Drivers of information disclosure on health information exchange platforms: insights from an exploratory empirical study

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ABSTRACT

Objective The objective of this research is to empirically explore the drivers of patients' consent to sharing of their medical records on health information exchange (HIE) platforms.

Materials and Methods The authors analyze a dataset consisting of consent choices of 20 076 patients in Western New York. A logistic regression is applied to empirically investigate the effects of patients' age, gender, complexity of medical conditions, and the role of primary care physicians on patients' willingness to disclose medical information on HIE platforms.

Results The likelihood of providing consent increases by age (odds ratio (OR) = 1.055; $P < .0001$). Female patients are more likely to provide consent (OR = 1.460; $P = .0003$). As the number of different physicians involved in the care of the patient increases, the odds of providing consent slightly increases (OR = 1.024; $P = .0031$). The odds of providing consent is significantly higher for the patients whom a primary care physician has been involved in their medical care (OR = 1.323; $P < .0001$).

Conclusion Individual-level characteristics are important predictors of patients' willingness to disclose their medical information on HIE platforms.

Keywords: Health information exchange, meaningful consent, patient privacy

INTRODUCTION

This study empirically explores the effects of patients' age, gender, complexity of medical conditions, and the role of primary care physicians on patients' willingness to share their medical information with the members of western New York's regional health information organization (RHIO). Our work provides useful insights for both health information exchange (HIE) platforms and policy makers to better understand the underlying factors that feed into the patients' decision making process and reveals the characteristics of the patients who are more/less likely to provide consent to sharing of their medical records among healthcare professionals. The consent data analyzed in this study is collected in the early growth stages of the RHIO. The number of participating providers and patients on the platform has grown significantly since then. The factors that affect a patient's decision to provide consent may now be different from those that are studied in this research. While the findings of this research may not apply to the fully developed RHIOs, they still provide practical implications for the HIE efforts that are still in their infancy.

MATERIALS AND METHODS

Setting

In this study we analyze the actual privacy decisions of patients with regards to sharing of their records with the members of HEALTHeLINK, the RHIO of western New York. HEALTHeLINK provides fully operational query-based HIE services to over 3300 healthcare providers. All of the major medical data providers (laboratories, radiology centers, and hospitals) in the region are members of this platform. These major data providers automatically upload an electronic copy of the results of procedures that they perform to the HIE database. When a patient provides consent, HEALTHeLINK subscribers who are involved in the care process of that patient will have access to his medical records through either a fully automated system that pushes the medical data into their interoperable electronic medical records systems or through a web portal in which they can search for the available medical history of the patient. HEALTHeLINK's website provides more details about its operations. http://wnyhealthelink.com/WhoWeAre/FAQs.

Although the patient consent to sharing medical records with other medical providers is not required under the federal Health Insurance Portability and Accountability Act (HIPAA), according to New York state law, the HIE platforms should establish an "opt in" process and share the medical records of the patients only after they have explicitly allowed the HIE platforms to share their records. HEALTHeLINK solicits the patient consent at various locations including testing facilities and the offices of the member providers. Patients can choose among different privacy options provided on a consent form. They can allow full access to their records by all of the members of the HIE platforms who are involved in their care. Patients can exclude some medical providers and prohibit their access to the medical records except in a medical emergency. They can also limit the access of all the HIE members only to emergency situations. Patients can also deny access to their records to all members of the HIE platform under all conditions including medical emergencies.

