of both system mentioned above. They implement a traditional PHR that is tethered to an existing health information system. The Mayo Clinic and the University of Pittsburgh are developing hybrid approaches; a traditional PHR that is connected to their health information system. This allows patients to edit and contribute to their medical record while at the same time receiving updates and information from the medical record that their doctors maintain. In many cases, patients will have multiple PHR implementations for each of the health providers that they visit.

Many Chief Medical Information Officers are starting to see the benefits of a hybrid approach. Hybrid PHR systems help increase workflow efficiency while at the same time increasing patient satisfaction. The current problem in implementing these systems is lack of standardization and security. Linda Reed, Chief Information Officer of Atlantic Health said, "Everyone wants secure records, but we found that putting robust security in place frustrates account owners and seems to discourage usage." I believe that this frustration can be eliminated or reduced if an efficient authorization access model was present in health information systems, which would still secure patient information but would make the system more dynamic and user friendly. [7]

In this paper I believe that the hybrid PHR approach can be used to help create a more secure and efficient health system. The details of the service and scope will be discussed in a later portion of the paper. Before the role that patient portals will play in the proposed solution, a discussion of electronic health records and authorization models must take place. [5]

Health Information Systems

Most of the current health system is reactive; a person seeks out medical help, whether at a local hospital, doctor's office, or clinic. Each individual health provider, if they implement electronic

medical records, will contain their own health information system which would house each patient's electronic medical record. According to ISO/TS 20514 a health information system has been formally defined as: "a repository of information regarding the health status of a subject of care in computer form stored and transmitted securely, and accessible by multiple authorized users. It has a standardized or commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continuing, efficient and quality integrated health care and it contains information which is retrospective, concurrent and prospective." Pertaining to the security aspect of the above definition ISO/TS 18308 states the following privacy and security requirements that current health information systems should conform to:

- System Security
    - Authentication
    - Authorization
    - Confidentially
    - Consent
    - Integrity
    - Non-repudiation
- Interoperability
- Author Responsibility
- Audit Trail
- Version Management
- Patient Access
- Archiving/Data Retention

Due to the unique nature and function of health information systems they are required to house large amounts of personal data and consequently they are also required to adhere to comprehensive security standards. This makes it incredibly difficult to fully implement a health information system that successfully implements all aspects of the previous list of security requirements. [5]

Now that health information systems have been discussed and introduced the scope of the paper can more clearly be defined. As stated earlier the focus of the paper is on how electronic health records and personal health records can be used together. More specifically, it will investigate problems associated with authorization, interoperability, and patient access of electronic health records. There are, however, many challenges with connecting health information systems together, especially regarding authorization systems. [5]

Health Information Exchanges

Most people today have a primary care doctor and then periodically visit specialists, labs, and a handful of other health care providers. Going along with the above paradigm, each health care provider that a patient visits would then contain a unique copy of that patient's electronic medical record. So now there are multiple copies of a patient's medical record at multiple health care providers that are in no way synchronized or networked. This makes diagnosing and treating patients extremely difficult and places a burden on both patients and doctors since it is now their responsible to transfer medical records from one location to another.

One solution currently being implemented to address the problem of interoperability among health information systems is health information exchanges (HIE). Health information exchanges are a way for multiple health care providers to share information and patient's

medical records. Currently, in New York State there is a state funded initiative to create regional health information exchanges. University of Rochester Medical Center and the Greater Rochester Regional Health Information Organization (GRRHIO) have agreed to provide access to data and feedback about security related issues in implementing exchanges and associated health systems. Their feedback will be used in conjunction with the data collected from my experiment. [4]

Currently GRRHIO requires that patients sign a "consent to view" form before their data is shared within the exchange. In emergency situations an unauthorized doctor can "break the glass" and view the information for a one-time basis. Since there are no standardized authorized access models that work efficiently in a health exchanges this type of consent grants most medical professionals within the network full access to view patient data. This type of consent/authorization model is also used at the University of Rochester Medical Center. When granting this much access to patient data, it requires heavy auditing practices to be in place in order to identify and trace misuse. In later sections of this paper this issue (lack of authorization models) along with potential solutions will be discussed.

The exchanges can be implemented in one of two ways: centralized and federated (decentralized). Currently in the United States the federated model has become the standard of choice and this model will be explored in this paper. The following is a brief explanation of both implementation methods. [6]

Centralized

In a centralized health information exchange environment, all health data would be stored in a central repository or database. Health care providers and organizations would then

access that centralized service in order to view patient's medical records. There are a variety of security and privacy issues related to storing vast amounts of health data in one place, which is why the decentralized environment has become the standard of choice in the United States. One problem with storing large amounts of personal data in a single location is accountability. Placing one organization and person accountable for the security and privacy of large amounts of medical data is unrealistic and litigiously irresponsible. Having a centralized environment would also create many problems with ownership of data since multiple sets of medical records exist and would need to be reconciled and then relocated to the central service. [11] [6]

Federated (Decentralized)

In a decentralized environment each health care provider would continue to maintain their own health information system and the health information exchange would act as a "broker" or pointer service to the location of requested data. This implementation model fits the current state of electronic health care systems currently being developed and also holds each entity that houses health data accountable for the data it holds. Now that there is a solution to the interoperability requirement of health information systems, there is also a new set of security and privacy requirements that arise. [6]

Security and Privacy Issues associated with Health Information Exchanges

Now that there is a way to connect multiple health information systems together, the security standards from ISO/TS 18308 must be applied to the exchanges along with new security issues that arise from connecting multiple health networks together. The following list is a summarization of the security requirements placed upon health information exchanges:

- Authorized Access

  o Now that many health systems can be connected together, administrators of the networks need to not only worry about who has access to private data within a localized organization, but also they need to worry about who has access outside of the organization.

- Confidentiality

  o Now that health systems are connected together confidentiality requires that proof can be given that unauthorized people do not view the health information shared within the network.

- Patient Consent

  o Due to the many state and federal regulations patients must give consent before any sharing of information can happen.

- Relevancy

  o Relevancy deals with both the doctor and patient only viewing information that is relevant to the case that is being worked on. When health networks are connected the question that arises is what doctors need what information?

- Ownership of Data

  o Since the patient is the actual owner of their medical record. The data provider that houses their information needs to figure out who manages the data. When multiple organizations have access to the data management of the data can become complicated.

- Infrastructure

    o   When exchanging health data across multiple locations the hardware that is used needs to be compatible with other systems and versions of software.

- Audit Logs

    o   Audit logs are created in order to create a history of transaction in case of abuse. In an interconnected health network the complication that arises is what entity stores the audit logs and what needs to be audited.

- Archiving

    o   Archiving is moving data out of the active system and into offsite locations. When there are many health systems connecting together issues with storage management and retention time arise.

This list adds another level of abstraction and complexity to the problem of creating an interoperable health network. With the above list and the introduction of health information exchanges the scope of the paper can once again be more clearly defined. As stated before, this paper will investigate problems associated with authorization, interoperability, and patient access of electronic health records. Even more specifically this paper will investigate problems associated with authorization and patient access of electronic health records that are brokered within an interoperable health information exchange and how hybrid patient portals can be used to create a more secure and efficient connected health system. The next topics to be discussed are the actual issues associated with authorization and what roles hybrid patient portals can play to alleviate them. [6]

Authorized Access and Health Information Exchanges

Authorized access in terms of a health network consists of three parts: reliable patient

identification, proper authentication of healthcare providers, and correct authorization of

healthcare providers. Reliable patient identification and correct authorization of

healthcare providers are still being heavily researched. Proper authentication although

important, has already been researched and protocols exist that can be used to ensure

proper authentication. [6]

Reliable Identification

Since a patient has multiple sets of medical records being shared within an

exchange there has to be a way to universally identity that patient and his/her

medical records across the different health systems. That can be done in two

ways:

Mapping

Reliable patient identification can be accomplished in two ways: by

mapping or by creating a national health ID (NHID). Mapping is

currently the method that many health information exchanges utilize, since

a national health ID does not yet exist. When the patient enters the

exchange, an enterprise master patient index (EMPI) must be created. The

MPI then maps the various user ID's from the various health information

systems connected to the exchange to one patient ID. Unfortunately this

method is not scalable and has been proven to produce errors when

applied to a large networked environment. This is problematic since

accuracy is critical when dealing with health data and scalability is one of

the ultimate goals of an interconnected health network. This is why I believe the creation of a national health ID is critical; unfortunately the reality of creating one is dim. [6]

National Health ID

The national health ID model is ideal for a large interoperable network and I believe will help alleviate some of the authorization issues that arise with the creation of these networks. Under the NHID model the government or a national institution would administer every patient, doctor and health care entity an identification number. This ID would then be used throughout the various exchanges and health systems, eliminating the need for mapping and dramatically increasing accuracy. In terms of authorization if the person attempting to access health data is already identified in the system the method and procedure for authorizing that user becomes much easier. [6]

Unfortunately, in reality, implementing a NHID is highly improbable. When the original Health Information Portability and Accountability Act (HIPAA) was drafted there was proposed legislation for a NHID. However when the bill was passed into law in 1998 the provisions for a NHID was stripped. This certainly did and still makes implementing many of the security functions of HIPAA difficult. This is the primary reason why patient ID mapping is the prominent system used in electronic medical systems. Although the federal government has prohibited the

development of a NHID some private organizations have picked up the research. [8]

In 2009 a private corporation called Global Patient Identifiers, Inc. created an alternate NHID system called the Voluntary Universal Healthcare Identifier (VUHID). The VUHID creates a secure identification system while at the same time meeting the needs of health professionals while satisfying some of the concerns that arise with a large identification system. VUHID is based on two standards developed by the American Society of Testing and Materials and the American National Standards Institute. The identification number would contain two parts, an open identifier and a private one. This would help ensure patient privacy and reduce clerical errors. Another major advantage of the VUHID is that patient information would not be stored in a central database; the VUHID simply provides an identifier and then the traditional mapping services would be linked to the newly created ID number. [8]

The critical flaw with this system is that it is voluntary and getting multiple health information systems and exchanges to use this particular system could be as polarizing as passing legislation for a NHID. Despite the political setbacks, this type of system would make creating an efficient authorization access model very feasible. I believe that the feedback from my experiment will show that using a NHID would be beneficial. Unfortunately development and implementation of a NHID system is beyond the scope of this paper, but an area that could use future research.

Correct Authorization of Healthcare Providers

This is the second area of authorized access that this paper will cover. Currently there are traditional access methods that are implemented within health systems and exchanges, but they are failing to meet the demands and unique needs of health data. Essentially there does not exist an access method that can be successfully used in a health setting that will accommodate the majority of the needs that are demanded in an interconnected health network. The following are examples of the unique demands that health systems put on authorization models.

Multilevel vs. Multilateral Security

Unlike most government information systems where information is prevented from flowing downwards (i.e. top secret to secret to confidential), health systems many times need information to flow downwards. For example, information that doctors enter into the system needs to be read by the nurses below them and then again viewed by lab technicians. If the information was not permitted to flow downwards the diagnosis process would not be able to be completed. In an electronic health system, information also will need to be allowed to pass laterally from one healthcare provider to another. This creates a need for multilateral security instead of multilevel security. Yet at the same time some information contained within electronic health systems must also be prevented from flowing downwards. Data that has no context or relevance with a current case a doctor is working on should not be viewable by all people on different access levels. Therefore many times in an electronic

health system it is simultaneously required to prevent information from

flowing down and across. This unique demand has made it difficult to

apply traditional access methods to electronic health systems and has

prompted new ones to be created. [11]

Hybrid Layered Approach

One method to try to make an access control model that can meet the

demands of electronic heath systems is a hybrid layered approach. In this

approach many of the traditional access control models are used together

to create a model that can be applied to both lateral and layered systems.

At the first level, mandatory access control would be used (MAC), which

uses classification (top secret, secret) to mandate who has access to which

data. Layer two would utilize discretionary access control (DAC), which

mandates access by the group a user belongs to. Then at the final layer,

role based access control would be used, which mandates control based on

the role the user plays in the organization. The three access control

models are used together in an effort to bridge the gap between

multilateral and multilayered security paradigms. Unfortunately this

model is not dynamic and the health care industry contains many granular

groups and roles. The hybrid approach is a step in the right direction, but

still would not be able to provide adequate access control to a large

interconnected heath system. [11]

Activity Oriented Access Control

Another theoretical access control model that was proposed is an activity oriented access control model. Although similar to role based access control, it is different. The model can be abstracted into three levels: the privilege level, the activity level, and the user level. Unlike role based access control, in which the user must be assigned a role to which they belong to, activity oriented access control grants access based on what activities a user performs. If the user performs multiple activities associated with an object then that user is granted access to that object. It allows for a more dynamic access control model to be created. This kind of control model gives the user more flexibility and lessens the amount of work that traditional access control models would require of administrators. This control model is still theoretical and has not been fully implemented in any major electronic health system. Because of this the, practicability of this model has not been tested, although it is a step in the right direction. More research still needs to be done in the area of types of access control model that can be used; this paper does not directly address that issue. [5]

Objective and Scope

Now that all major aspects of electronic health care have been addressed that hold relevance to this paper, the scope and objectives of this paper can be fully formed. In summary, there are many areas that are currently being researched in the field of electronic health. For the purpose of this paper the issues associated with electronic health records have been discussed and how a

hybrid patient can play a role to help create a scalable, more secure interconnected health network. It was determined that in order to securely store electronic health records within a health information system a list of security and privacy requirements would have to be met and that when connecting multiple health information systems together using health information exchanges the list of security and privacy requirement grew and compounded to the following:

- Authorized Access (Focus of Research)
  - Now that many health systems can be connected together, administrators of the networks need to not only worry about who has access to private data within a localized organization, but also they need to worry about who has access outside of the organization.
- Confidentiality
- Patient Consent
- Relevancy
- Ownership of Data
- Infrastructure
- Audit Logs
- Archiving

As mentioned earlier, the scope of this paper will focus only on authorized access, specifically on the correct authorization of healthcare providers within an interoperable health information exchange.

I believe that patients not only should be able to view their electronic medical records, but are also capable of making informed decisions concerning authorized access of the information

contained in these systems. By allowing patients access to their electronic medical records and then giving them the ability to grant and deny access to those records, I believe some of the above mentioned issues surrounding authorized access can be alleviated and a new type of authorization model can be developed.

The following questions arise from the above hypothesis and will be answered through a study explained below.

1. If patients had the ability to control access to their medical records would they want to use it?

2. Do medical professionals believe a user-centered access control model is feasible? If not, what are the factors that affect their conclusion?

3. What areas do patients feel they should have access to on their medical records? What areas to medical professionals feel need further refined patient access control on medical records?

4. Are patients capable of making decisions concerning authorized access of information contained in their medical records?

5. What are contributing to the lack of a developed authorization model in health systems and what are possible ways to alleviate the problem?

6. If patients had such control could it have a negative impact on the ability of medical doctors to deliver safe and quality healthcare?

7. At what level of control could patients be granted that would not affect the quality of healthcare afforded to them.

Even though the scope has already been narrowly defined there are still multiple avenues of research that can be studied off the above stated hypothesis. For the purpose of this paper the research is only focused on the user's ability to make informed decisions concerning authorized access using a central authorization access service. Patient-doctor interactions and other third party interactions are outside the scope of this study. There are also many unique situations that arise in the health field, for example emergency care, where patients would not have the mental capacity to make decision. These kinds of situations will not be covered in this study, but this is a basis for developing an authorization model that would fit the unique needs of the health care system. These are topics that require further research.
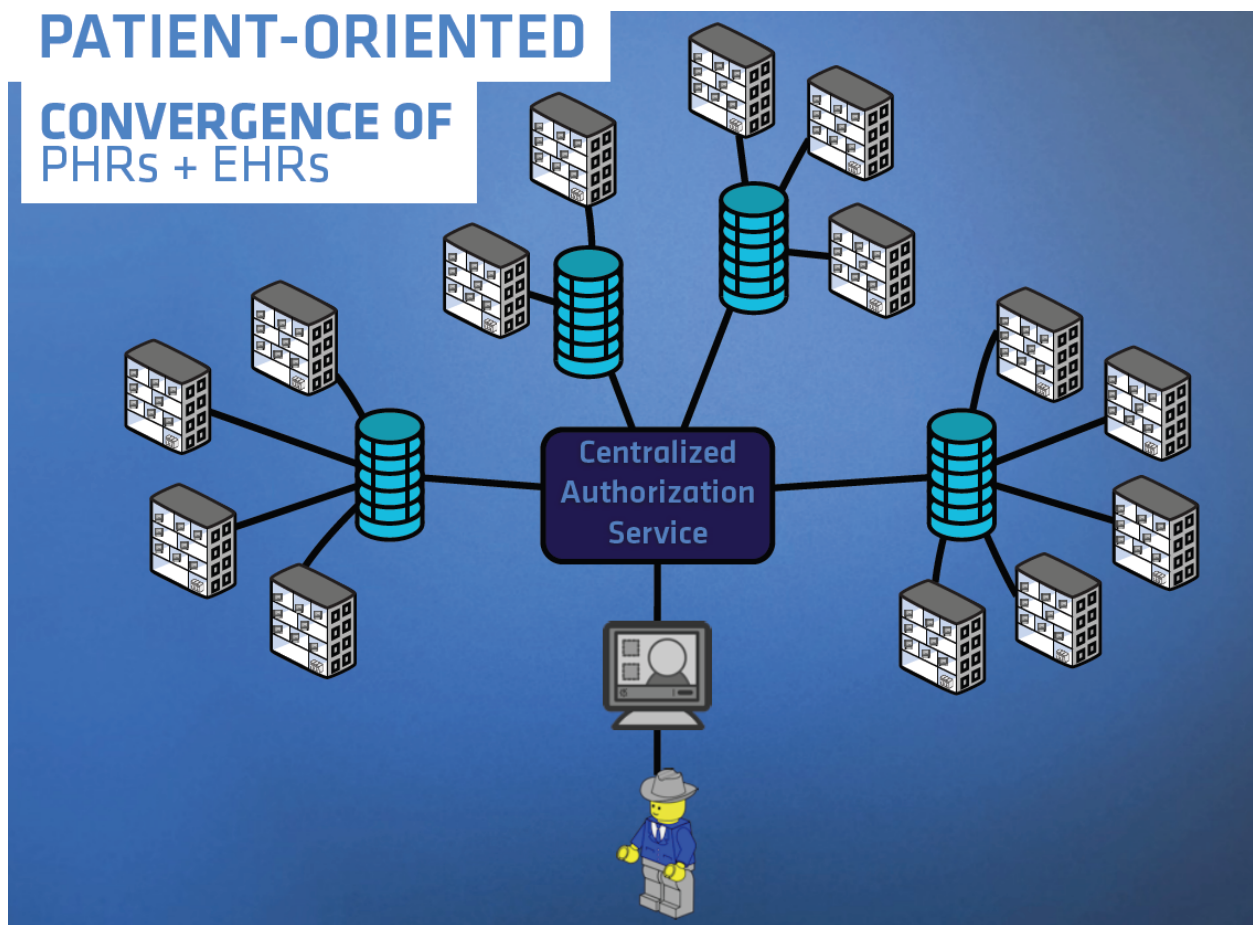
Figure 1. Depiction of Proposed Idea

Methodology

In order to answer the above questions a comparative study will be done based on the results of two surveys. The methodology will closely mirror two comparative survey studies done (see referenced articles for more details) in 2006 and 2010. [10] [12]

Procedure

All participants of the survey will be over the age of 18 and from the Greater Rochester Area. The survey will be administered online. The RIT Human Subjects Research office have approved the proposed methodology.

Inclusion/Exclusion Criteria and Stratification of Participants

The subjects that will be allowed to partake in the study will be limited to individuals who are over the age of 18 and who are either: a medical professional or an individual who has a medical record. The survey that each participant receives will depend on whether he/she is a medical professional or a patient. Each survey will contain identical questions in order to be able to properly compare the two subgroups. Then depending on which survey the participant receives there will be unique questions asked in order to gather more focused data that will be used in the comparison.

According to the 2000 census there are 136,061 people in the age range of 18-64. Out of the (136,061), 25,618 of them have an occupation in the educational, health and social services field. That leaves 110,443 individuals who have or at some point will have a medical record. Since I will be performing a stratified random sample my smallest subgroup is the health professionals and the larger subgroup will be the patients. Using a sample size formula, a 10% error margin,

and a 90% confidence level I would need to survey at least 68 medical professionals and 293 individuals who have a medical record.

Statistical Analysis

After the survey has been completed and the data finalized proper statistical analysis will be used in order to ensure the integrity of the results. The type of analysis performed will be determined after the completion of the survey.