Data

Our analysis is based on two datasets provided by HEALTHeLINK; the *consent* and the *medical tests* datasets. The consent dataset includes age, gender, and the consent choice of 20 076 unique patients over the period of June 2008 and August 2011. This dataset comprises the population of all patients who were asked about their decision to share their medical records on the HIE platform during the above-mentioned period and is not limited a specific sample. The medical tests dataset includes the type and the reporting date of all the medical tests that

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are performed on the patients by any of the member laboratories, radiology centers, or hospitals in western New York. This dataset also includes the specialty of the ordering physician for each of the reported medical tests. Since all of the major medical data providers have already adopted HEALTHeLINK services, when a specific type of medical test is performed, regardless of the membership status of the ordering physician, the test results will be uploaded into the HIE system. If the physician who had ordered the medical test is a member of HIE and the corresponding patient has previously consented to sharing his medical records, these tests will be accessible. This feature of the HIE platform allows us to identify the number of all medical tests ordered by all of the medical specialties in the population of study, even if they have not adopted HIE or even if the patient has not consented to sharing of their medical records. Both of these two datasets are de-identified and merged with each other using a scrambled patient ID.

Measures

The dependent variable in our analysis is consent. It equals one if the patient has allowed all members of the HIE to access his medical records and zero otherwise. Using the medical tests dataset, we define a *complexity* measure in terms of the number of different physicians who have been involved in providing medical care to each of the patients in the consent dataset. Specifically, complexity measures the number of unique medical providers who have ordered at least one medical test for a given patient. We also use this dataset to identify if a medical test was performed for a patient based on an order by a primary care physician. Primary care physician (PCP) specialties include obstetrics and gynecology. We define PCP involvement as a binary variable that equals 1 if a PCP has ordered at least one medical test for the patient, and zero otherwise. Gender is also a binary variable and equals one if the patient is female and zero otherwise. Age is measured on the date when a consent form is signed. An online appendix provides detailed discussions on the rationale of including these measures in the model.

Analysis

Since the dependent variable is binomial, we use logistic regression to model the log odds of providing consent as a multivariate function of age, gender, interaction between age and gender, complexity, and PCP involvement as follows:

$$\log\left(\frac{p_i}{1-p_i}\right) = \beta_0 + \beta_1 \text{Age}_i + \beta_2 \text{Gender}_i + \beta_3 \text{Age}_i \times \text{Gender}_i + \beta_4 \text{Complexity}_i + \beta_5 \text{PCP_Involvement}_i,$$

where p_i represents the probability that patient i provides consent to sharing of his/her medical records on HIE.

RESULTS

We analyzed the consent choices of 20 076 patients of which 2021 patients have not consented to sharing of their medical records with all of the members of the HIE platform while the remaining 18 055 patients have agreed to have their medical records be shared among all of the HIE members. The overall consent rate was 89.9%. Female patients constituted the majority (68.2%) of the population. Table 1 represents the distribution of consent choice, gender, age, and PCP involvement in the population of this study.

According to the results presented in Table 2, the strongest predictor of providing consent is gender. 9.80% of males and 10.19% of females did not provide consent. Although the consent rate between men and women only differs by a fraction of a percentage, after controlling for the other variables, gender will play a more salient role. For female patients, the odds of providing consent is 46% more than their male counterparts (odds ratio (OR) = 1.460). With 1 year of increase in age, the log-odds of providing consent increases by 0.054 units (OR = 1.055); however, the effect of age for females is slightly less than males (OR = 0.987). Complexity is positively associated with a patient's willingness to provide consent (OR = 1.024). PCP involvement also has a strong impact on the patient's consent. The patients for whom a PCP had ordered a medical test are much more likely to provide consent (OR = 1.323).

DISCUSSION AND CONCLUSIONS

As HIE efforts grow, the factors that affect patients' decision to disclose their medical information on such platforms can potentially change. In particular, we expect patients' awareness about the existence of such technologies and the benefits of sharing data on HIEs to increase substantially and thus play a more salient role on patients' decision to provide consent. The consent data analyzed in this research pertain to the early development years of HEALTHeLINK and thus cannot be generalized to the HIE efforts that have already grown their network of providers and have reached a stable level. The conclusions of this research still have practical implications for the majority of the HIE efforts which are still in early development stages and do not have a sustainable business model.[1] The potential of HIE platforms in reducing the costs and increasing the quality of healthcare services will only be realized if the healthcare providers use these technologies effectively. Healthcare providers would not actively use such technologies unless they see a tangible value in HIE platforms.[2–4] The value of the HIE platforms is strictly dependent on the volume of accessible medical records on them. For a maximal realization of their potential value, HIE platforms need to earn the trust of the patients and obtain their consent to share their medical records with the medical providers. This research directly addresses this issue and provides insights on the effects of individual-level patient characteristics which are associated with higher likelihood of providing consent.

This is the first study that analyzes a large dataset of actual patient consent choices and empirically investigates the effects of age and gender of patients and the number and specialty of the physicians involved in patients' medical care on their decision to disclose their medical information on HIE platforms. Our results indicate that female and older patients, along with the ones who visit multiple physicians, are more likely to share their records on the HIE systems.

Our study also reveals the influence of primary care physicians on the patients' consent to disclose medical information on HIE systems. This underscores the legal and ethical responsibility of providers to educate their patients on both the risks and benefits of HIE platforms and to ensure that the patients are sufficiently informed about their consent choices. The results of this study may also be of interest to policy makers in designing educational programs to increase public awareness on the risks and benefits of sharing medical information on HIE platforms. Furthermore, this study provides significant practical implications for HIE platforms. As HIEs struggle to develop sustainable business models[1] increasing the volume of accessible data on their system is of crucial importance. To do so, HIE platforms need to understand the drivers of patients' willingness to disclose their medical information and design strategies accordingly to enhance consent rates and the resultant usage of available medical data on their systems.

In this study, both the complexity and PCP involvement variables are derived from the HIE database of ordered medical tests. This dataset does not include the patient visits in which no medical tests are ordered. This is a limitation of this study, since we can identify a visit to a given physician only if that particular physician has ordered a

Table 1. Distribution of patients' age and consent choice.

Consent Status	Did Not Provide Consent: 2021 (10.06)				Provided Consent: 18 055 (89.94)			
PCP Involvement	With Primary Care		Without Primary Care		With Primary Care		Without Primary Care	
Gender	Female	Male	Female	Male	Female	Male	Female	Male
Number of Patients (%)	976 (4.86)	301 (1.50)	419 (2.08)	325 (1.62)	9286 (46.25)	2998 (14.93)	3007 (14.98)	2764 (13.78)
Average Age	39.19	28.52	30.72	27.78	53.33	55.25	55.67	59.62
Std. Dev. of Age	21.41	21.97	23.06	23.20	18.12	20.71	20.12	18.86

Table 2. Estimation results.

Parameter	β	OR	Standard Error	Wald χ^2	*P*-Value
Intercept	−0.3338	0.716	0.0885	14.2422	.0002
Age	0.0540	1.055	0.00196	754.2707	<.0001
Gender	0.3785	1.460	0.1034	13.3956	.0003
Age × Gender	−0.0129	0.987	0.00242	28.2323	<.0001
Complexity	0.0233	1.024	0.00790	8.7317	.0031
PCP Involvement	0.2800	1.323	0.0536	27.3245	<.0001

Model fit statistics: AIC = 11 259.950; −2LogLiklihood = 11 247.950; AUC = 0.7538