Survey

Questionnaire for medical professionals:

1. Which of the following classifications apply to you?

    a. Medical Professional

    b. Patient

2. Are you…?

    a. 18-24

    b. 25-29

    c. 30-34

    d. 35-39

    e. 40-44

    f. 45-49

    g. 50-59

    h. 60-65

3. And are you…?

    a. Male

b. Female

4. In your opinion is the information contained in your medical record more sensitive than your financial information?

   a. Yes

   b. No

5. Are you comfortable with the amount of health care workers who have access to a patient's medical records?

   a. Yes

   b. No

6. Do you believe that patients should have access to certain parts of their medical record?

   a. Yes

   b. No

7. Would you document as honestly if a patient could view their full medical record?

   a. Yes

   b. No

8. The following are common sections of a medical record. Circle the items you believe a patient should not have access to.

   a. Medical History

      i. Surgical History

      ii. Obstetric History

      iii. Medication and Medical Allergies

      iv. Family History

      v.   Social History

     vi.   Habits

    vii.   Immunization History

   viii.   Growth chart and developmental history

   b. Medical Encounters

      i.   Chief Complaint

     ii.   History of the present illness

    iii.   Physical examination

    iv.   Assessment and Plan

   c. Orders and Prescriptions

   d. Progress Notes

   e. Test Results

9. If you answered "no" to question 4: If the above sections of a patient's medical record were blocked would you document honestly?

   a. Yes

   b. No

10. Do you think a system where the patient controls who have access to their medical record would work?

   a. Yes

   b. No

11. If you answered no to question five, please check the reasons below.

   a. Timeliness of treatment

   b. Patient Error

Questionnaire for patients:

1. Which of the following classifications apply to you?

    a. Medical Professional

    b. Patient

2. Are you…?

    a. 18-24

    b. 25-29

    c. 30-34

    d. 35-39

    e. 40-44

    f. 45-49

    g. 50-59

    h. 60-65

3. And are you…?

    a. Male

    b. Female

4. In your opinion is the information contained in your medical record more sensitive than your financial information?

    a. Yes

    b. No

5. Are you comfortable with the amount of heath care workers who have access to your medical record?

    a. Yes

   b. No

6. Do you know what a health information exchange is?

   a. Yes

   b. No

7. Do you know where your medical record is currently being stored?

   a. Yes

   b. No

8. Do you know if you medical record is being shared within a health information exchange?

   a. Yes

   b. No

9. If yes, have you signed a Regional Health Information Organization (RHIO) consent form or if your health provider (i.e primary care physician) asked you to sign a "consent to view" form?

   a. Yes

   b. No

10. Do you believe that patients should have access to certain parts of their medical record?

   a. Yes

   b. No

11. If you had access to your medical record would you view it?

   a. Yes

   b. No

12. The following are common sections of a medical record. Circle the items you believe

    a patient should access to.

    a. Medical History

        i. Surgical History

        ii. Obstetric History

        iii. Medication and Medical Allergies

        iv. Family History

        v. Social History

        vi. Habits

        vii. Immunization History

        viii. Growth chart and developmental history

    b. Medical Encounters

        i. Chief Complaint

        ii. History of the present illness

        iii. Physical examination

        iv. Assessment and Plan

    c. Orders and Prescriptions

    d. Progress Notes

    e. Test Results

13. If you were able to control who has access to your medical record would you utilize

    that tool?

    a. Yes

    b. No

14. Do you believe, as a patient, you have enough knowledge of the information in your

health record to safely limit access to parts of it?

    a. Yes

    b. No

Timeline

The following will provide a timeline for the completion of my capstone project. I have broken down the project into four phases: Proposal and Committee Search, Data Gathering, Analysis, and Finalization and Defense. I plan to be done with phase one by the end of March 2011. Phase two would be completed by November 2011. Phase three would be completed by February of 2012 and finally I would like to have had my defense by the end of December 2014.

Deliverables

After the completion of my research I will present my findings and data. I will fully document my methodology, results and conclusions in a final paper form. Also with the data that I collect I will theorize authorization models that could involve the patient.

Statistics

According to a 2010 survey conducted the New York Times currently only 20% of doctors and 10% of hospitals use basic electronic health records. In 2014 accordingly to HealthIT.gov the number of hospitals that have adopted a basic EHR's is almost 60%. Lastly according to Healthcare Informatics, as of 2013 there are over 280 active health information exchange initiatives in the country and over 50% of hospitals in the country are participating in an exchange. This means that the way healthcare data is being shared is changing and growing and there will be a need for an effective authorization system. [1] [9] [2]

Results

As stated in the methodology section, the intended total surveys that were to be taken was 293, with 68 of them being a medical professional (10% error margin, 90% confidence level). The

actual amount of people that took the survey was 213, with 77 being medical professionals. With the amount of actual surveys taken and using a 90% confidence interval, there was a 4.1% error margin.

The results will be presented as follows: how the survey and data answers each of the questions from my original thesis statement, additional results from survey, and the final section of the results will be a summary of the data and possible conclusions and applications that can be drawn from it.

The raw data from the survey (questions answered by both non-medical professionals and medical professionals, questions answered by non-medical professionals only, and questions answered by medical professionals only) can be found in Appendix A.

Results as they Apply to Thesis Statement:

The following seven questions that arose from my above stated hypothesis can now be answered. Conclusions and application of this data will be covered in later sections.

1. If patients had the ability to control access to their medical records would they want to use it?

    - Yes. As seen from the three graphs below, out of everyone that took the survey 98 % of them believed that patients should at least have access to certain parts of their medical records. Of the patients who took the survey 96% of them would view their medical record if they had access to it. Finally 92% of patients said that they would utilize a tool that would allow them to control who has access to their medical records.

Do you believe that patients should have access to certain parts of their medical records?
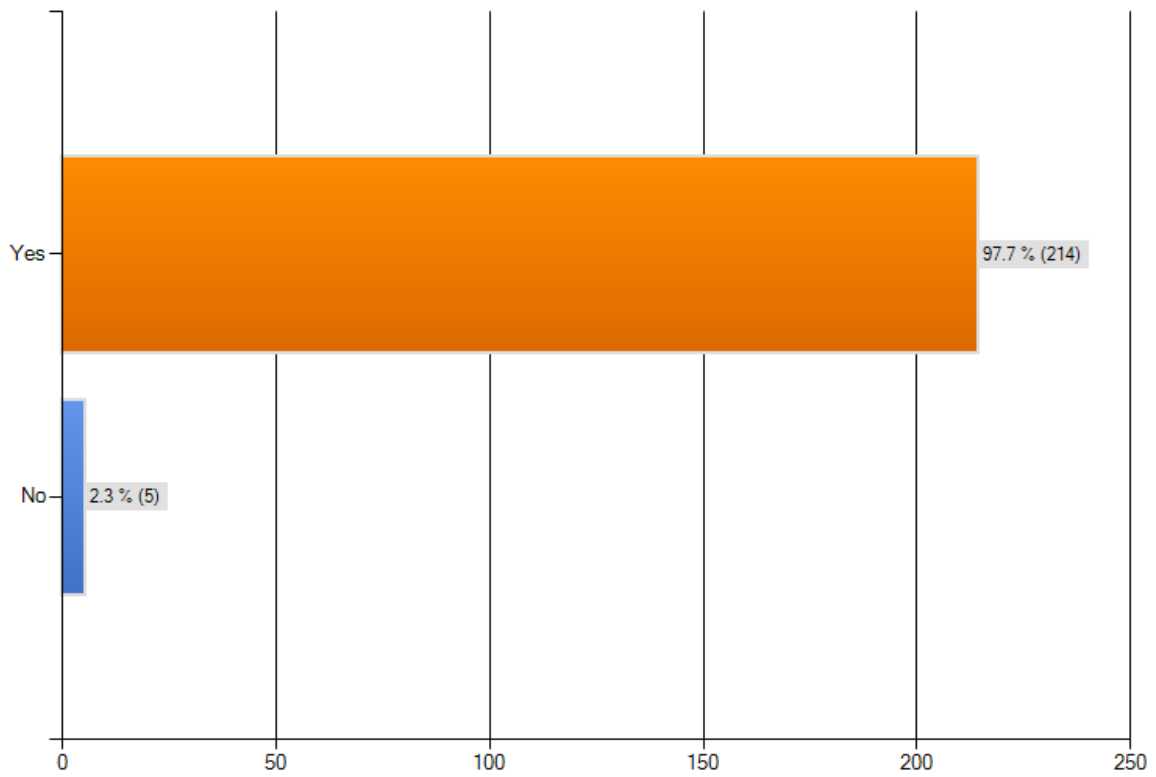
(Patient Survey) If you had access to your medical record would you view it?
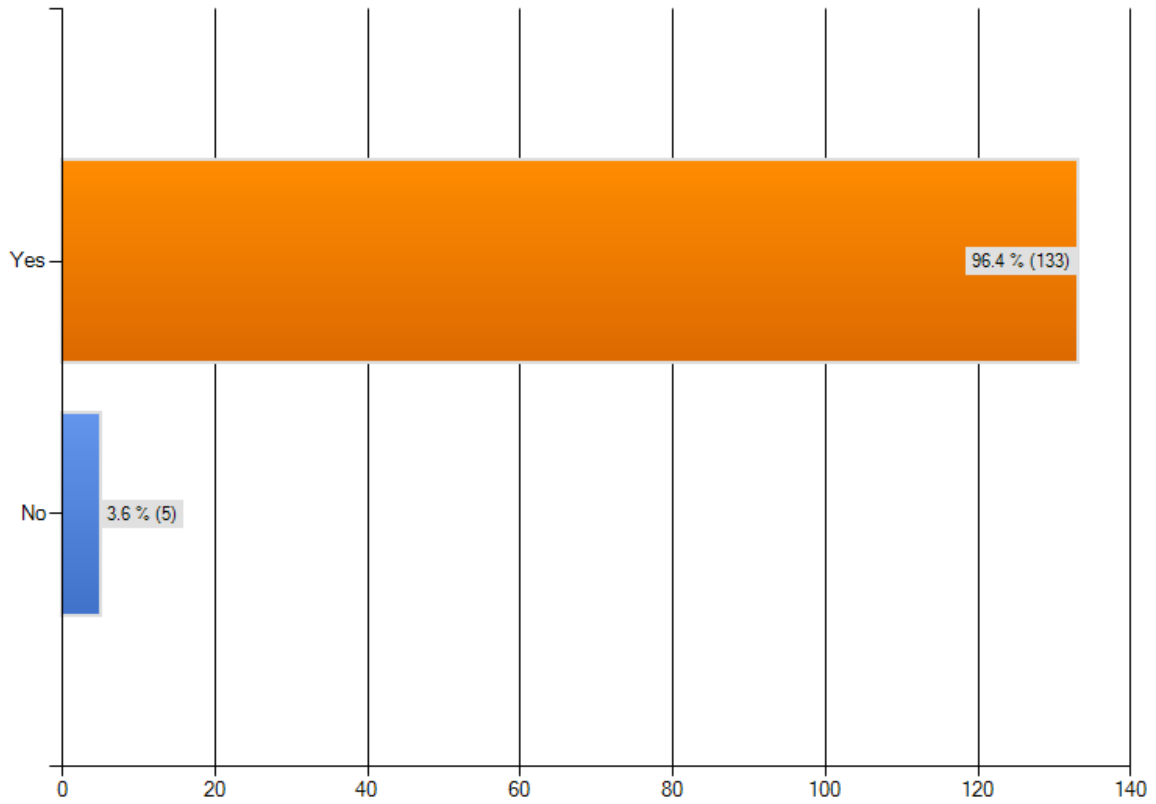
(Patient Survey) If you were able to control who has access to your medical record would you utilize that tool?

Yes — 92.0 % (127)

No — 8.0 % (11)
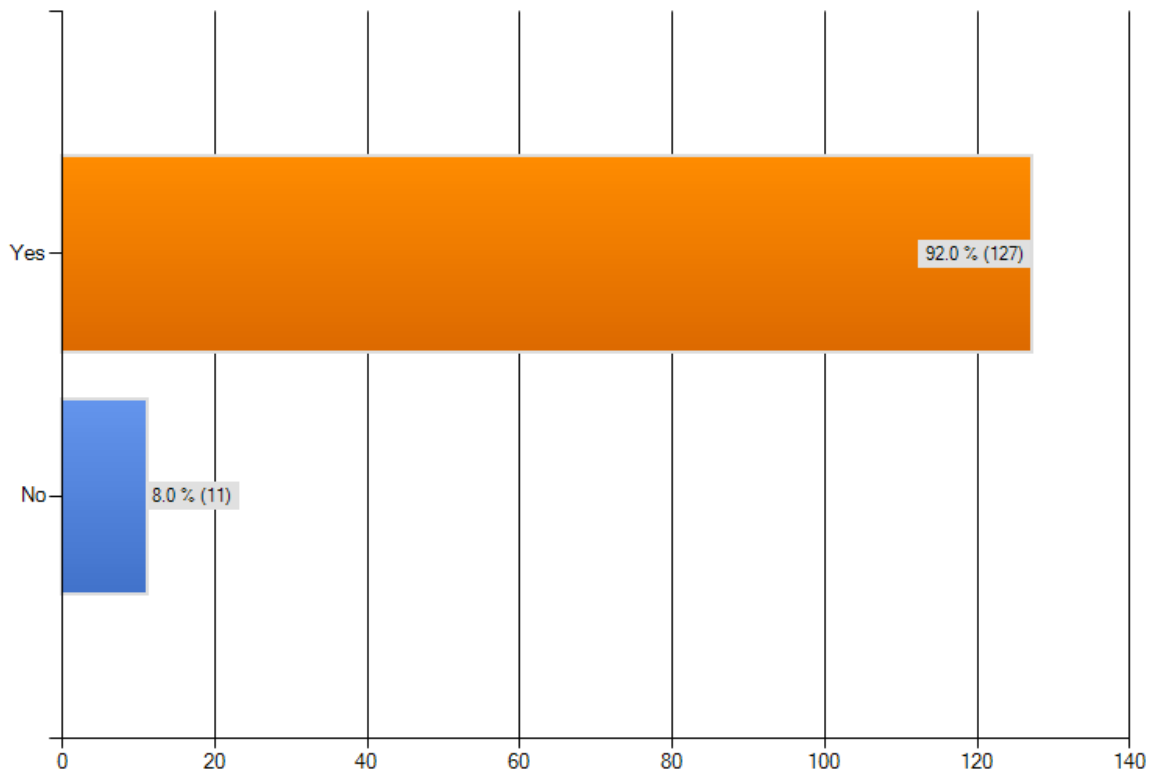
2. Do medical professionals believe a user centered access control model is feasible? If not, what are the factors that affect their conclusion?

- Yes. Of the medical professionals that took the survey 69.3% believed that a system where the patient has some control over who has access to their medical records would be a feasible solution.

(Medical Professional Survey) Do you believe that a system where the patient has some control over who has access to their medical records would work?

Yes — 69.3 % (52)

No — 30.7 % (23)

0   20   40   60
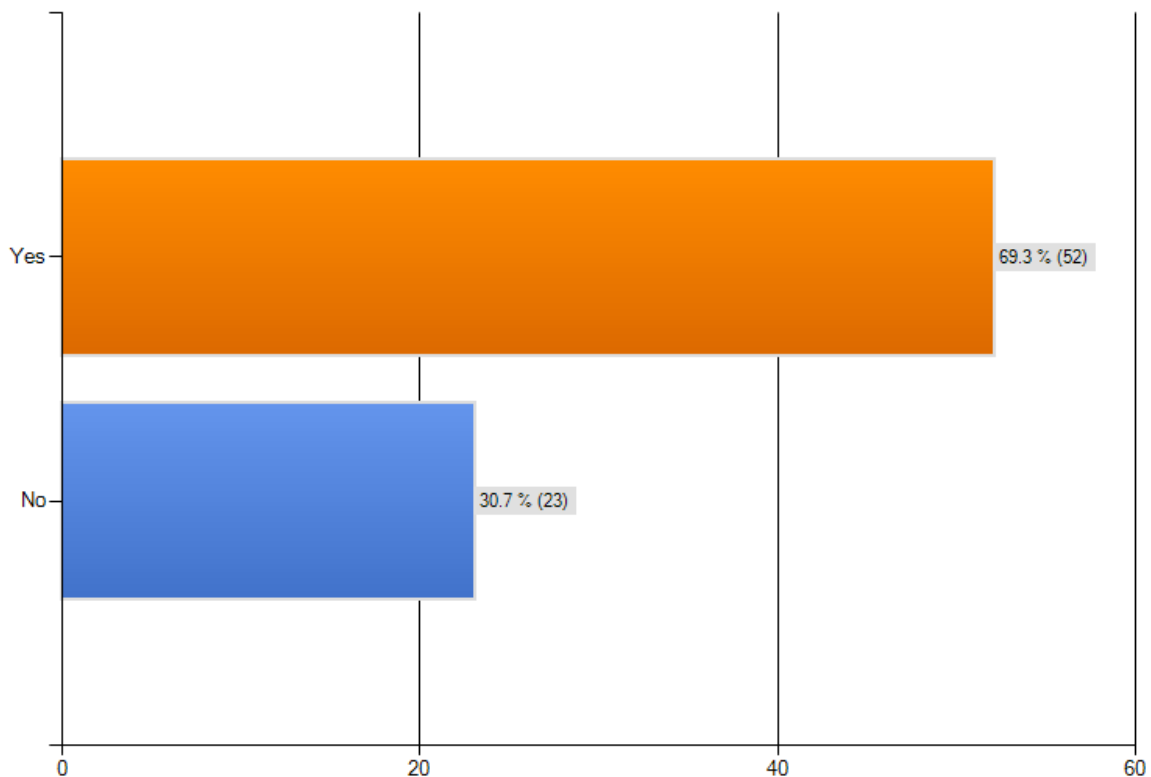
3. What areas do patients feel they should have access to on their medical records? What areas to medical professionals feel need further refined patient access control on medical records?

- The top five areas that patients believe they should have access to on their medical records are (please refer to the below chart for full list):

  o Immunization History (history of any vaccines that a patient has received) – 95.7 %

  o Medication and Medical Allergies (a list of medications that a patient is currently on and a summary of any known drug allergies) – 94.2%

  o Surgical History (an archive of all surgeries performed on a patient) – 91.3%

  o Test Results (results from any tests that were performed on the patient) – 89.9%

  o Physical Examination (results of physical examination performed by a medical professional) -87.7%

(Patient Survey) The following are common sections of a medical record. Select the items you believe as a patient or non-medical professional, that you should have access to.

Section	Value
Immunization History (history of any vaccines that a patient has rece...	95.7 % (132)
Medication and Medical Allergies (a list of medications that a patien...	94.2 % (130)
Surgical History (an archive of all surgeries performed on a patient)	91.3 % (126)
Test Results (results from any tests that were performed on patient)	89.9 % (124)
Physical examination (results of physical examination performed by a ...	87.7 % (121)
Orders and Prescriptions (list of written orders given by medical pro...	86.2 % (119)
Family History (health status of immediate family members)	83.3 % (115)
History of the present illness (detailed explanation of symptoms that...	81.2 % (112)
Assessment and Plan (summary of the causes of symptoms and treatment)	81.2 % (112)
Growth chart and developmental History (history of growth as a child/...	80.4 % (111)
Obstetric History (a list of prior pregnancies and outcomes)	76.1 % (105)
Progress Notes (summary of the progress of a patient)	76.1 % (105)
Chief Complaint (the problem that the patient currently is presenting...	74.6 % (103)
Habits (any habits that a patient has i.e. tobacco use, alcohol intak...	73.2 % (101)
Social History (record of patients interactions with other people i.e...	65.9 % (91)
Psychiatric History (an archive of all mental health interviews held ...	62.3 % (86)
Mental health examination (results of a mental health examination per...	60.9 % (84)
I believe that I SHOULD NOT have access to all of the above	3.6 % (5)

- The second half of this question had interesting results. The top five areas that medical professionals feel need further refined patient access control are (see below chart for full list):

    o No Refinement. (medical professional believes that a patient should have access to all areas of a medical record outlined in the question) – 65.3%

    o Psychiatric History (an archive of all mental health interviews held with patient) – 21.3 %

    o Mental Health Examinations (results of a mental health examination performed by a medical professional) – 14.7 %

    o Family History (health status of immediate family members) – 9.3%

    o Social History (record of patient's interaction with other people i.e career, relationships, schooling) – 8%
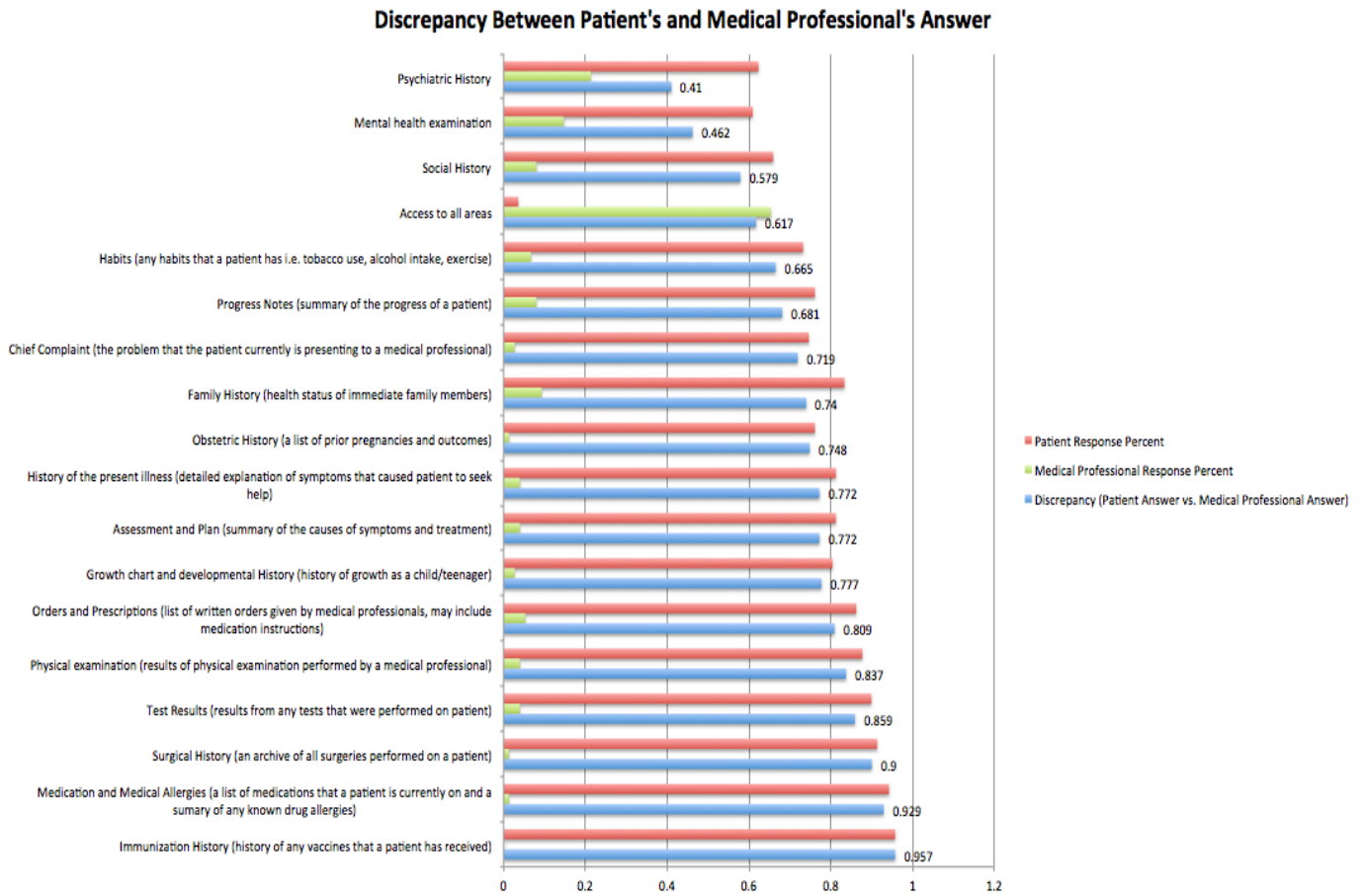
(Medical Professional Survey) The following are common sections of a medical record. Select the items you believe as a medical professional, that a patient should NOT have access to.