medical test for the patient. This limitation can be addressed by analyzing insurance claims datasets in which all of the patient-physician interactions are recorded. The other limitation of this study is its empirical treatment of consent choices as binary variable. States have varying requirements, and some may specifically require patients to explicitly consent prior to their data being shared through HIE. Patients may not authorize all HIE members to access their records, but rather only those members having reason to access for treatment, payment or healthcare operations purposes. Role-based access restrictions in the HIE typically allow access to more detailed clinical information only by users who need it for treatment or treatment-related purposes. In the HEALTHeLINK system, patients have three choices for limiting the access of the medical providers to their records: no access under any condition, access only at emergency situations, and full access under all conditions excluding a set of providers who can only access the records at emergency situations. These three choices of limited access are grouped together and treated similarly in our analysis. The reason for this grouping is the fact that most of the patients either allow full access to their records or limit the access to emergency situations only. The number of patients with the other two types of consent choices is very limited and hence, including these patients in the analysis may not yield meaningful insights. Furthermore, in order to distinguish between all of the three choices of limited access, an ordered or a multinomial logistic regression model is required. Given the small number of observations in two groups of choices of limited access, meaningful interpretation of the results of these regression models will be unnecessarily complicated. This limitation can be addressed by analyzing a larger number of patients who have limited the access to their records at different levels. Interpretation of the results of such analysis would be further facilitated by conducting focus groups and interviewing the patients who have decided to choose a very rare option in the consent forms. While we acknowledge this limitation, we also note that grouping the different levels of limited access to medical records in one group has practical justifications. The potential value of the HIE platforms in reducing the number of repeated tests and increasing the quality of medical decisions will be fully realized only if the patients allow all of the medical providers who are involved in their care to access their records. Although limited access to the medical records at emergency situations can still help an ER physician to save the life a patient, it will not have a large effect on reducing the number of repeated tests or increasing the quality of care in other medical encounters outside of the emergency rooms.

Given the conclusion that the presence of a PCP increases the likelihood of providing consent, it would seem important to test for variation among PCPs to examine if patients of certain PCPs are more likely to consent (or not consent) than patients of certain other PCPs. It is also possible that the location of the consent (at the testing facility, at the PCP office, at a specialist office) is a factor. We are currently working on extending this analysis on a richer dataset and addressing the above mentioned limitations.

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COMPETING INTERESTS

The first author is a Scientific Adviser to HEALTHeLINK. He does not receive financial compensation from HEALTHeLINK.

CONTRIBUTORS

- Design and conduct of the study: N.Y., R.R., R.G., R.S.
- Acquisition and preparation of data: R.S., R.S.
- Analysis and interpretation of the data: N.Y., R.S., R.G., R.R.

- Drafting of the manuscript: N.Y., R.R., R.S.
- Critical revision of the manuscript for important intellectual content: R.S., R.R.
- Administrative and academic support: R.S.
- Study supervision: R.R.

SUPPLEMENTARY MATERIAL

Supplementary material is available online at http://jamia.oxfordjournals.org/.

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Online Supplement for "Drivers of Information Disclosure on Health Information Exchange Platforms: Insights from an Exploratory Empirical Study"

1. The Importance of Patient Consent in the Success of Health Information Exchange Platforms

With 17.2% of its GDP spent on Healthcare in 2012, United States continues to lead the world in healthcare spending.[1] Despite the 2.8 trillion dollars of expenditure, the US healthcare system lags behind many developed countries on dimensions of access, patient safety, coordination and efficiency.[2] By the most optimistic estimates, waste accounts for at least 20% of the total healthcare expenses in the US[3] and therefore, reducing the costs and increasing the efficiency of healthcare services are now among the high priorities of many healthcare sectors.[4] Information Technology may potentially address many of the persistent challenges of the US healthcare system including quality[5–7] and efficiency.[8–10] As a result, the Health Information Technology for Economic and Clinical Health Act (HITECH) of 2009 authorizes significant incentives to set up Health Information Exchange (HIE) platforms through which providers can access medical data in a timely and cost-effective manner.[11]

Federal and state laws mandate Health Information Exchange platforms to obtain patients' permission before sharing their medical records.[12] Increasing the number of patients who consent to sharing of their medical information will directly affect the value of a HIE platform to its members by increasing the number of accessible medical documents. Medical providers would join and use HIE platforms only if they can access the medical records of their patients on these systems. Unless the patients' consents are acquired, their records cannot be accessed by HIE members and thus the potential benefits of HIE will not be realized. That is why the challenges with managing and protecting patient privacy have been identified as some of the most important obstacles in expanding HIE systems.[13]

Although the literature sheds significant light on our understanding of the patients' concerns with regards to their medical records (see Appari and Johnson[14] for a systematic literature review on patient privacy), the research on patient privacy in the context of Health Information Exchange (HIE) platforms is still in its infancy. Unlike other health IT systems, an HIE platform enables *multiple* medical providers to access the records of patients. This unique difference leads to unique privacy concerns in the HIE context. Rather than deciding whether or not to share their medical records with a particular physician, many of the HIE platforms (including the one in this study) have established a consent process in which patients have to decide about allowing all HIE members to access their records. Moreover, to decide about information disclosure on an HIE platform, patients should consider the specific risks and benefits that are unique to the HIE platforms. In particular, the security risks are highly critical in HIE platforms. Since more users can potentially have access to the patients' data on an HIE platform, there is higher potential for harmful data breaches. From the patient's perspective, receiving potentially better care during critical conditions is one of the most important benefits of information disclosure on HIE platforms. Given the unique factors affecting patients' decisions on disclosing medical information and their significant influence on the proposed underlying value of HIE platforms,[15,16] a more comprehensive understanding of patient privacy concerns is warranted.

The potential of HIE platforms in reducing the costs and increasing the quality of healthcare services will only be realized if the healthcare providers use these technologies effectively. Healthcare providers would not actively use such technologies unless they see a tangible value in HIE platforms. The value of the HIE platforms is strictly dependent on the volume of accessible medical records on them. For a maximal realization of their potential value, HIE platforms need to earn the trust of the patients and obtain their consent to share their medical records with the medical providers. This research directly addresses this issue and provides insights on the effects of individual-level patient characteristics which are associated with higher likelihood of providing consent.

2. Rationale for Model Variables

The approach of this research is exploratory. Rather than establishing a theory, we aim to discover the possible associations between patients' characteristics and their consent choice. However, to shed light on the casual links between the above mentioned variables, we briefly discus the reasons for which each of the variables are included in our analysis.

Complexity: When a patient visits only one physician, then the patient's records will already be available either in the EMR systems or the traditional hardcopy archives of that provider. Since the patient does not need to share his medical records with other providers, HIE will not have tangible and immediate benefits for the patient. On the other hand, when multiple physicians are involved, then the patient has to provide all of them with access to his medical records. The patient can either provide consent so that the physicians can use HIE services to access these medical records, or obtain the records on hard copy and provide them in person to all of the physicians that he visits. As the number of different physicians who are involved in the care process of the patient increases, the complexity of sharing hardcopy records with them also increases and hence, the value of HIE for a patient increases with the number of different physicians that are involved in his medical care process. As described in the previous section, we denote *complexity* as the number of *different physicians* that order medical tests for a patient. As the complexity factor increases, the value of HIE for a patient also increases and we expect the willingness to consent to also increase. Note that the measure of complexity is designed in such a way that it can capture the potential benefits of HIE to a patient. The total number of ordered medical tests would not be an appropriate measure of complexity since as long as patients do not visit more than one physician, regardless of the number of ordered medical tests, the results will be readily available to their physician and there is no need to share the records with other providers electronically.

PCP-Involvement: Due to the relative newness of the HIE technology a large number of patients may not be familiar with the HIE system and its benefits and risks. Consequently, they may tend to depend on the advice of their physicians, especially their primary care providers. The patient-physician interaction and provision of sufficient information to patients has been shown to help their decision making process and improve the level of adherence to medical recommendations.[17–19] Similarly, physicians can have a significant role in building patients' trust in HIE platforms, since they serve as important and trusted sources of medical advice to the patients. More specifically, primary care physicians generally have longer relationships with their patients, and consequently, possess higher degrees of knowledge about their patients and their conditions. The length of relationships and the degree of knowledge about patients together serve as important emotive drivers of trust and the consequential consent decisions. The higher level of trust in primary care physicians is reflected in the recent findings that the patients are much more likely to share their medical records with them rather than with other specialists.[20] In summary, the primary care providers tend to be at a more significant position due to these reasons and we expect their advice to have a strong impact on the patient's decision to provide consent.