Category	
I believe that a patient SHOULD have access to all of the above	65.3 % (49)
Psychiatric History (an archive of all mental health interviews held ...	21.3 % (16)
Mental health examination (results of a mental health examination per...	14.7 % (11)
Family History (health status of immediate family members)	9.3 % (7)
Social History (record of patients interactions with other people i.e...	8.0 % (6)
Progress Notes (summary of the progress of a patient)	8.0 % (6)
Habits (any habits that a patient has i.e. tobacco use, alcohol intak...	6.7 % (5)
Orders and Prescriptions (list of written orders given by medical pro...	5.3 % (4)
History of the present illness (detailed explanation of symptoms that...	4.0 % (3)
Physical examination (results of physical examination performed by a ...	4.0 % (3)
Assessment and Plan (summary of the causes of symptoms and treatment)	4.0 % (3)
Test Results (results from any tests that were performed on patient)	4.0 % (3)
Growth chart and developmental History (history of growth as a child/...	2.7 % (2)
Chief Complaint (the problem that the patient currently is presenting...	2.7 % (2)
Surgical History (an archive of all surgeries performed on a patient)	1.3 % (1)
Obstetric History (a list of prior pregnancies and outcomes)	1.3 % (1)
Medication and Medical Allergies (a list of medications that a patien...	1.3 % (1)
Immunization History (history of any vaccines that a patient has rece...	

4. Are patients capable of making decisions concerning authorized access of information contained in their medical records?

- Yes, but there are caveats. 58.7% of patients that took the survey believed that they lacked the knowledge to safely and efficiently limit access to specific sections contained in their medical records. At the same time 65.3% of medical professionals that took the survey believed that a patient should have access to all parts of their medical record. The 3 major discrepancies between what a medical professional

believed a patient should not have access to on their medical record and what a patient believed he/she should have access to on their medical was: psychiatric history, mental health examinations, and social history. Meaning that patients do not care if the above areas are hidden from them and doctors want them to be – which in turn would eliminate the need for a patient to make granular authorization access decisions on data contained in their medical record. The answer to this question will help shape the level of granularity that a user needs to be given and will be elaborated on in question seven.

Discrepancy Between Patient's and Medical Professional's Answer

Category	Discrepancy
Psychiatric History	0.41
Mental health examination	0.462
Social History	0.579
Access to all areas	0.617
Habits (any habits that a patient has i.e. tobacco use, alcohol intake, exercise)	0.665
Progress Notes (summary of the progress of a patient)	0.681
Chief Complaint (the problem that the patient currently is presenting to a medical professional)	0.719
Family History (health status of immediate family members)	0.74
Obstetric History (a list of prior pregnancies and outcomes)	0.748
History of the present illness (detailed explanation of symptoms that caused patient to seek help)	0.772
Assessment and Plan (summary of the causes of symptoms and treatment)	0.772
Growth chart and developmental History (history of growth as a child/teenager)	0.777
Orders and Prescriptions (list of written orders given by medical professionals, may include medication instructions)	0.809
Physical examination (results of physical examination performed by a medical professional)	0.837
Test Results (results from any tests that were performed on patient)	0.859
Surgical History (an archive of all surgeries performed on a patient)	0.9
Medication and Medical Allergies (a list of medications that a patient is currently on and a sumary of any known drug allergies)	0.929
Immunization History (history of any vaccines that a patient has received)	0.957

Legend:
- Patient Response Percent
- Medical Professional Response Percent
- Discrepancy (Patient Answer vs. Medical Professional Answer)

5. What is contributing to the lack of a developed authorization model in health systems and what are possible ways to alleviate the problem?

- It appears that there are multiple factors from preventing the proposed model or any other authorization model from being successfully developed and implemented. The results will be analyzed based on the perspective of the patient and then of the medical professional.

    o Analysis based from patient perspective

        ▪ The main trend that can be observed from the perspective of the patient is lack of user knowledge and engagement:

            - 61.6% of the patients surveyed have never viewed their medical record. 77.5% of the patients surveyed do not know where their medical record is being stored. 68.1% of the patients surveyed no not know what a health information exchange is and 78.3% of the surveyed patients are not sure if their medical record is being shared within an exchange. The trend from the survey is that a majority of the patients have a limited knowledge of their medical record – including where it is stored, shared and available from. As seen from pervious questions, users would like to see their records and they would like to be involved in deciding who has access to it, but they have no conduit to do so. User education and engagement by local health institutions and medical professionals could help mitigate this problem. The more information users have on

their medical records and health information exchanges the

easier it will be to implement an authorization model and a
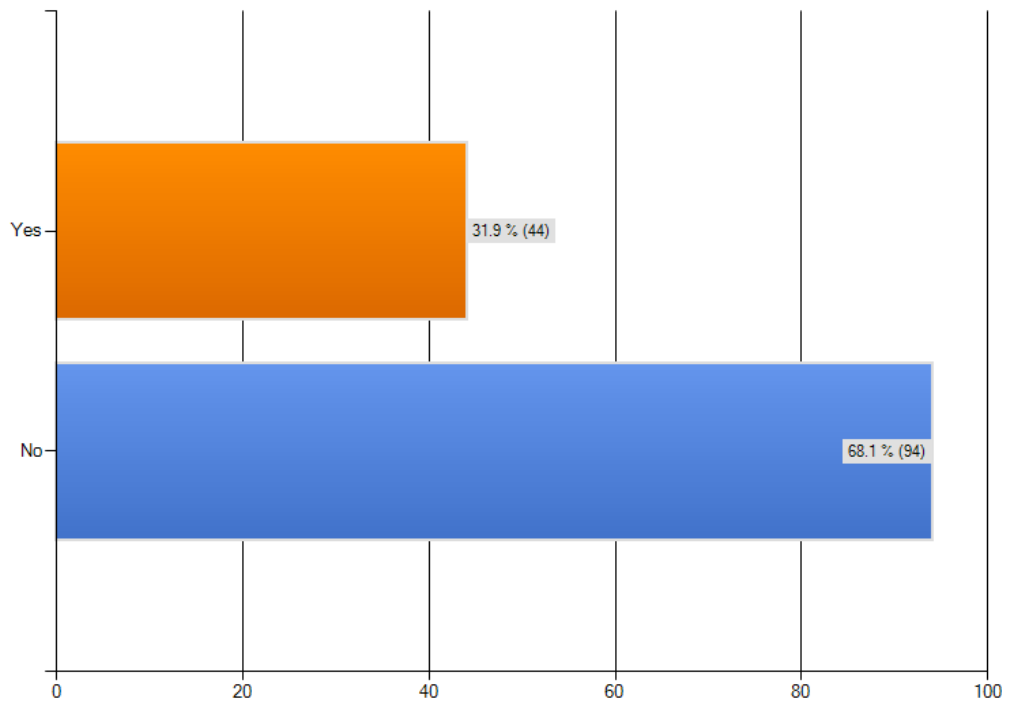
health information exchange in general.

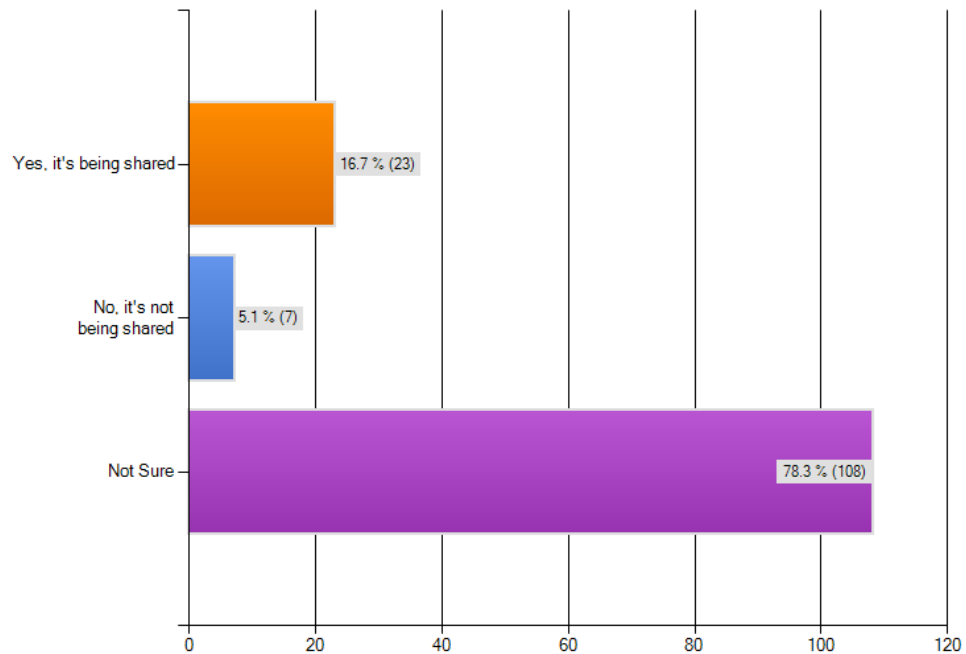**(Patient Survey) How many times have you viewed your medical record?**
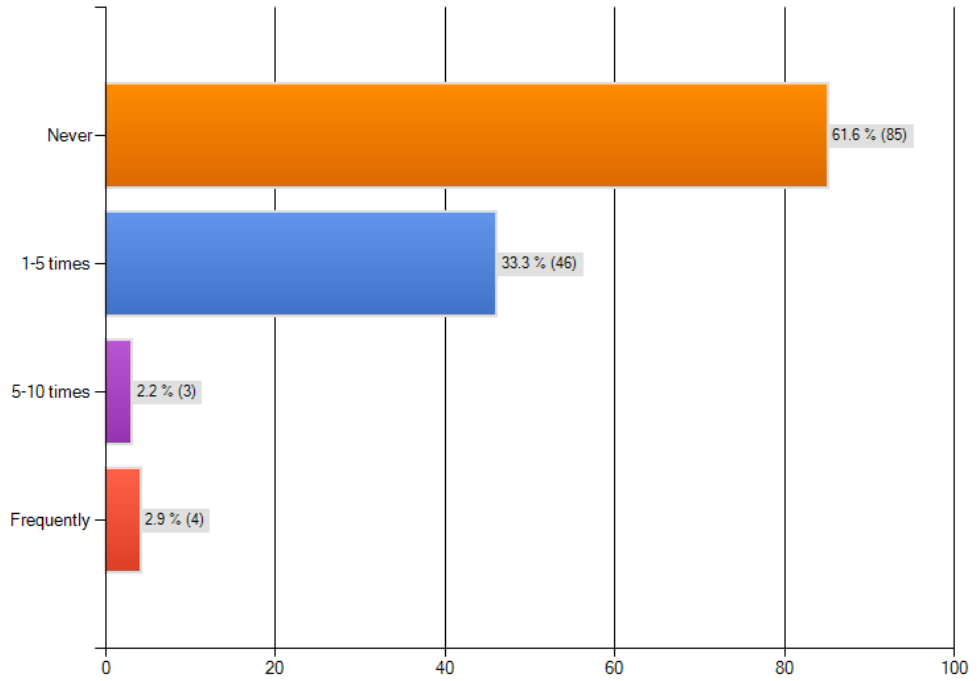
(Patient Survey) Do you know where your medical record is currently being stored?
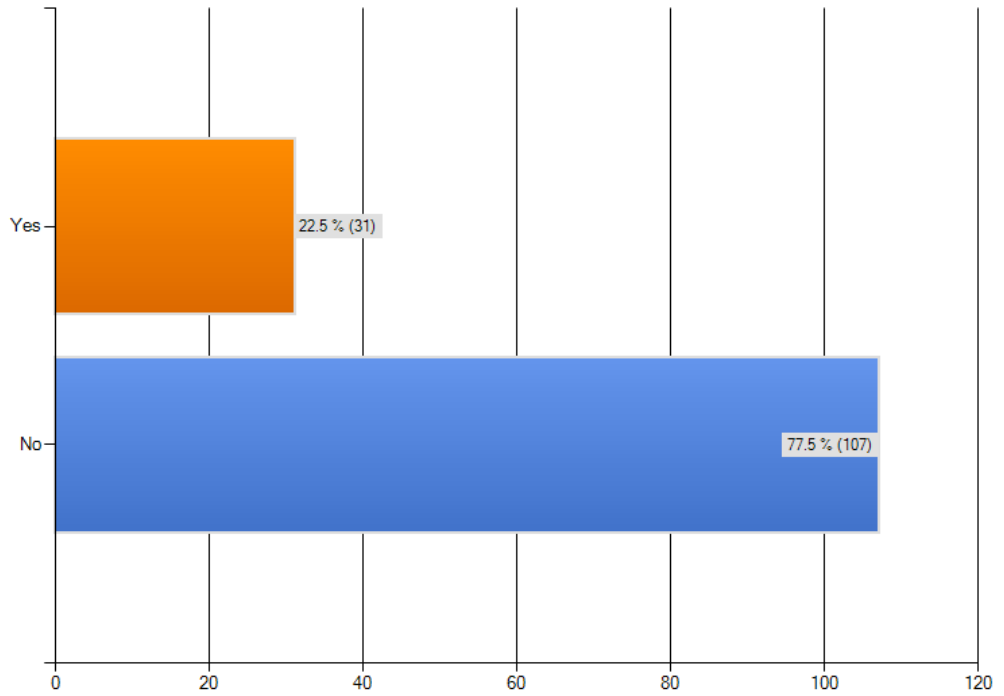
Yes — 22.5 % (31)

No — 77.5 % (107)

Do you know what a health information exchange is?

Yes — 31.9 % (44)

No — 68.1 % (94)

(Patient Survey) Do you know if your medical record is being shared within a health information exchange?

- o Analysis based on medical professional.

    - ▪ The results from the medical professionals yielded far more possible reasons for a delay in the development of a functioning authorization model. The following categories emerged from the open ended question analysis of the survey: fear of litigation or malpractice, misinterpretation by patients, too costly to implement, implementation too complex, tradition, insurance companies and/or politics, lack of user knowledge/engagement, timeliness. These categories were also broken down even further between medical professionals who beveled that a user centered authorization access system was feasible and those who did not.

- Medical professionals who agree with thesis statement

(Medical Professional Survey) Roadblocks to Implementation - User Agrees with Thesis

Category	Response Count
Litigation/Malpractice Fear	24% (12)
Misinterpretation by Patients	20% (10)
Lack of User Knowledge/Engagement	18% (9)
Insurance Companies/Politics	14% (7)
Complex Implementation	12% (6)
Timeliness	4% (2)
Tradition	4% (2)
Costly	4% (2)
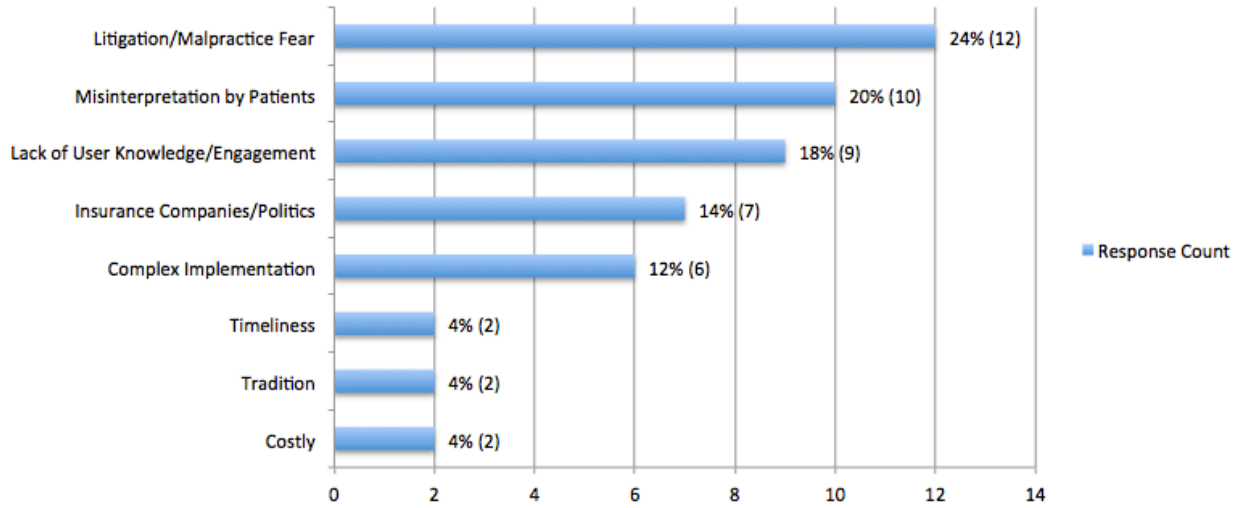
- Medical professionals who disagree with thesis statement

(Medical Professional Survey) Roadblocks to Implementation - User Disagree with Thesis
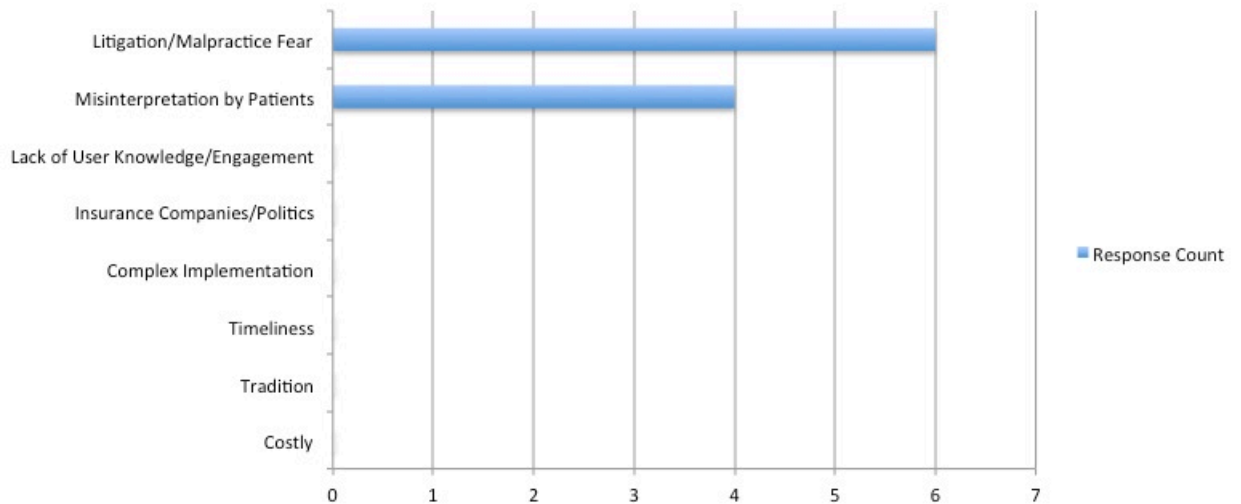
- o The largest overlap in the medical professionals analysis is litigation/malpractice fear and misinterpretation by patients. These two roadblocks aren't technical in nature and could be addressed by user engagement and training. Like most new technical concepts and systems the fear of the unknown can create misinformation among a user base and cause unnecessary delay in the implementation process.
- o Combining all groups together, according to the results from the survey, the three biggest road blocks to implementing a authorization system are: lack of user engagement/knowledge, litigation/malpractice fear, and misinterpretation by patients.