Age: The *age* factor is also likely to affect the potential value that patients receive from sharing their medical records on HIE systems. As patient's age increases, the likelihood and gravity of illness also increase and thus the potential benefits of sharing medical records and receiving better care increase consequently. We should also note that age is an important factor in determining a patient's attitude toward technology as well as his trust on primary care physicians. While older patients may be more pessimistic about technology in general and HIE in particular, they tend to have higher levels of trust in their primary care physicians and value their opinions more. [21]

Gender: The patients' *gender* is influential in shaping their risk-taking behaviors[22] and their perceptual evaluation of the benefits and risks of sharing sensitive medical information on HIE platforms. While female patients have been shown to have higher adherence to the medical recommendations of their physicians,[23] male patients may be more willing to take risks, including the sharing of their medical records on HIE systems.[24] Prior studies show that the incidence of specific diseases such as Parkinson's for instance, vary significantly over age and this variation differs by gender.[25] This implies that the potential value that older patients may receive from HIE can be moderated by their gender. To investigate the potential effect of gender on the relationship between age and willingness to disclose information, we allow for the interaction of the *age* and *gender* variables in our model.

3. Further details on Analysis and Results

For each patient, our model estimates a probability of providing consent. This probability is then used to predict a consent choice $\hat{Y}_i$ which can either be one or zero. The probability of the model correctly predicting a positive consent by a patient ($\hat{Y}_i = 1$) who has actually provided a positive consent is the *sensitivity* of the model and is defined as $P(\hat{Y}_i = 1 | Y_i = 1)$. The probability of the model correctly predicting a negative consent by a patient ($\hat{Y}_i = 0$) who has actually provided a negative consent is the *specificity* of the model and is defined as $P(\hat{Y}_i = 0 | Y_i = 0)$. Sensitivity and specificity denote "True Positives" and "True Negatives", respectively. Being probabilities, they both range between 0 and 1 and are together graphically represented by the Receiver Operating Curve (ROC). The ROC plots sensitivity against (1-specificity) of a dataset. In a perfect model, both sensitivity and specificity would equal 1 and accordingly, the ROC for a highly discriminant model will be close to the top left corner of the plot space. The 45-degree diagonal of the ROC shows a null model with no discriminating ability. The area under the

ROC Curve, denoted as AUC and ranging between 0.5 (no discriminant ability) and 1 (full discriminant ability) is used to assess the predictive power of the model.

Figure 1 shows the ROC for our model and the AUC is 0.7720. Intuitively, this indicates that the probability of true positives is greater than the probability of false positives 77.2% of the time. This demonstrates the goodness of fit of the proposed model to the dataset employed in this research.