6. If patients had such control could it have a negative impact on the ability of medical

   doctors to deliver safe and quality healthcare.

   o No, when medical professionals were asked if they would document as

     honestly if patients had full access to their medical records, 89%, said they

     would. When asked that question again, after they identified sections of a

     medical record that they would want to stay hidden from the patient, 69% said

     that they would still document just as honestly. Meaning that either way,

     medical professionals would provide the same quality of care to patients

     regardless of the level of access control a patient has. It is safe to say based

     on the results that the quality of care for patients would not be impacted

     depending on the level of control patients are granted over their records.

(Medical Professional Survey) Would you document as honestly if a patient could view their full medical record?

(Medical Professional Survey) If patients did not have access to the sections of their medical records that you selected in question 8, would you document more honestly?


Yes — 30.7 % (23)

No — 69.3 % (52)
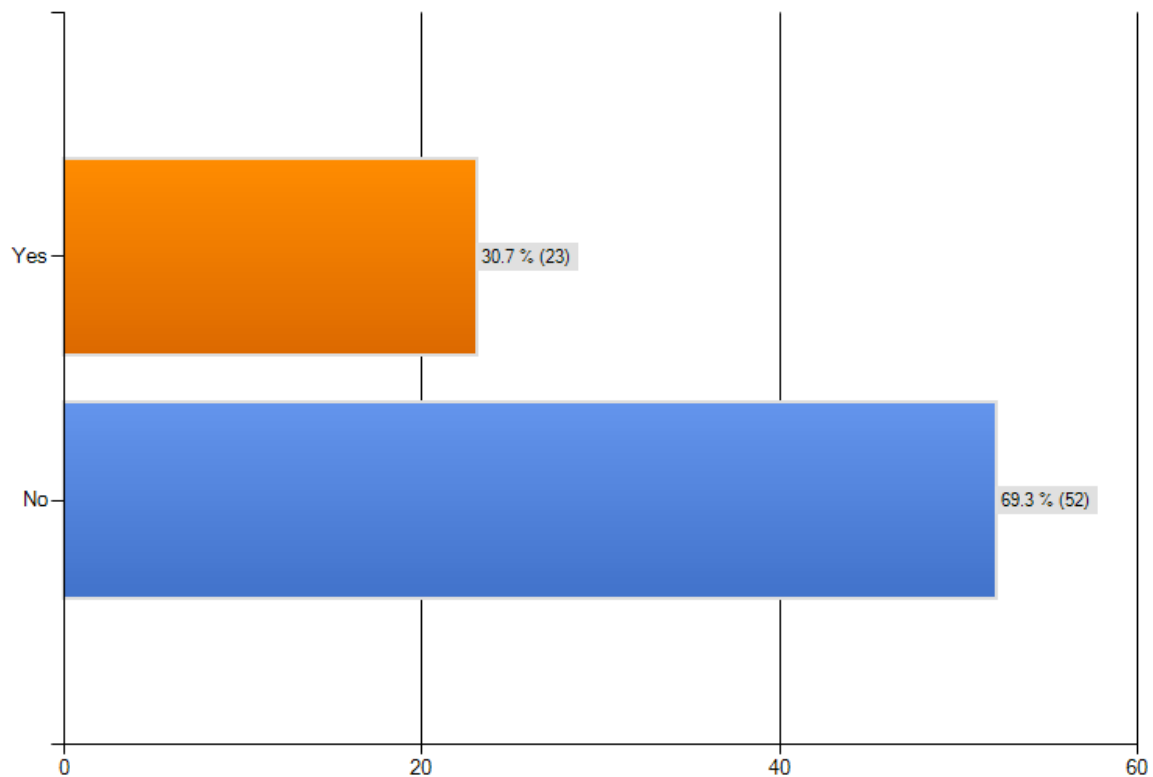
7. At what level of control could patients be granted that would not affect the quality of healthcare afforded to them.

- o Based on the results

   - o Patients want access to their medical record and medical professionals want patients to have access to their medical records

      - ▪ There are a handful of areas on a medical record that according to the survey should remain hidden (at least until they are discussed with a medical professional) from the patient:

         - • Psychiatric history, mental health examinations, and social history, and test results

- Also based on the survey, patients do not want nor do they feel

  like they could manage granular access to their medical

  records, but they do want control in a macroscopic level of who

  has access to them and that is the level of control that should be

  given to a patient.

Additional Results

So far in order to research authorization and access control systems, researching areas that need access control was a necessity. I also wanted some insight into the daily behaviors of medical professionals. This type of data could eventually help form new types of access control systems. As seen from the data below, health care professionals: work closely and repeatedly with a small group of people, some of which may include people outside of their department or healthcare institution.
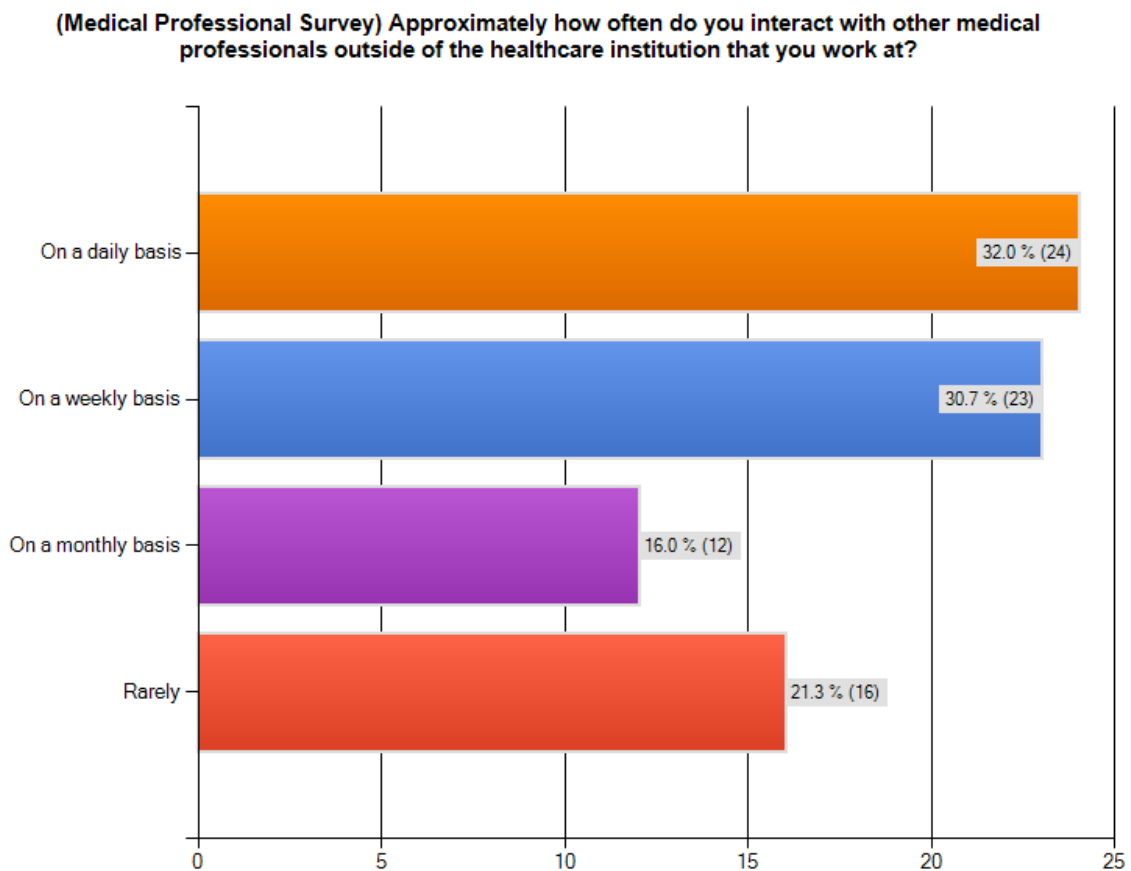
(Medical Professional Survey) Approximately how often do you interact with other medical professionals outside of the healthcare institution that you work at?

Category	Value
On a daily basis	32.0 % (24)
On a weekly basis	30.7 % (23)
On a monthly basis	16.0 % (12)
Rarely	21.3 % (16)

(Medical Professional Survey)Approximately how often do you interact with other medical professionals outside of the department that you work in?

On a daily basis	49.3 % (37)
On a weekly basis	22.7 % (17)
On a monthly basis	5.3 % (4)
Rarely	22.7 % (17)
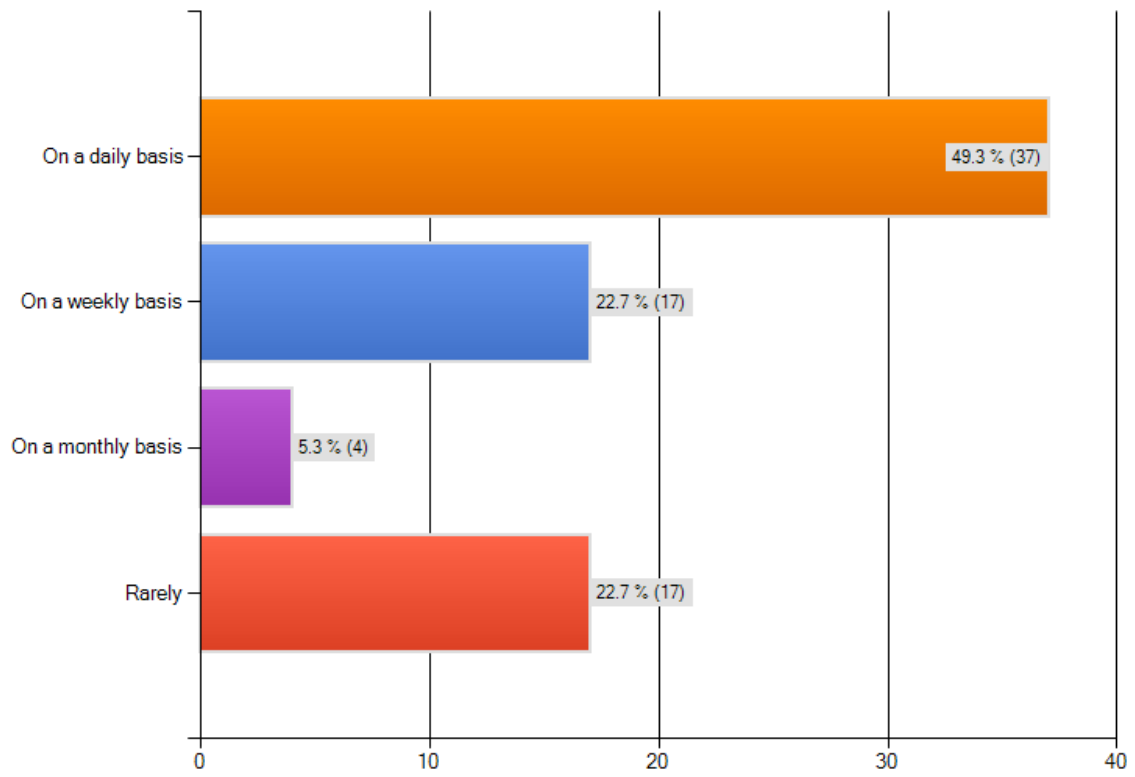
(Medical Professional Survey)Approximately how many other colleagues do you work with repeatedly on a daily basis?
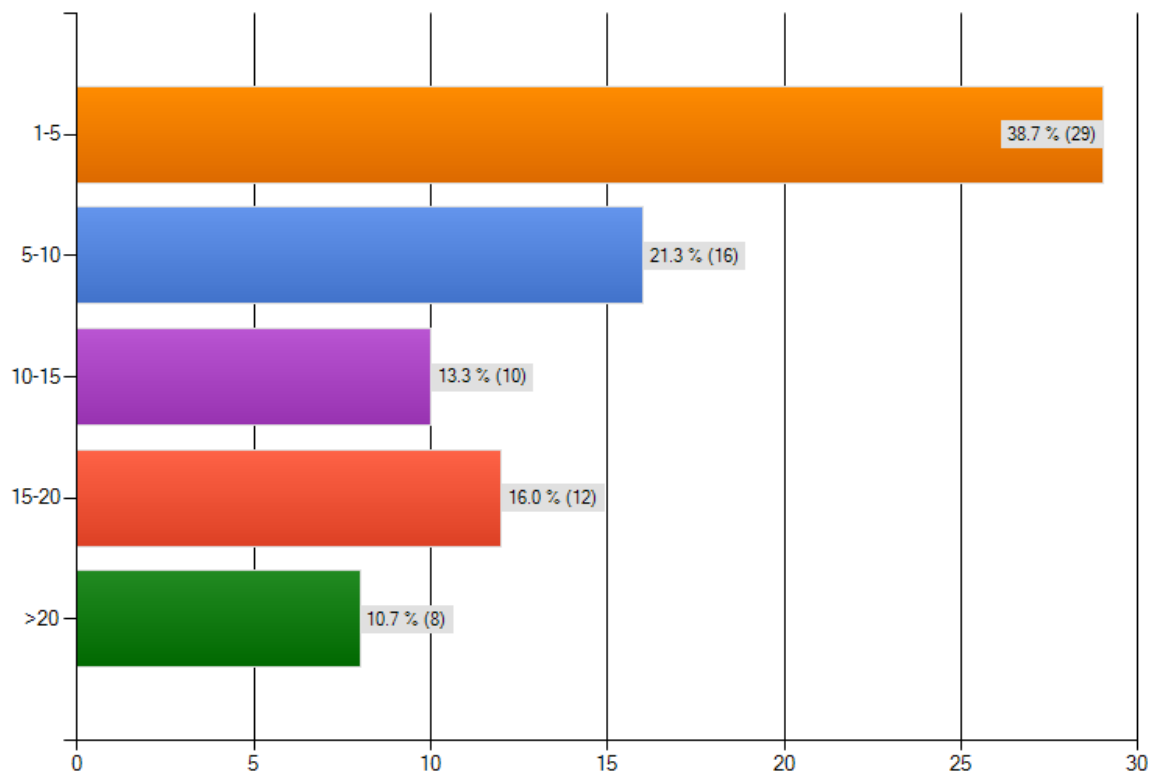
Analysis

The premise of this paper was to prove whether or not a user centric authorization access system was feasible. Before we could answer that question we had to see what areas in a heath record needed access control, what obstacles are currently presenting this type of system from forming, the views of both patients and medical professionals, and the behaviors of the players in a health environment. My analysis shows that:

- Both patients and medical professionals believe that a user centric authorization access model could work and would use such a tool.

- Patients want access to their medical records and medical professionals want patients to have access to their medical record.

- Granular controls over individual sections of a patient's medical record are not needed. Instead, the medical record should be treated as one single entity. The focus of access should be on the macroscopic level.

- The roadblocks to implementation are not technical in nature but more bureaucratic and political.

- There would be no detriment to the level of healthcare provided to a patient if such a system exists.

- Medical professionals work with small groups of people repeatedly both inside and outside of their primary healthcare institution and department.

It is safe to conclude at this point that a user centric authorization access model is feasible and that the premise of my paper is correct. Here is one type of system that arises from the above research. I call it a heuristic based clan access control model.

A heuristic based clan access control (HBCAC) model is a dynamic model, which focuses on the interactions between the players/entities in the model and a medical record. Once a player in the model reaches a threshold or trust boundary they are placed into the clan or trusted zone. That player then has full access to the medical record without going through trust negotiations. The interaction value would have a decay factor to it and would eventually decrease over time, so if a player in the model does not interact with a medical record for long enough, they would fall out of the trusted zone. Whether or not a player is allowed access to a medical record is determined by the trust values of the department and organization they are tethered to. A department's trust value is increased when a player that belongs to that department is part of a clan and is decreased

when that player falls out of the clan. The trust value of the organization is then determined by added up all of the trust values for each of the departments that are bonded to it.
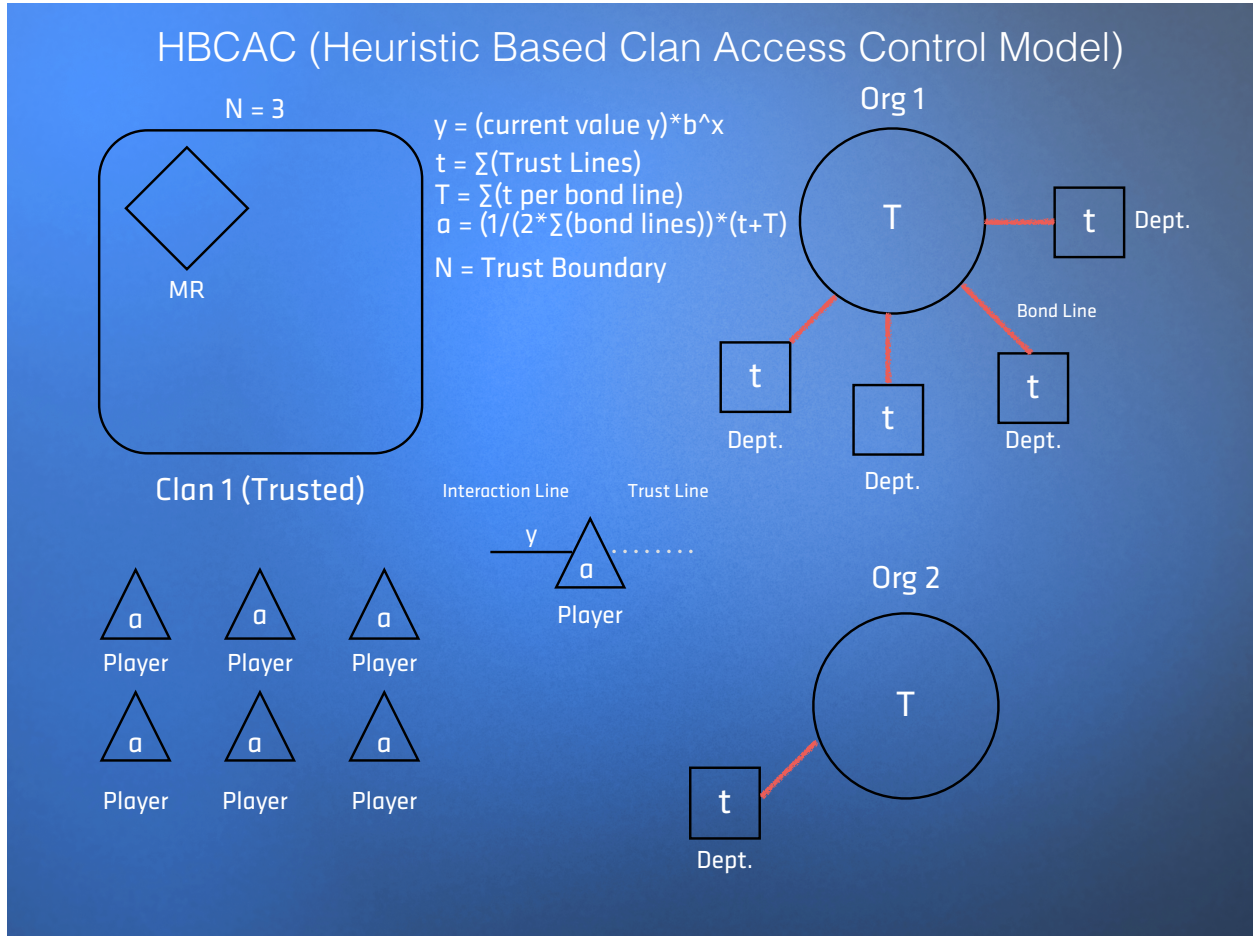
This type of model would overcome a lot of issues with current rigid access control model and merge some of the ideas of theoretical model into one that provides a proactive and protective approach to securing health data, while still dynamic enough to allow a majority of the entities in a system access to the data that they need to provide quality healthcare. A potential platform that could utilize this type of system could look like the mockups below.
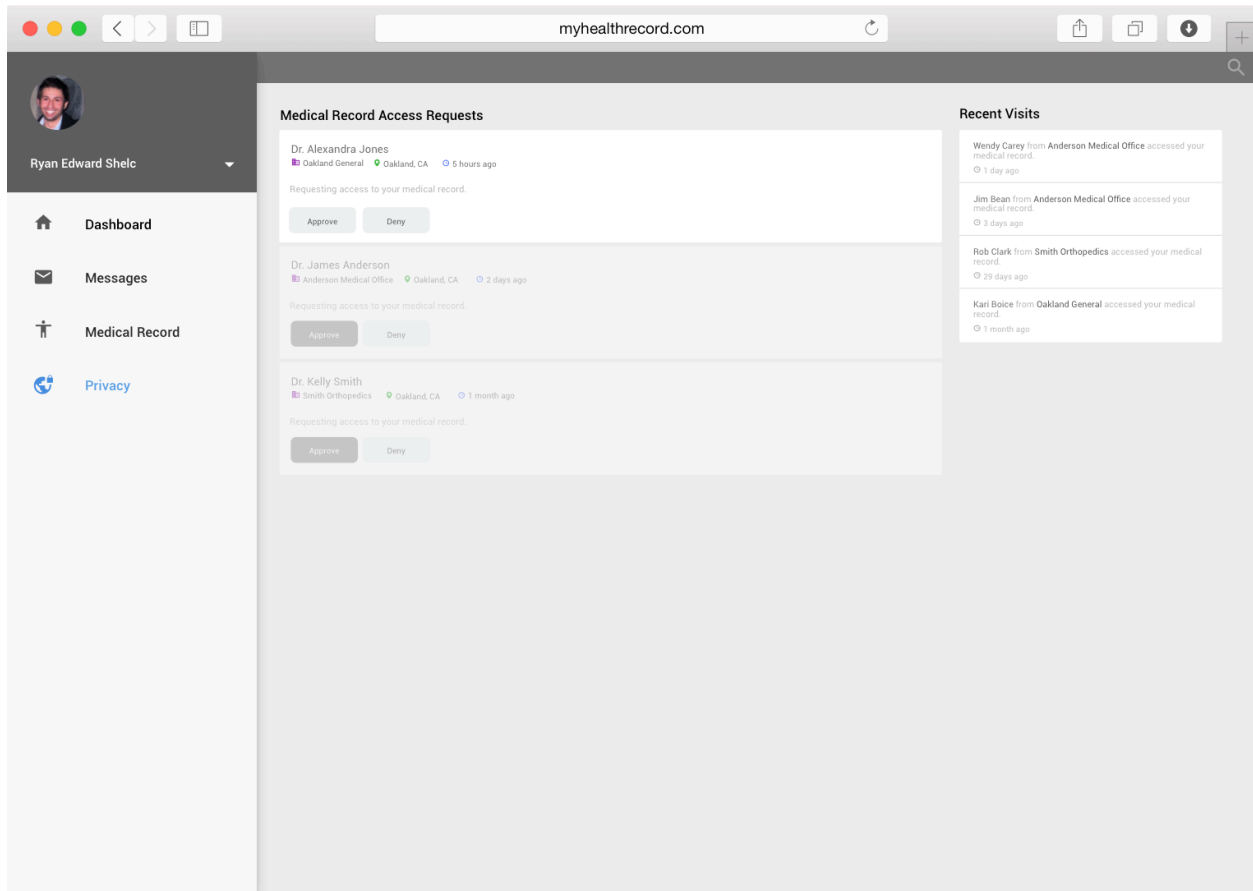
The above outlined platform would allow a user to aggregate all of the health information exchanges that their data is being exchanged on and by implementing a HBCAC access control model – they could be alerted to potential fraudulent activity and put a stop to it immediately. There would need to be thresholds set and different protocols would apply to emergency situations, but this type of system and platform would be a major step forward in protecting a patient's privacy while still providing them with quality secure healthcare.

Continued Areas of Possible Research

HIE-HIE/HIS-HIS Communication

In order for the above proposal to work there would need to be data exchanged between the

central authorization service and multiple HIE's and HIS's. Since there is no universal standard

for implementing exchanges and furthermore no universally accepted method to communicate

between health information systems and exchanges, the above service would need to ingest data

from multiple sources and formats. There has been some research already performed that the

above service could utilize in order to ingest the needed data to perform authorization services.

The Office of the National Coordinator of Health Information Technology (ONC) has been

developing standards that organization and healthcare institutions can use to transfer data

between exchanges and health systems. ONC's goal to provide a framework that allows health

organization to easily implement health systems and exchanges that allows health data to flow

securely and efficiently.

One program that ONC has launched is the DIRECT project. The aim of the DIRECT project is

to provide technical standards and services necessary to securely push content from a sender to a

receiver. This type of framework could be used to push data from a HIE to the central

authorization service outlined above. The project outlines how to securely transmit data using

SMTP and x.509 certificates. This is one area that would need continued research. The

DIRECT program is still in its infancy and this type of communication still needs to be

developed further.

Minimal Viable Product (MVP)

Since the authorization model proposed above is still theoretical, proving that it works is essential to developing an efficient model. One way to do that would be to create a minimal viable product (MVP), meaning that we would actually implement the above idea to a bare bones working model3 and actually start testing it in different environments and audiences. By gathering input from actual use cases, removing and improving areas of the model that don't work would be very easy and streamlined. This type of approach allows for fast pivoting on failed ideas and allows for more streamlined ideation. This is another area that would need continued time and research.

Conclusion

As seen from the above statistics and information contained in the proposal, there is a strong need for research into the authorization models that are used for electronic medical records. Without some kind of an authorized access model, health administrators can only take a reactive approach to ensuring patient privacy. Creating and implementing an authorized access model for health care systems and exchanges will proactively protect patient data and ensure the continued growth of interconnected health networks.

Currently health exchanges are in their early stages of development. Due to the small size of the networks they can grow without having a sound authorization access model and in its place the networks rely almost entirely on audit logs; a reactive measure. While auditing is a good practice to develop in any information system there must be other measures to ensure complete data control and privacy. Especially as health exchanges and systems begin to grow to meet the eventual nationwide interconnected health network, relying solely on audit logs will not suffice.

Traditional authorization access models are too rigid to conform to the dynamic and ubiquitous nature of the healthcare system. Implementing an authorization model centered on user control of access can help alleviate some of the shortcomings of traditional access models.

Although there still will exist barriers before a user centered authorization model can be implemented this paper aims to begin research into the feasibility of such a system. The movement of personal information into a networked environment has happened in almost all other major industries today. Users can view their financial, social and personal information online and in some cases control who has access to it. The ability of users having access to their many forms of personal information creates awareness and empowers them with the ability to make informed decisions on authorized access. When it comes to a patient's health no one knows their medical record better than themselves, allowing users some control over access control will create a system that can allow the digital health revolution to continue.

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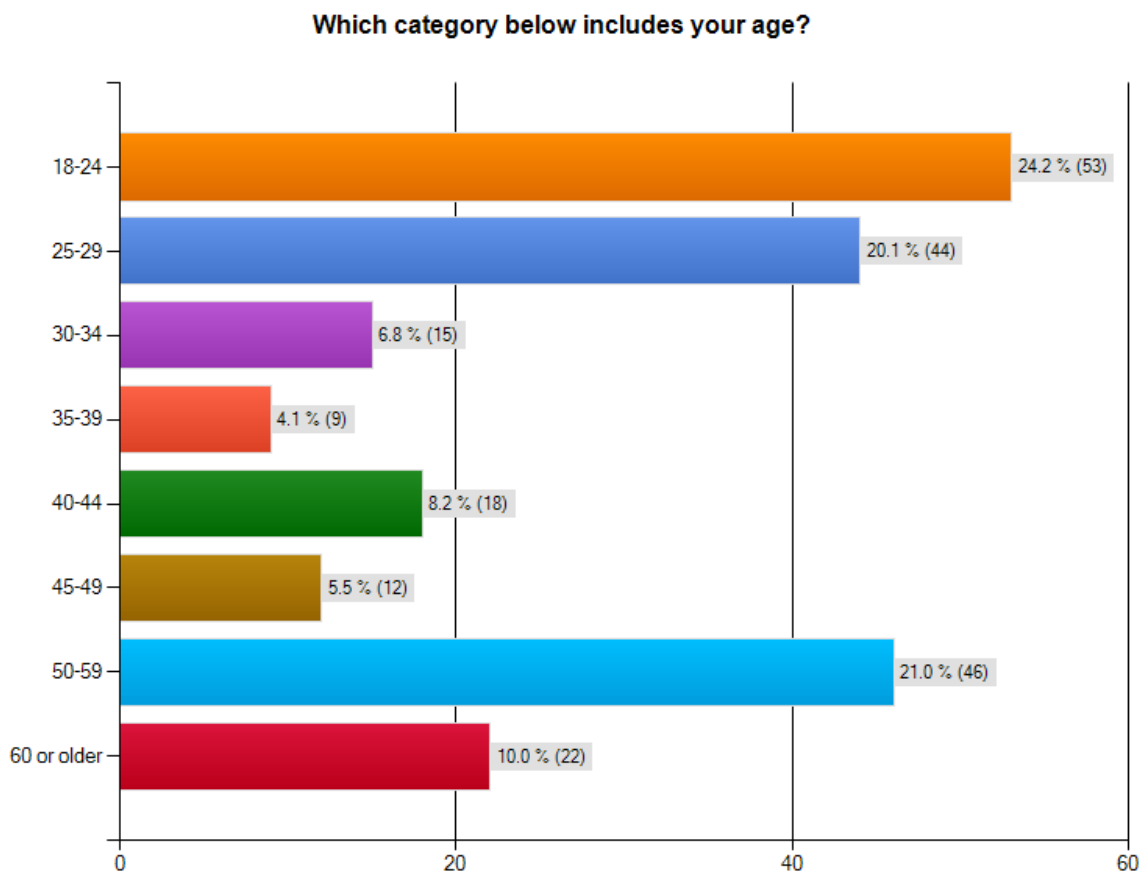   alcohol and tobacco use in urban and rural populations in the Huaihua District oh Humnan

      Proince, China. Alcohol, 39, 87-96.
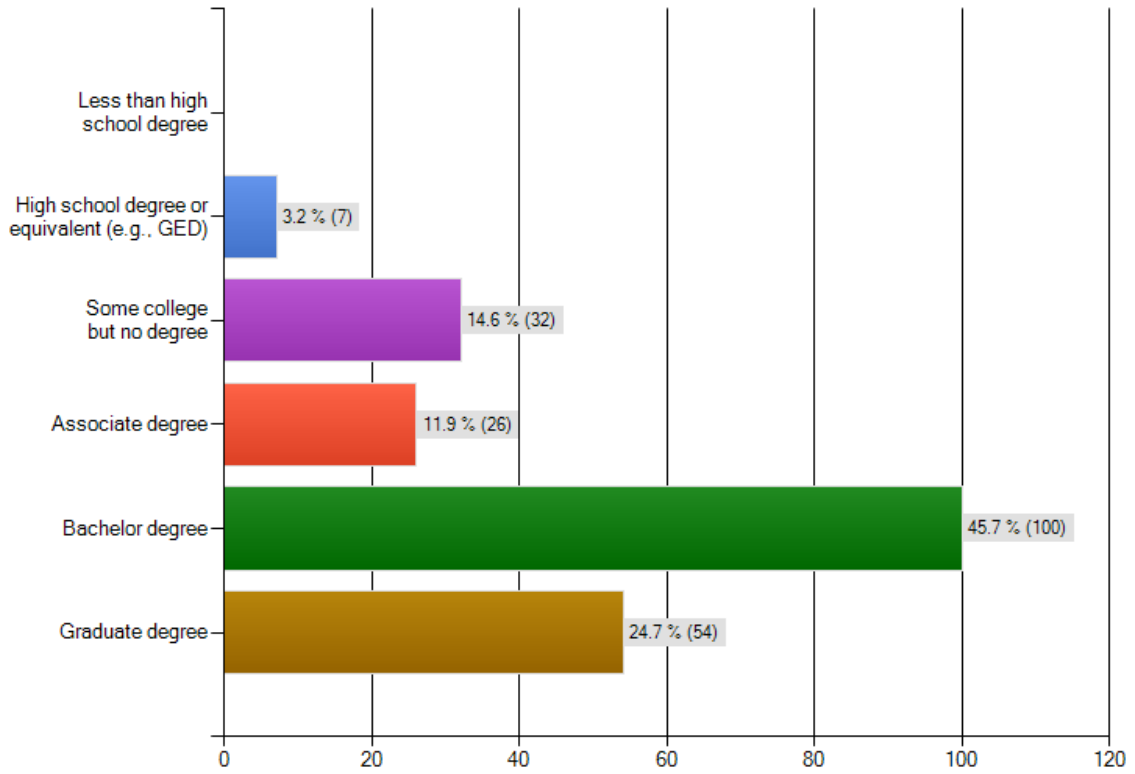
Appendix A: Raw Results

Raw Survey Results

Questions Answered by both Medical and Non-Medical Professionals

Age:

Which category below includes your age?

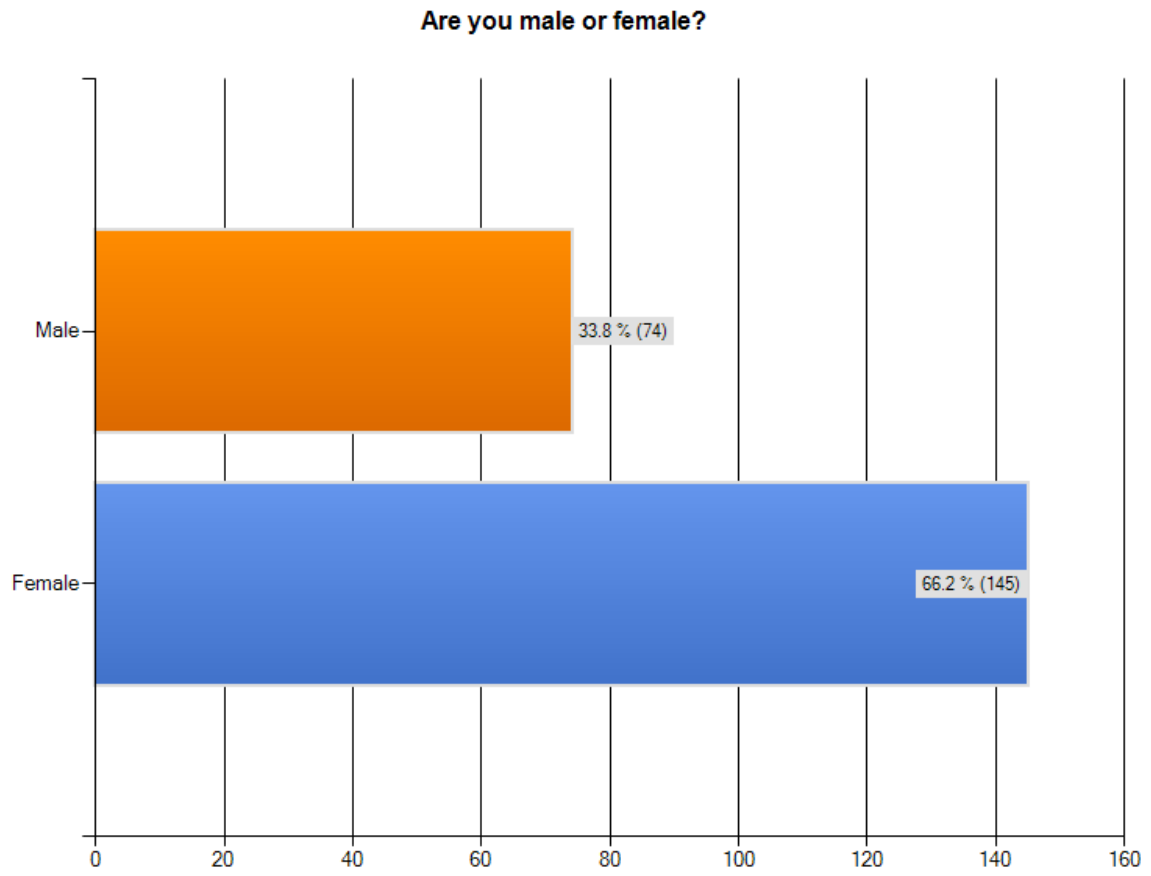| Age	Percentage (Count)
18-24	24.2 % (53)
25-29	20.1 % (44)
30-34	6.8 % (15)
35-39	4.1 % (9)
40-44	8.2 % (18)
45-49	5.5 % (12)
50-59	21.0 % (46)
60 or older	10.0 % (22)

Education:

What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (e.g., GED): 3.2 % (7)
- Some college but no degree: 14.6 % (32)
- Associate degree: 11.9 % (26)
- Bachelor degree: 45.7 % (100)
- Graduate degree: 24.7 % (54)

Sex:

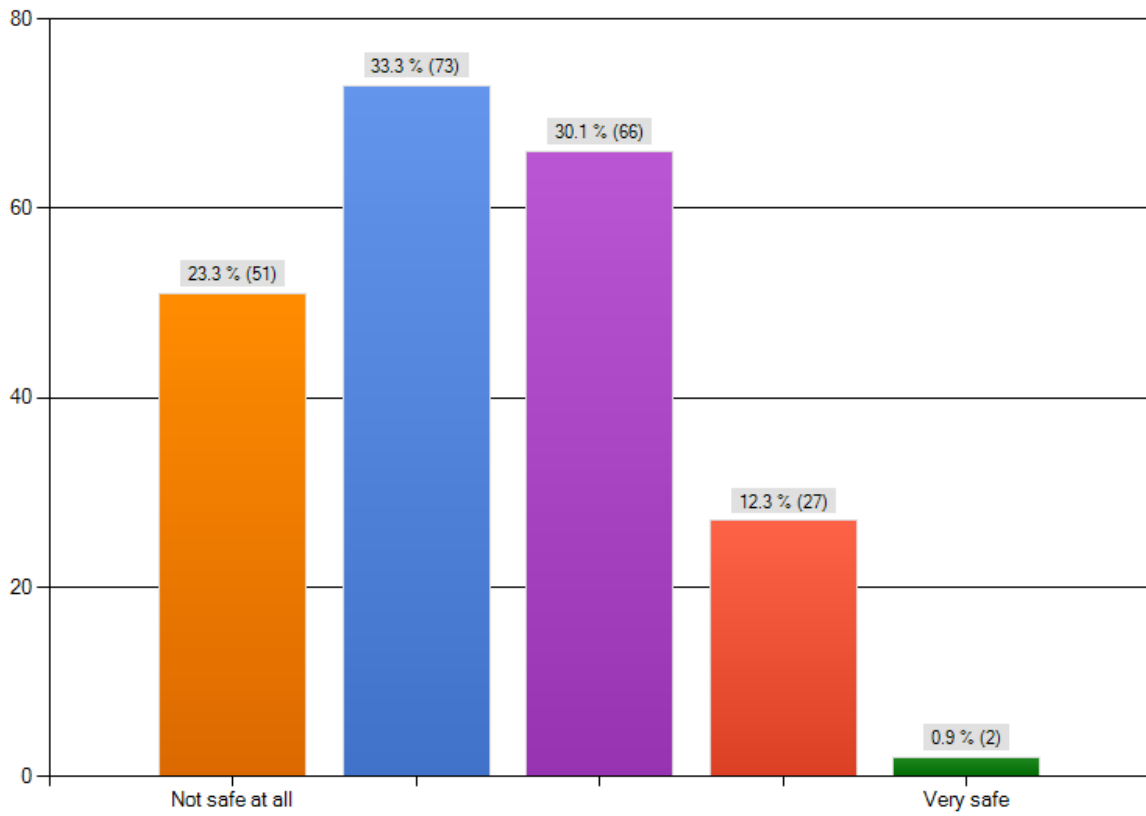**Are you male or female?**

Male	33.8 % (74)
Female	66.2 % (145)

**In your opinion is the information contained in your medical record more sensitive than your financial information?**

Yes — 45.2 % (99)

No — 54.8 % (120)
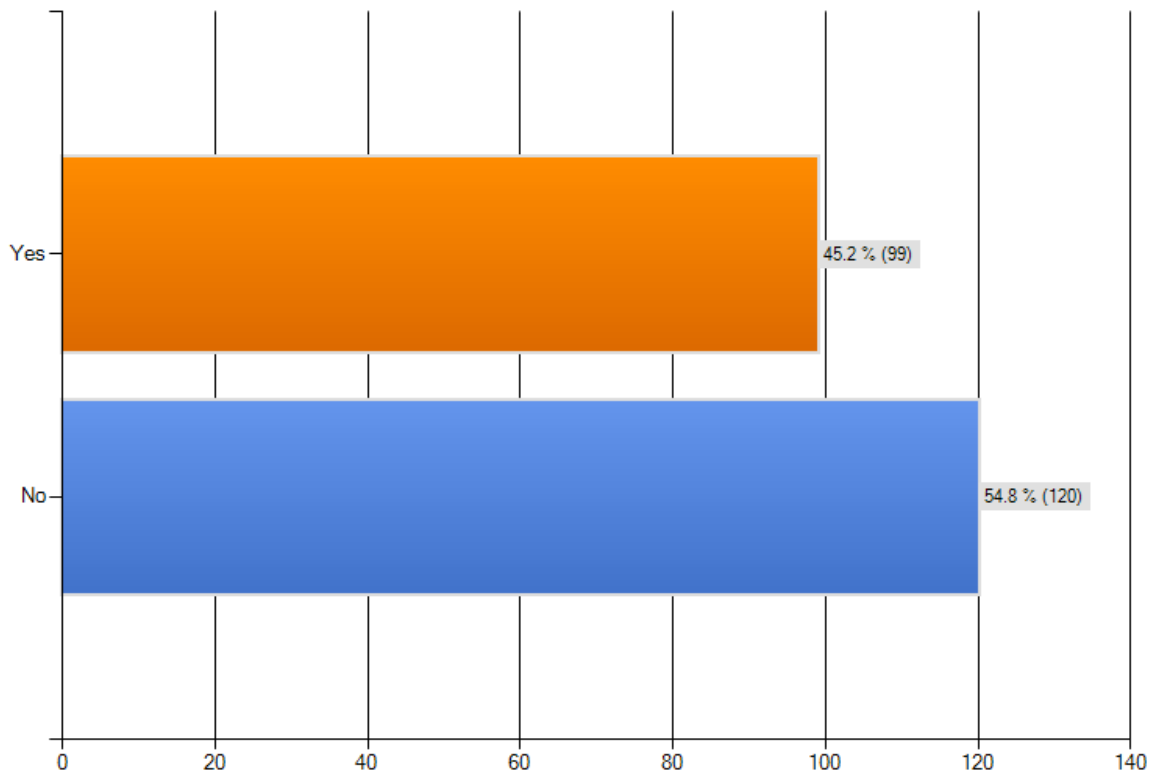
On a scale of 1-5 do you feel that your personal information is safe on the Internet?