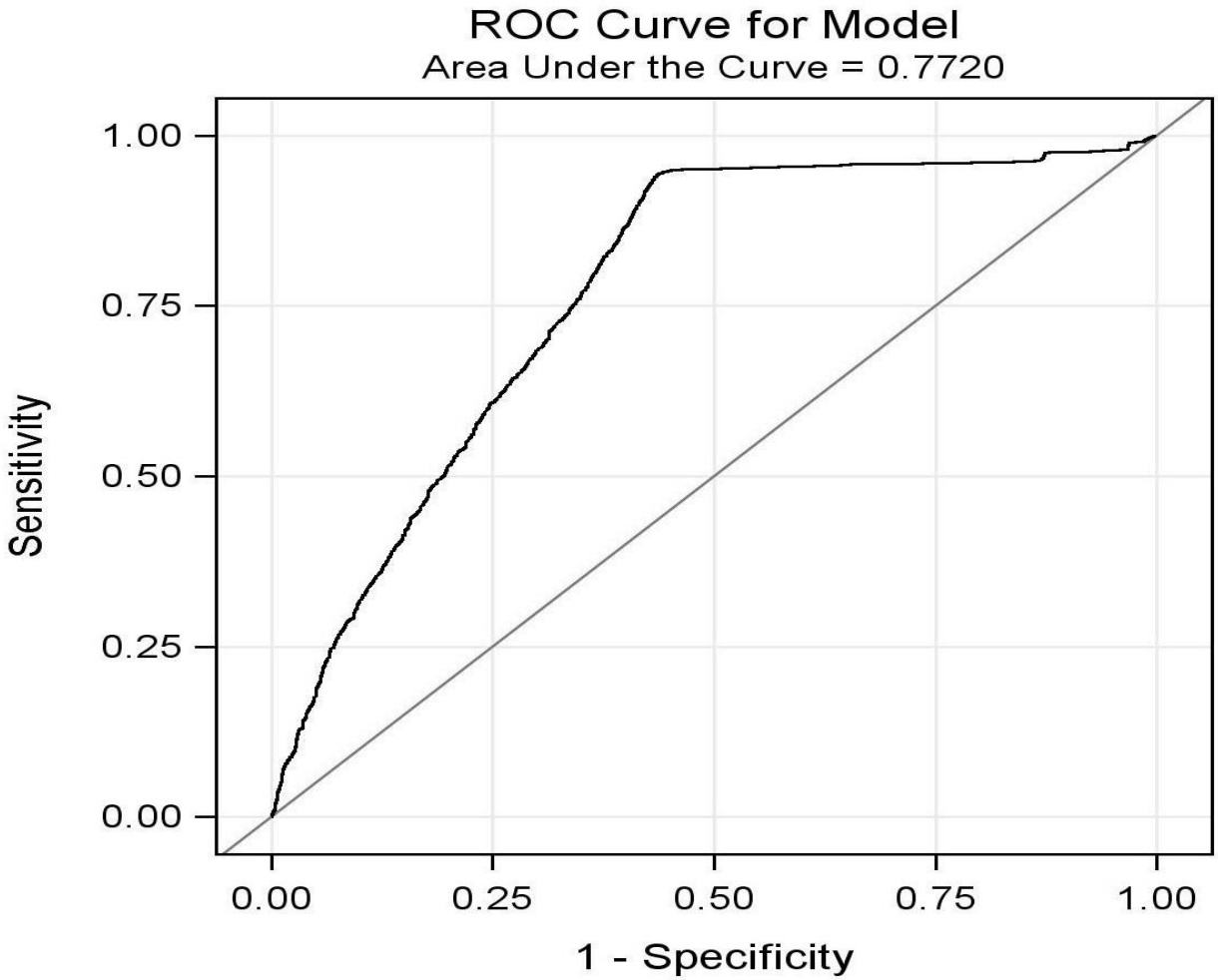

Figure 1: The operating characteristic (ROC) curve

Table 1 provides the mean, standard deviation and correlations among all of the model variables. In the first column, the mean and standard deviation of each independent variable is represented. The last three columns present the correlation between each pair of independent variables along with the

corresponding p-values. It is important to note that *complexity* and *age* variables are not strongly correlated with each other. This is due to the way that we operationalize *complexity* as the number of unique medical providers who have ordered at least one test for a patient. The overall utilization of the healthcare services by older patients include a wide variety of services including office visits, prescriptions, hospitalizations, ER visits, medical tests, etc. Our dataset is limited to only medical tests and does not include the other encounters between patients and medical providers. Additionally, rather than measuring the total number of medical tests performed, the *complexity* variable measures the number of unique providers who have ordered a test for the patient. Many of the medical tests may be ordered by only one provider and thus are only counted once in our measure of complexity.

	Mean **Std. Dev.**	**age**	**Gender**	**complexity**
Age	52.88668 20.53052			
Gender ***(=1 if female)***	0.68181 0.46579	-0.05320 <.0001		
Complexity	2.14580 3.90348	0.2271 0.013	-0.02621 0.0002	
PCP-Involvement ***(=1 if involved)***	0.67548 0.46821	0.04939 <.0001	0.02320 <.0001	0.08588 <.0001

Table 1: Descriptive statistics and correlations among model variables

Note: The values in parentheses represent p-values of correlations between pairs of variables

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