Bar chart data:
- Not safe at all: 23.3 % (51)
- 33.3 % (73)
- 30.1 % (66)
- 12.3 % (27)
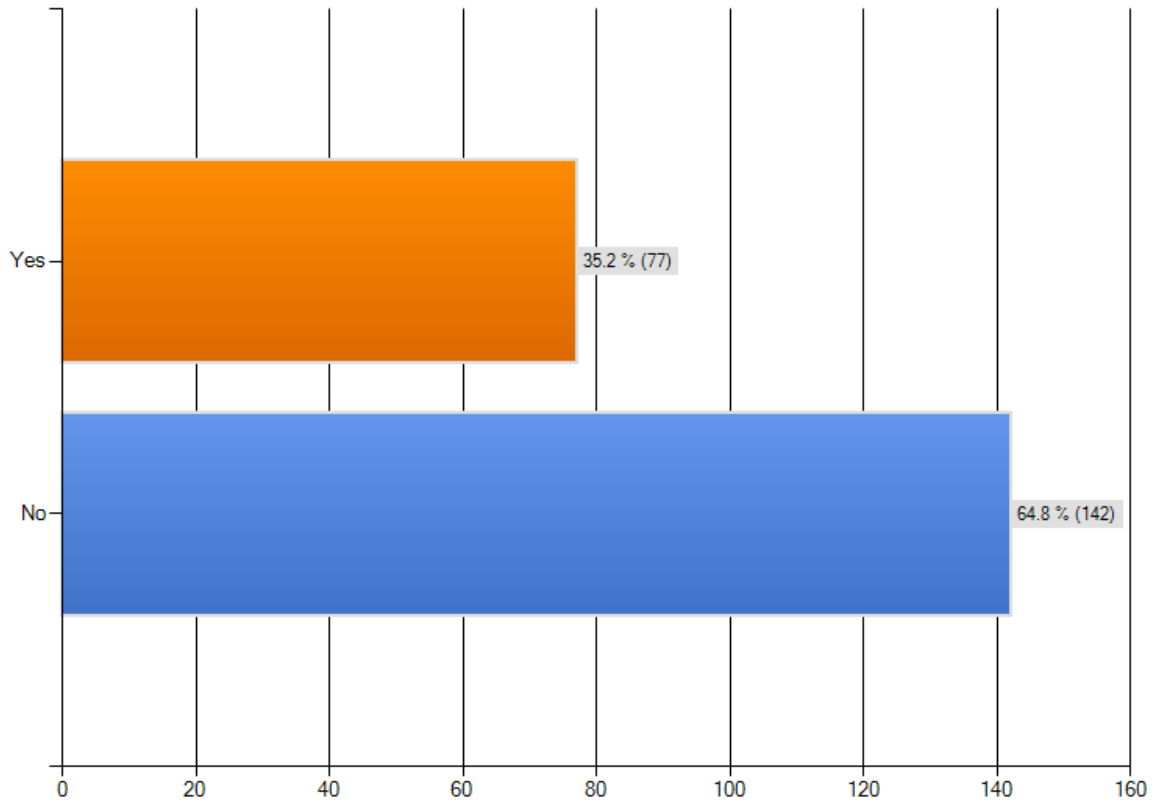- Very safe: 0.9 % (2)

One a scale of 1-5, 1 being the least comfortable. How comfortable are you with the amount of health care workers who have access to your medical record?
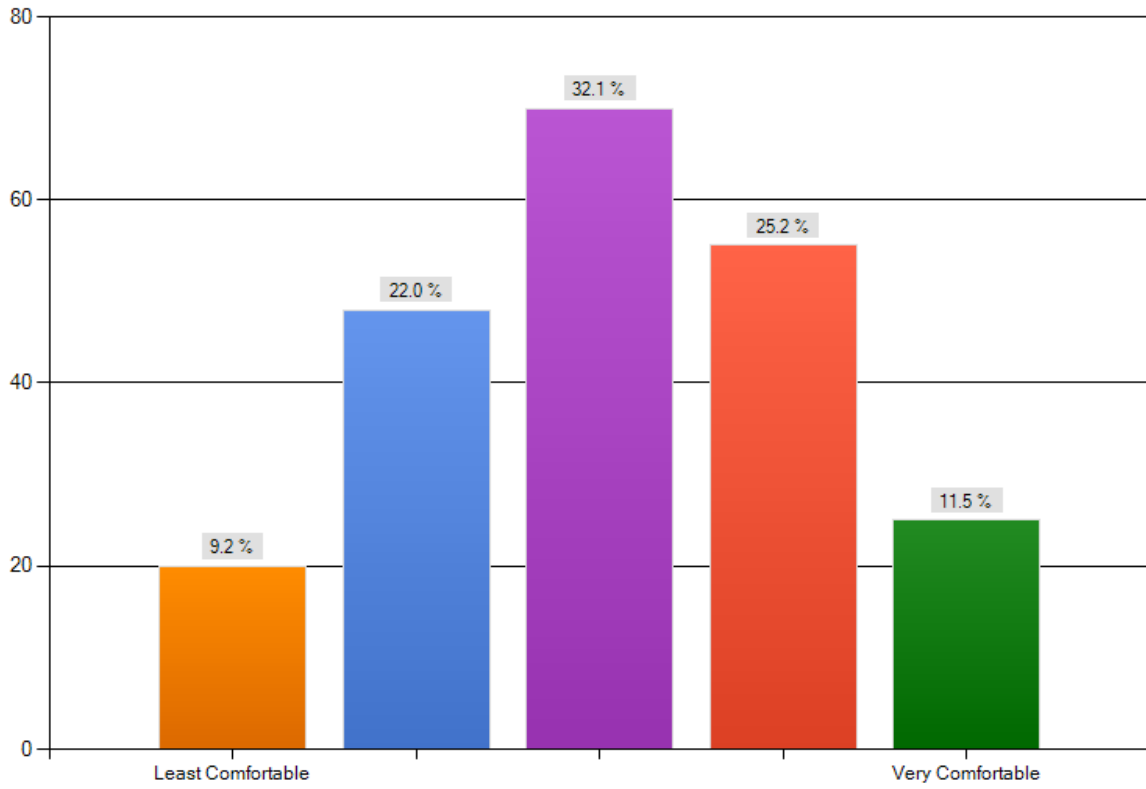
Do you believe that patients should have access to certain parts of their medical records?
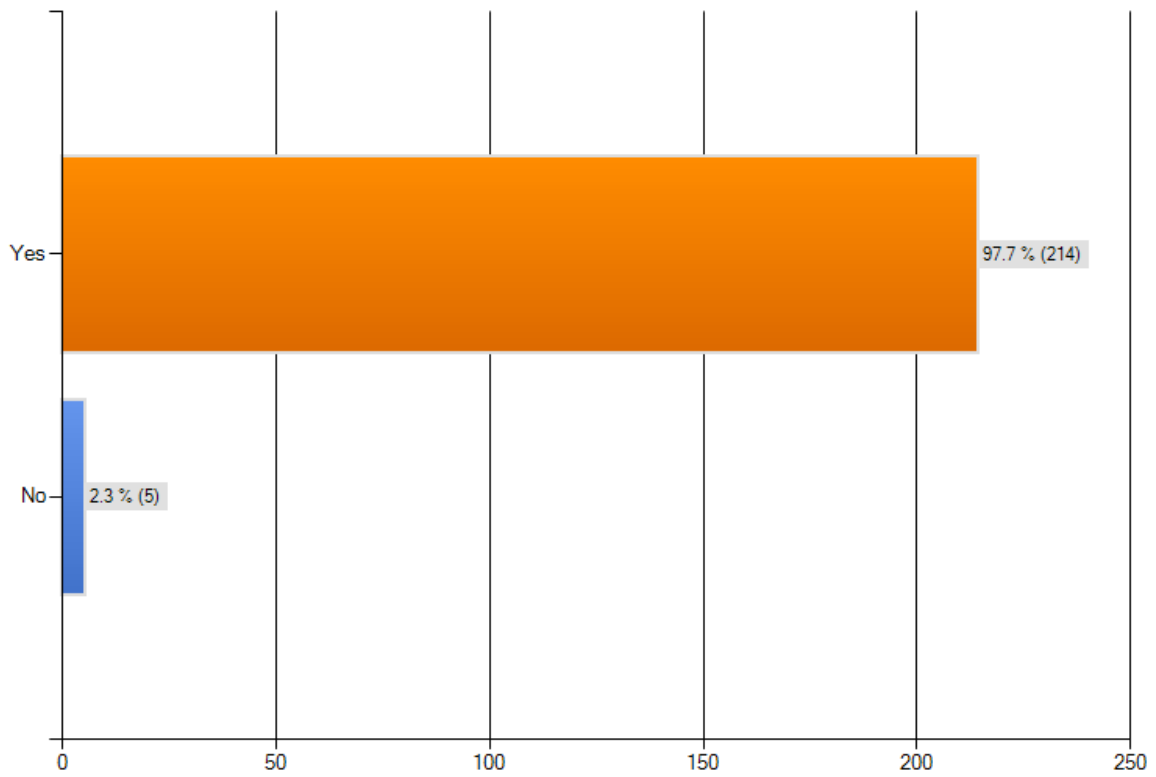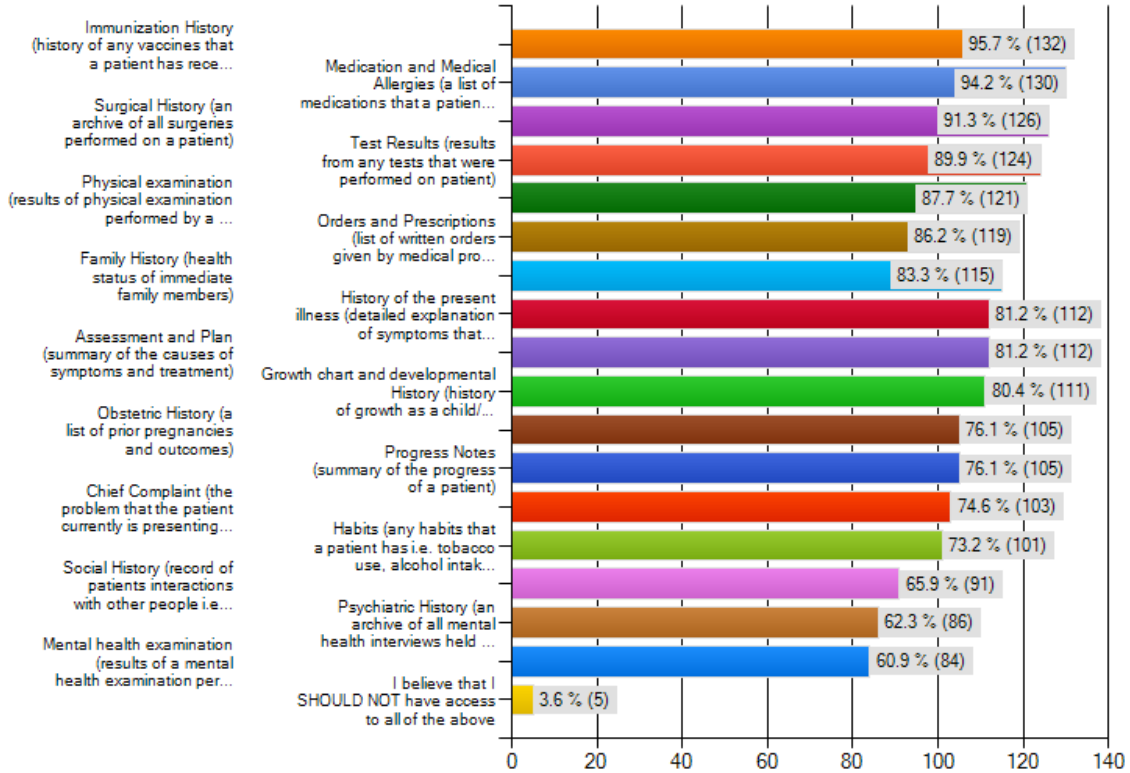
Are you a medical professional? (i.e medical doctor, nurse, lab technician)

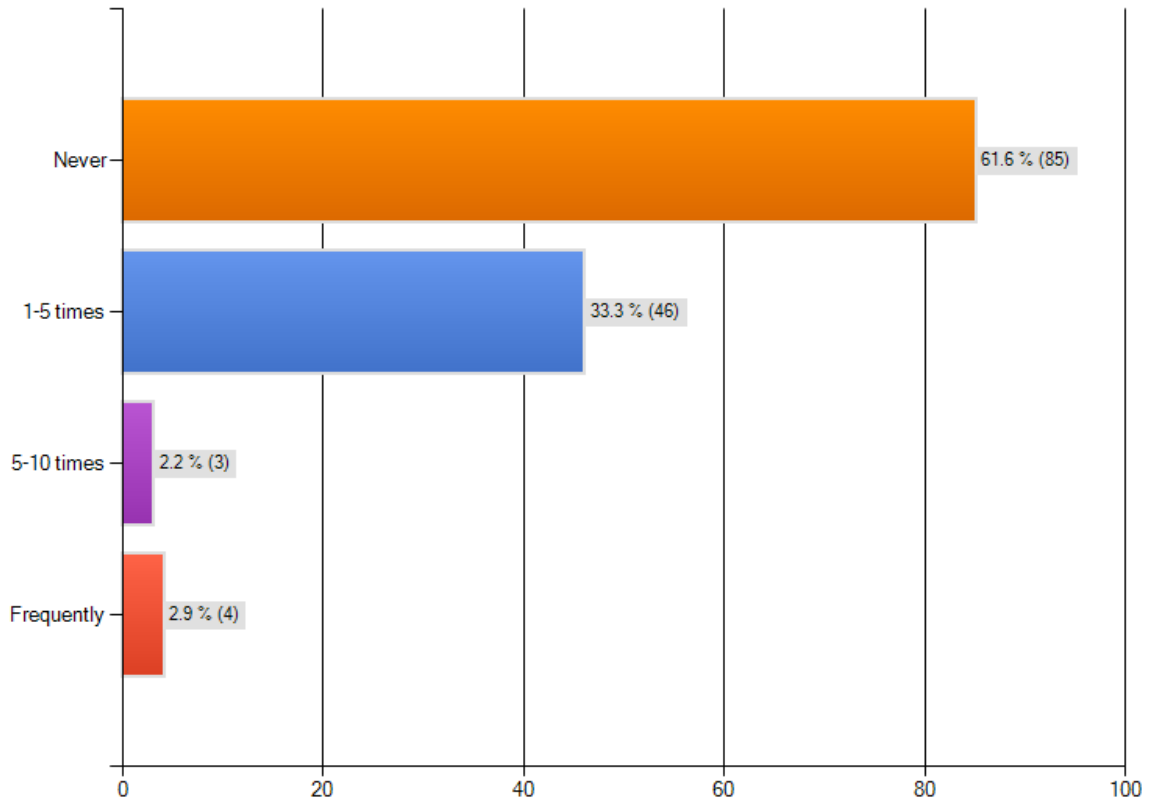
Yes — 35.2 % (77)

No — 64.8 % (142)
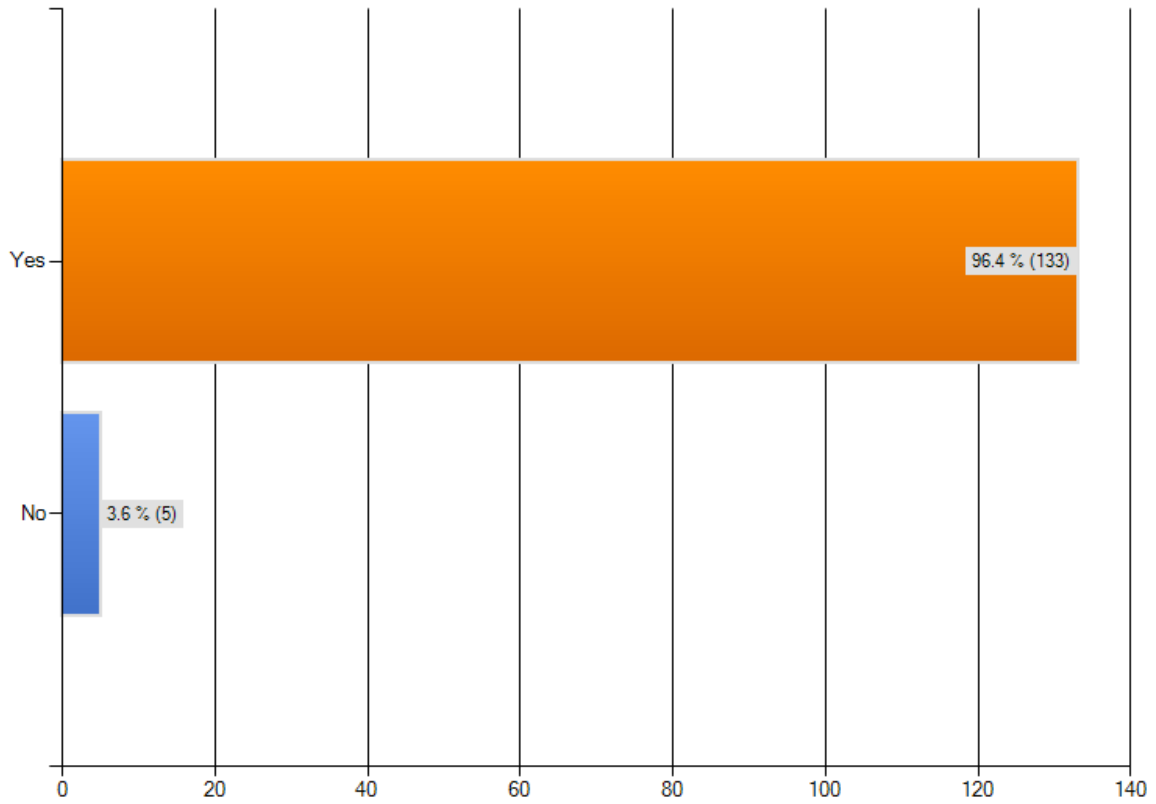
Questions Answered by Patients Only

(Patient Survey) The following are common sections of a medical record. Select the items you believe as a patient or non-medical professional, that you should have access to.
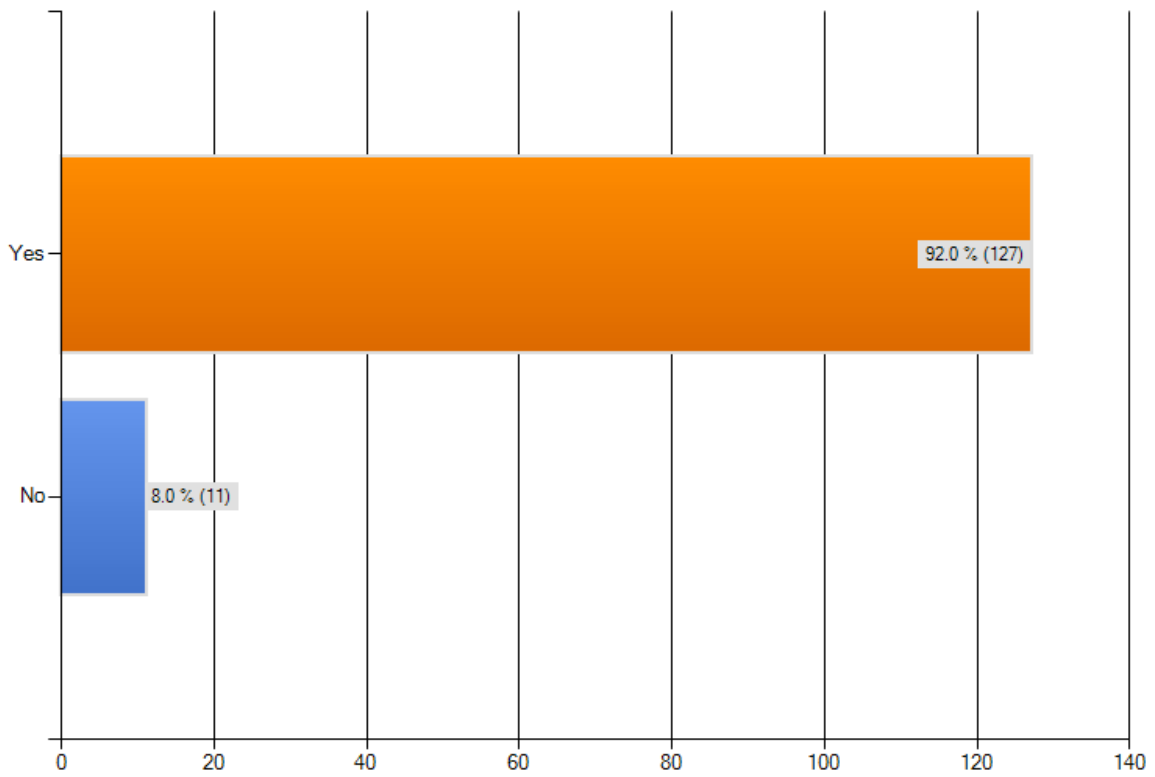
Item	Percentage (Count)
Immunization History (history of any vaccines that a patient has rece...	95.7 % (132)
Medication and Medical Allergies (a list of medications that a patien...	94.2 % (130)
Surgical History (an archive of all surgeries performed on a patient)	91.3 % (126)
Test Results (results from any tests that were performed on patient)	89.9 % (124)
Physical examination (results of physical examination performed by a ...	87.7 % (121)
Orders and Prescriptions (list of written orders given by medical pro...	86.2 % (119)
Family History (health status of immediate family members)	83.3 % (115)
History of the present illness (detailed explanation of symptoms that...	81.2 % (112)
Assessment and Plan (summary of the causes of symptoms and treatment)	81.2 % (112)
Growth chart and developmental History (history of growth as a child/...	80.4 % (111)
Obstetric History (a list of prior pregnancies and outcomes)	76.1 % (105)
Progress Notes (summary of the progress of a patient)	76.1 % (105)
Chief Complaint (the problem that the patient currently is presenting...	74.6 % (103)
Habits (any habits that a patient has i.e. tobacco use, alcohol intak...	73.2 % (101)
Social History (record of patients interactions with other people i.e...	65.9 % (91)
Psychiatric History (an archive of all mental health interviews held ...	62.3 % (86)
Mental health examination (results of a mental health examination per...	60.9 % (84)
I believe that I SHOULD NOT have access to all of the above	3.6 % (5)

(Patient Survey) How many times have you viewed your medical record?

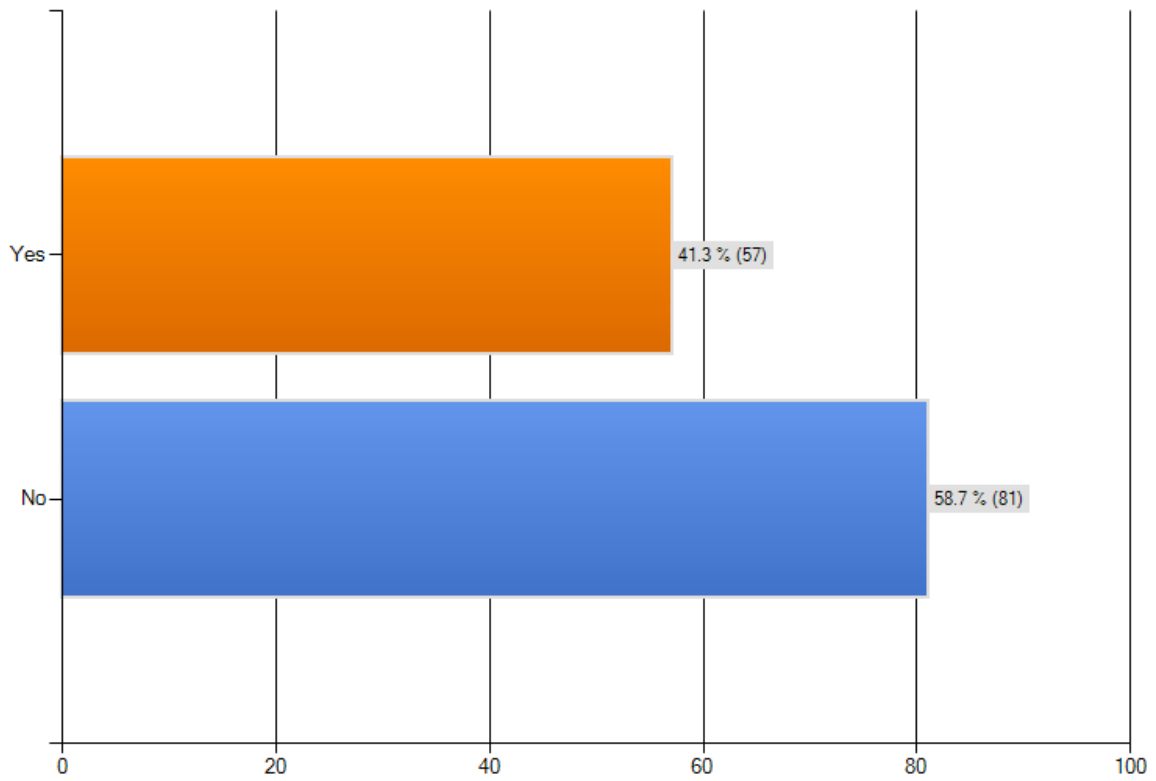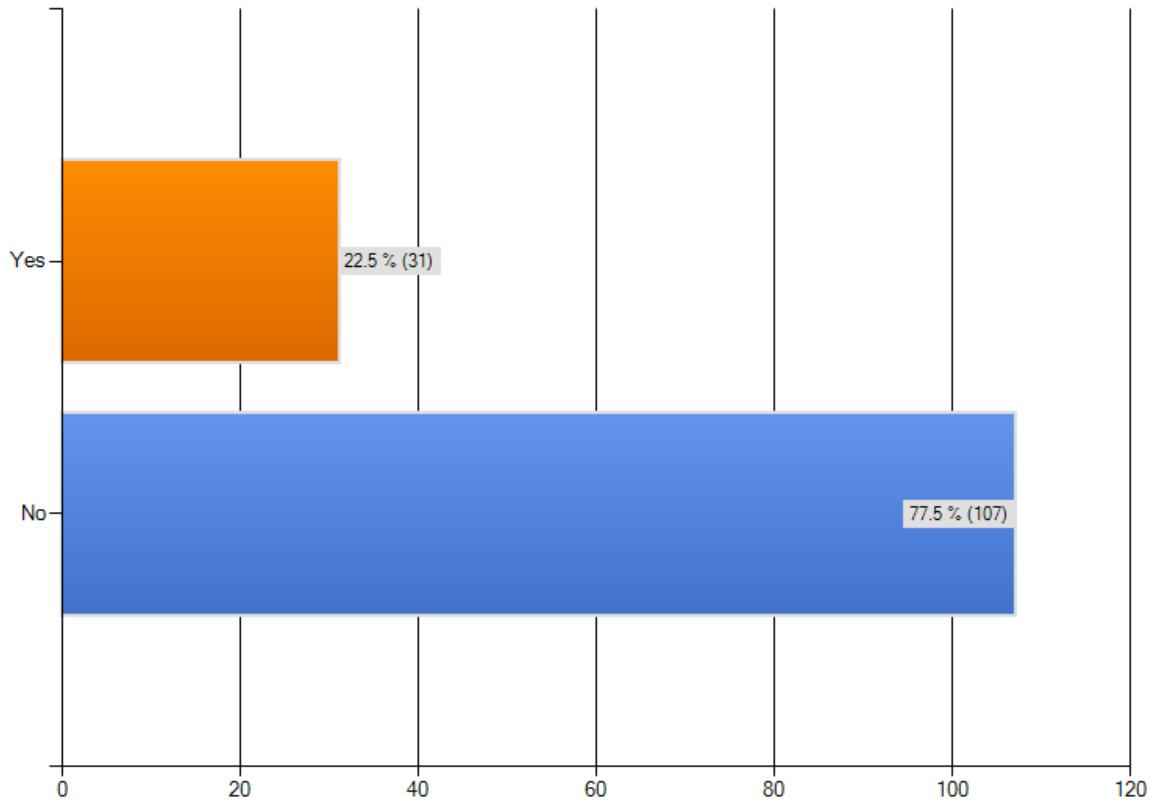| Category	Percentage
Never	61.6 % (85)
1-5 times	33.3 % (46)
5-10 times	2.2 % (3)
Frequently	2.9 % (4)

(Patient Survey) If you had access to your medical record would you view it?

(Patient Survey) If you were able to control who has access to your medical record would you utilize that tool?

|	
Yes	92.0 % (127)
No	8.0 % (11)

(Patient Survey) Do you believe, as a patient or non-medical professional, you have enough knowledge of the information in your health record to safely limit access to parts of it?
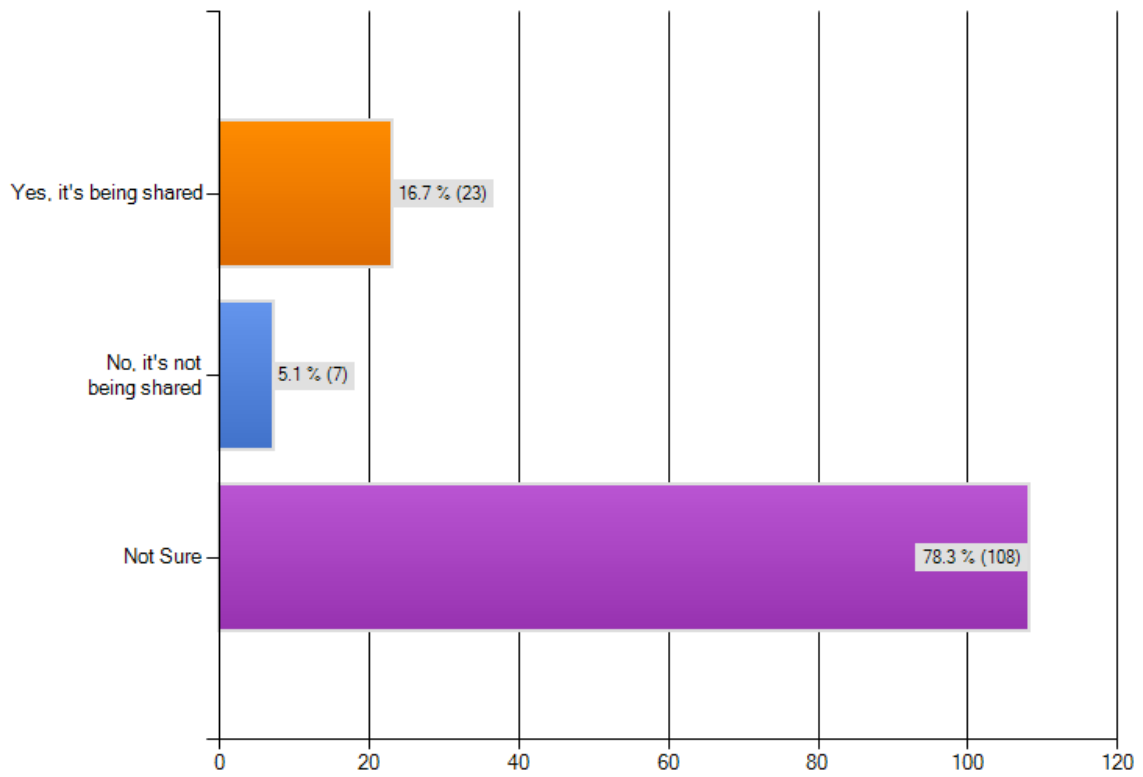

Yes — 41.3 % (57)

No — 58.7 % (81)

(Patient Survey) Do you know where your medical record is currently being stored?

Yes — 22.5 % (31)

No — 77.5 % (107)

Do you know what a health information exchange is?

|	
Yes	31.9 % (44)
No	68.1 % (94)
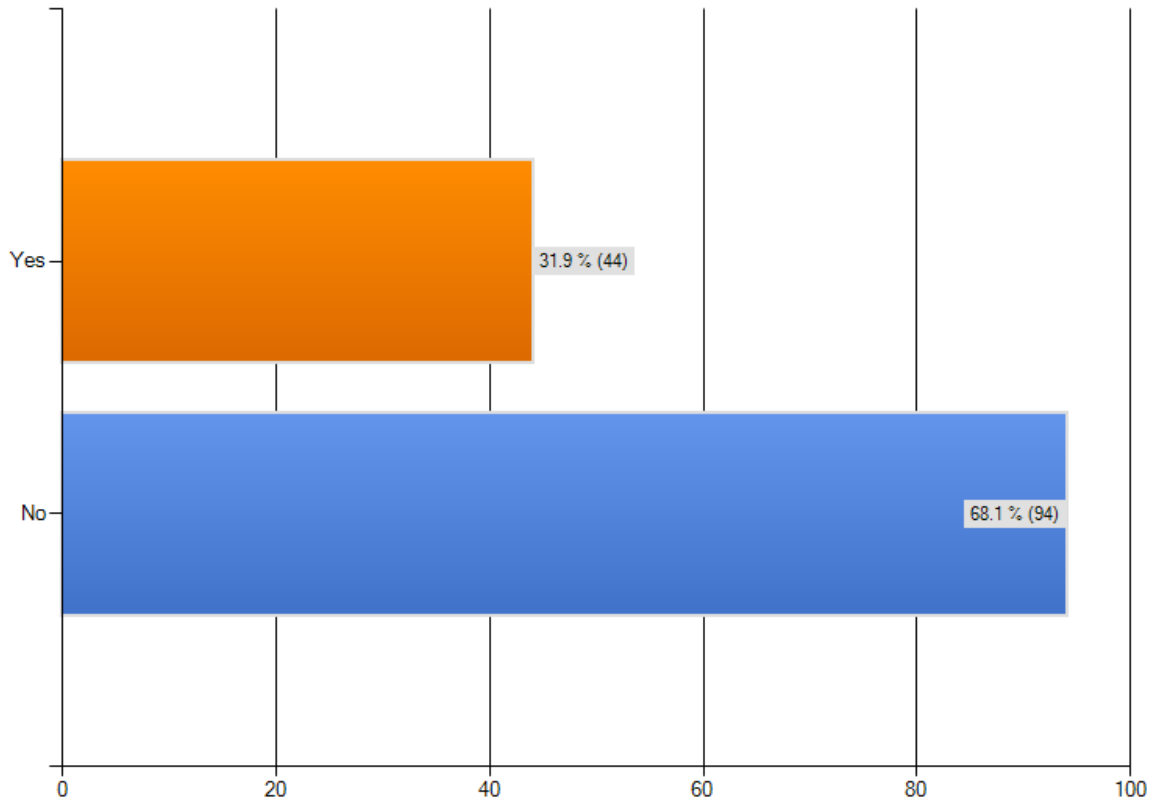
(Patient Survey) Do you know if your medical record is being shared within a health information exchange?


Of the 23 people who answered, "Yes" to the above question, the following question was asked.

(Patient Survey) Have you signed a Regional Health Information Organization (RHIO) consent form and/or has your health provider (i.e. primary health care provider) asked you to sign a "consent to view" form?
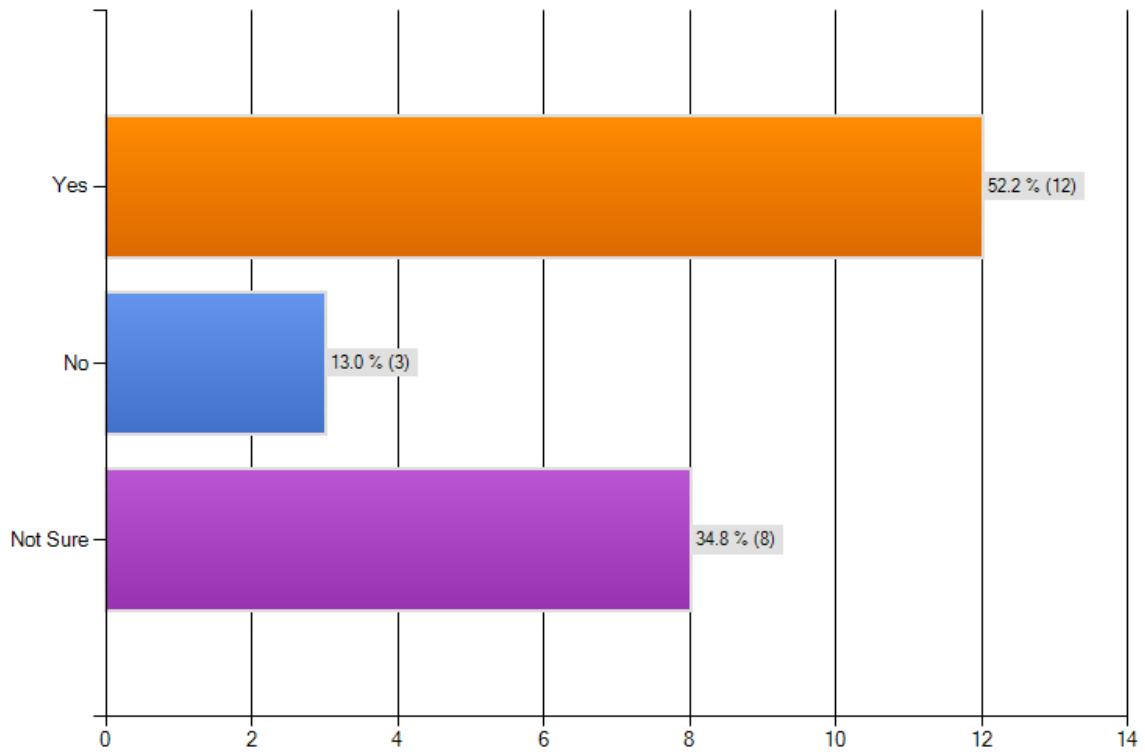
Questions Answered by Medical Professionals Only

(Medical Professional Survey) Which of the following best describes your profession?
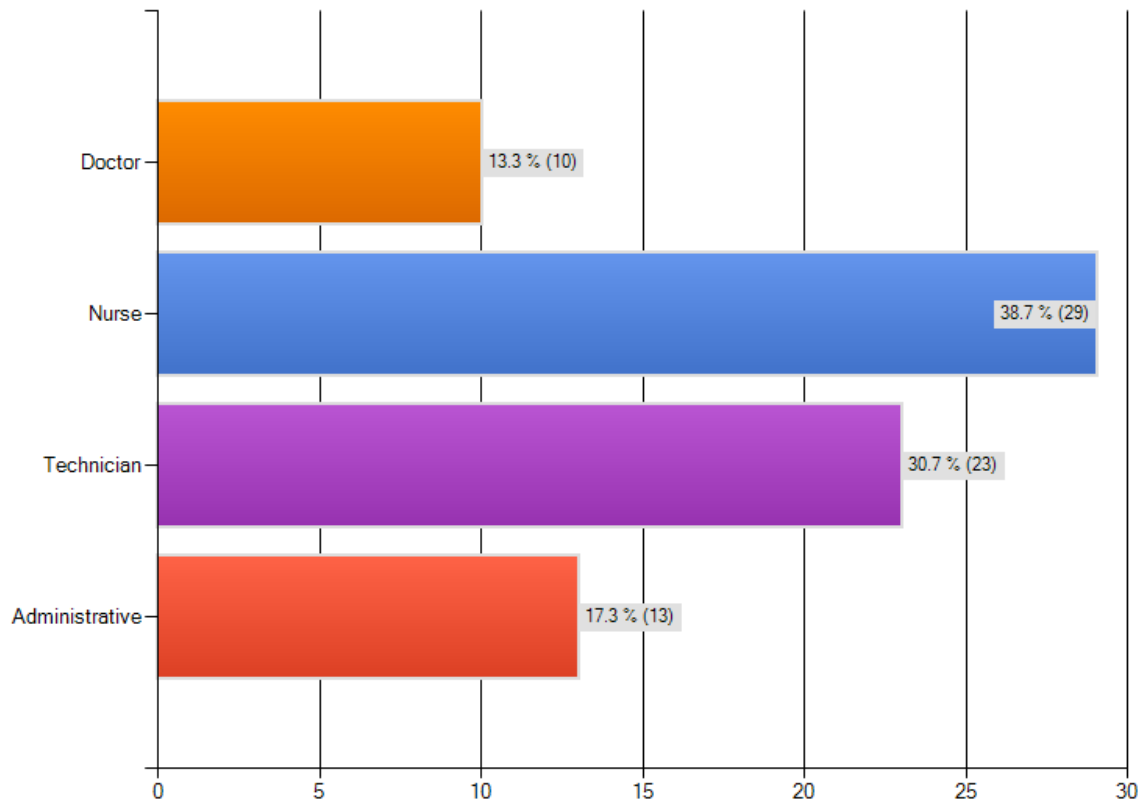
Other Responses for above Question:

Nursing student

physician assistant

Licensed massage therapist

social worker

Respiratory Therapist

I release medical records for a large hospital system.

Flight paramedic

HEALTH PROGRAM SPECIALISTS, SR.

Medical Assistant

medical assistant

Respiratory therapist

Technologist

retired

Collegiate Nursing Instructor - Retired

medical assistant

dietitian

no longer practice clinical nursing but maintain license

Acupuncture Assistant

nurse practitioner

Educator

PACS/RIS

laboratory medical technologist

dietitian

Radiology Technologist by trade; now application consultant

Health Information Management (med rec) professional

RIS/PACS Administrator\

(Medical Professional Survey) Approximately how often do you interact with other medical professionals outside of the healthcare institution that you work at?

On a daily basis	32.0 % (24)
On a weekly basis	30.7 % (23)
On a monthly basis	16.0 % (12)
Rarely	21.3 % (16)
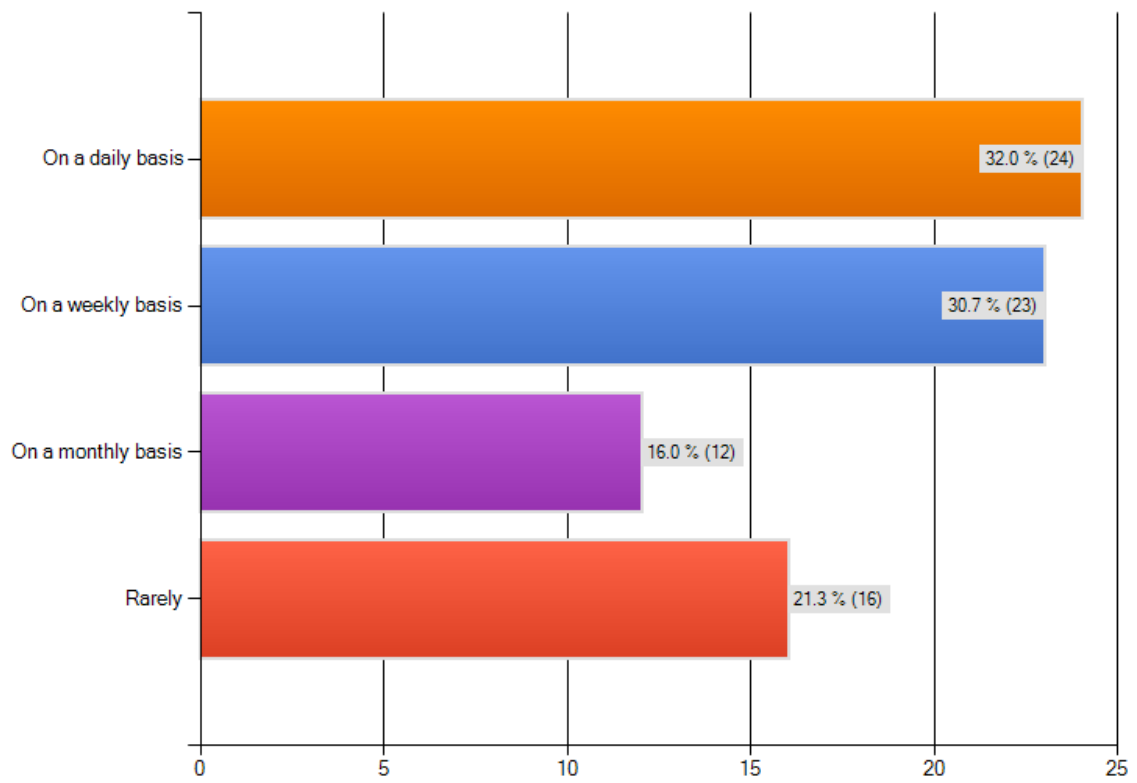
(Medical Professional Survey)Approximately how often do you interact with other medical professionals outside of the department that you work in?

(Medical Professional Survey)Approximately how many other colleagues do you work with repeatedly on a daily basis?

Category	Percentage (Count)
1-5	38.7 % (29)
5-10	21.3 % (16)
10-15	13.3 % (10)
15-20	16.0 % (12)
>20	10.7 % (8)

(Medical Professional Survey) Would you document as honestly if a patient could view their full medical record?

Yes — 89.3 % (67)

No — 10.7 % (8)

(Medical Professional Survey) The following are common sections of a medical record. Select the items you believe as a medical professional, that a patient should NOT have access to.

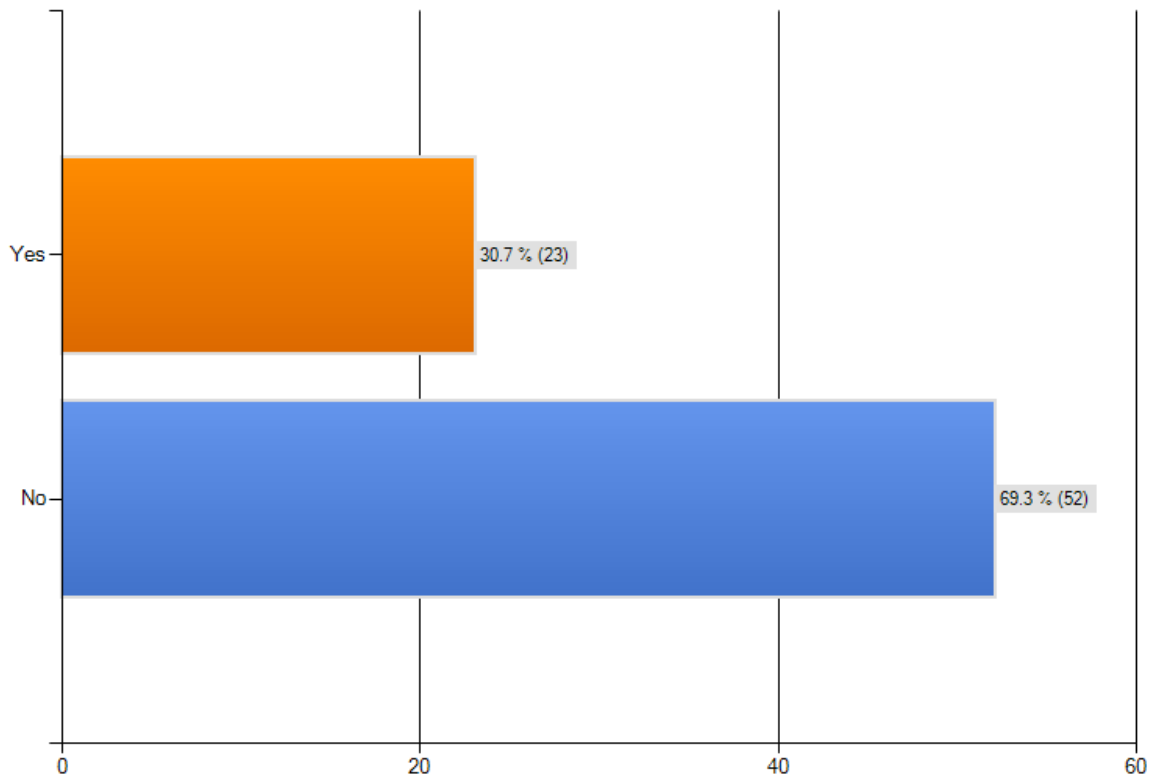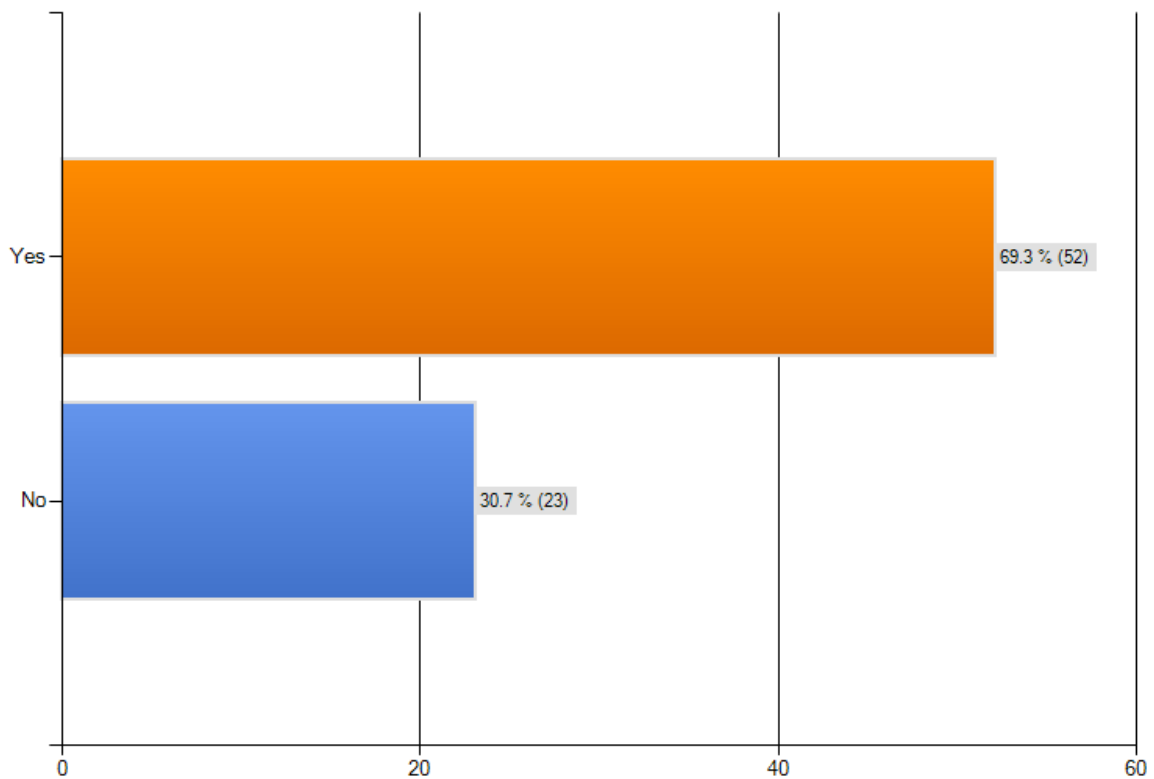I believe that a patient SHOULD have access to all of the above — 65.3 % (49)

Psychiatric History (an archive of all mental health interviews held ... — 21.3 % (16)

Mental health examination (results of a mental health examination per... — 14.7 % (11)

Family History (health status of immediate family members) — 9.3 % (7)

Social History (record of patients interactions with other people i.e... — 8.0 % (6)

Progress Notes (summary of the progress of a patient) — 8.0 % (6)

Habits (any habits that a patient has i.e. tobacco use, alcohol intak... — 6.7 % (5)

Orders and Prescriptions (list of written orders given by medical pro... — 5.3 % (4)

History of the present illness (detailed explanation of symptoms that... — 4.0 % (3)

Physical examination (results of physical examination performed by a ... — 4.0 % (3)

Assessment and Plan (summary of the causes of symptoms and treatment) — 4.0 % (3)

Test Results (results from any tests that were performed on patient) — 4.0 % (3)

Growth chart and developmental History (history of growth as a child/... — 2.7 % (2)

Chief Complaint (the problem that the patient currently is presenting... — 2.7 % (2)

Surgical History (an archive of all surgeries performed on a patient) — 1.3 % (1)

Obstetric History (a list of prior pregnancies and outcomes) — 1.3 % (1)

Medication and Medical Allergies (a list of medications that a patien... — 1.3 % (1)

Immunization History (history of any vaccines that a patient has rece...

Axis: 0 10 20 30 40 50

(Medical Professional Survey) If patients did not have access to the sections of their medical records that you selected in question 8, would you document more honestly?

Yes	30.7 % (23)
No	69.3 % (52)

(Medical Professional Survey) Do you believe that a system where the patient has some control over who has access to their medical records would work?

Results For Question 18: Please elaborate on your response to question 17 (above question). In your opinion what are the obstacles that are currently preventing patients from having this type of control? (These are the responses for the people that selected "Yes" to question 17)

- Doctors fear they will be sued based upon what they write on the patients progress notes

- Patients do have control on who can access their file. And any health care professional careing for that patient has access to their file. I feel that there are no obsticals in the current system and no one but the patient can allow access to their file.

- Too many variables

- you might be afraid of the response you would get

- I think most medical professionals dread the questions and disagreements they would

receive from patients who had access to their own files. Often the secrecy of records is defended by saying that patients either will not or can not accept the truth about their own faults or failings concerning their health. Given all the errors made in my records by my doctors, I suspect there is an element of concern that health care providers will have to answer for their mistakes and then the God like image will be lost.

- I'm not sure...patients should have full access to their record because it pertains to THEIR health.

- Fear that they may be offended by notes written by the healthcare provider.

- In the system I work a patient can designate who has access to there medical records. With EMR their record of the visit is often given to the patient if the are referred out to another facility (ER< ORTH>etc)

- The institutions themselves would rather not deal with it or spend the money on electronic records that would allow selective viewing.

- The process of obtaining an up-to-date authorizations from all patients is complicated and increases the cost of medical care. It provides a new profit line for litigious attorneys.

- many hospitals in a particular area utilize the same system for record keeping and there should be an option for patient's records to stay at the particular hospital or doctor office where they seek service and not be available just because they share the same system.

- Physicians being afraid of frivolous lawsuits and the control that insurance companies have over medical treatment.

- Patients already do have the right to see their records, and have them sent to themselves or anyone else of their choosing, by law.

- Not sure

- The average patient does not know how to read or interpet what is in their records. Medical pros have to be careful how they word progress notes because auditors are more important to our current system than patient care. If we do not document everything that happens in a case, we can be held liable for the outcome of the treatment. This includes how the patient lies and tells you they are following your suggestions but the end results show they are not.

- DOCTOR/HEALTH CARE FACILITY THINK RECORDS ARE PRIVATE

- Lack of knowledge

- I think having their co workers see all their tests

- N/A

- Doctors and hospitals' policies and habits. I believe that each person with a sound mind should have complete access to their medical records. It is a service that doctors, nurses, lab. personnel, and hospitals in general perform. Nothing should be hidden or secret. It's your body and to make "informed consent" a person should have all the information available. Empower the patient, not the doctors and hospitals. They make enough money obviously to empower themselves. Medical records are to assist medical personnel to all be on the same page in caring for the patient, and provide a record of what was done or not done in their care. Withholding information is a breech of trust and doesn't make for good decision making in critical choices with your health.

- patients have very little information or knowledge about their medical records. They need to become more involved in their own health care.

- Too much control held by insurance companies

- Access to their chart.

- Majority of pts don't lnow

- Doctors always balk at the idea of patients seeing their records because they don't understand medical terminology. Some medical professionals aren't comfortable with pt. seeing records.

- I have been in the profession for 40 years and there is no reason why a person cannot see their own medical records and I believe the obstacle is the fear of malpractice. The medical profession is only human and makes mistakes. Because of lawsuit and medical professionals being held to such a high level of perfection, they fear that the information in the medical records could be used against them. This fear over the years has increased due to frivolous lawsuits. Please medical records were also on paper and written, nothing was digital nor did we have the speed and accuracy that digital has given us. Thus again room for human error in how people document and interpret. Now with digital we can choose the answers and everyone has the same choices. Thus the fear of interpretation, mistakes (and believe me we make mistakes as does every human) and malpractice has caused the profession to want to hide the information so that that 'patient' cannot misinterpret the information and never be given the opportunity to clarify and allow for human interpretation.

- If a patient has no acess to their own records they are unable to control their own physical future. if they have no control over who else has access over their med records they loose confidence in the medical professionals.

- I think patients are more concerned over there own well being. I think continuity of care would followed better.

- I think that patients don't realize they DO have control over their records. I guess I don't know for sure about medical office records - but working in our birthing center, I know that patients do ask for their records. I've gone over records with patients sometimes. And when I am charting - I always keep in mind that the patient may read it later. That means I am honest, and I say things in the most objective way I can. (for example, we may say a patient DECLINES some education or care, not that they REFUSED it - the words make a difference)

- Judgement instead of objectivity often leads documentation. Having a patient read what you write keeps you honest and objective. Documenting in a way that present just facts is good for both parties.

- Tradition

- patients should be given records after every visit upon request.

- I think insurance companies have controll over it all. I feel if patients were aware of the inappropriate and worthless charges they have acquired, by reviewing their charts, they would be apt to question WHY.

- Sometimes it is important to document things like slurred speech, smell of alcohol, ill kept not exactly things I would want the patient to read. Also if I disagree with a patient or have issues with the sincerity of their answers.

- Not readily available,need to call the office,get approval etc.If all your info was on your computer and easily accessable the person would have better control

- My concern is not what the patient themselves have access to. I believe the patient should have access to all . . .it is his information. My concern is how many other people have access to medical records. HIPPA is a farse. It pretty much does nothing to really

protect privacy and it prevents necessary information from being shared because stupid people go overboard with HIPPA intentions.

- Red tape. Patient's can access their medical records (some areas, I believe) but it is a difficult and time consuming/costly process. The only other obstacle I envision is "misinterpretation" of lay public of professional terms etc.

- time consumtpion and cost required to provide the information to the patient

- I think physicians are not comfortable allowing the patients total access to their medical records.

- politics

- I believe that patients currently do not have control of accessing their medical records because of the way that they are written, stored, and read. Medical records that are not standardized leave too much open for misinterpretation.

- I believe if people were more informed about their health and clinical history they would be able to make better decisions regarding their health. If they could see that over a 10 year span a value has changed significantly they could change their habits. Governmental constraints, ie: HIPAA, on the hospital have prevented patients from gaining control of their medical records. Fear that someone else may obtain someone's information has led to greater constraints and made it difficult to view patient data. In reality knowing other people's history can greatly help individuals get a proper diagnosis and therefore help them.

- Currently I believe it's a logistical nightmare for the primary care to know who to give access to and not. As well as the hospital to gain records for patient exams can be very difficult. If we can't get the information the patient's care suffers. It's a tough problem

to strike a balance.

- According to HIPAA a pattient has the right to request a copy of their medical records at any time. EHRs such as practice fusion which is free and solely Internet based even supplies the patient with a username and password they are then able to log in and look at their records and even see who has viewed their files. Practice fusion allows you to set admin limits as to what data other providers can see and allows you to link up with numerous labs and facility's. The current obstacles are dishonest professionals who are afraid of what the patient might find out such as biking for services not rendered or falsifying notes.

- HIPPA laws, multiple sites where information exists (ie: no unified system where a full history, treatment, surgical, and mental health records are)

- I believe patients should have not, yet not complete, control over who sees their medical records. Whether it be family, friends, medical professionals or self access, the patient should have some control over their private information, just as any citizen has some control over their financial records.

- Patients having full access to their medical records would hold physicians to a whole new standard.

- Regulatory - there are so many regulations that either prevent or hinder this. In addition, I fear that some patients would not have the knowledge to understand parts of their record. Laboratory, diagnostic imaging results for example.... if the patient misinterprets the results and takes it upon themselves to change medication etc... that could be dangerous for the patient.

- Actually, not a response to 17 but 15- survey forced me to pick something when I did

not wish to choose anything since I believe a patient should have access to all the

examples. Need a choice that allows submission of page

- Not knowing their patient rights in regards to their medical history.

Results for Question 19: Please elaborate on your response to questions 17(above question).

What are the reason why you think this type of system will not work? (these are the answeres

for the people that selected "No" to questions 17)

- Patients could be "forced" to release info in order to obtain care from certain physicians

  or health care organizations.

- The patient may not know the reason for sharing of medical information, or may not be

  in their right mindset to understand the information. Some information needs to be

  shared with others for the benefit of the patient.

- I feel that a patient has the right to see any and all parts of any medical records.

- It could hinder the diagnostic process.

- The medical staff know who needs access. A patient may not realize that a phlebotomist

  may need access to their medical information so that an add-on order can be made to

  prevent the patient from being re-drawn, so they would not allow the phlebotomist

  access. This creates more pain for the patient and less efficiency of the phlebotomy

  staff.

- These areas are subjective. The pt. my no understand terminology used. Therefore,

  confusion and misunderstanding of the documented material will cause complications

and trust issues in further meetings.

- People really do not understand that it helps their care management if the whole health team has access to their records. Not only does it add to the cost ie: test being repeated but also over prescribing medications. Now that I am thinking about it Psych may have to be protected even more then it is now.

- The pt might want to restrict access to someone due to lack of knowledge of why that person should have access. Also - some parts of the record - the pt should only have access after it has been explained to them by a health professional - so that the pt does not misinterpret something; many times it needs to be explained first.

- Patients don't know who, throughout an institution, needs access to their records. Restricting access could definitely slow care. From personal experience, physicians have reviewd my records before I even met with them or knew I needed to meet with them. It made my visit more effective since my records had already been reviewed.

- accessibility, the patient's ability to fully understand all parts of the medical record and it's content. I am not a med professional that documents in the record but rather I work in Medical Records (HIM) and we are the keepers of the records who protect the patient's privacy while at the same time allowing accessibility to those that need it for patient care