

# **Consenting Adults: Why Do Patients Disclose Their Medical History on Health Information Exchange Platforms?**

**(A Major part of this work has been carried out by a PhD student)**

## **Abstract**

The benefits of Health Information Exchange platforms will not be realized unless patients allow their medical records to be shared on these systems. We investigate the effects of patients' medical conditions on their decisions to disclose their medical histories on HIE platforms and the inherent privacy concerns. We employ a multinomial logit model to analyze a longitudinal database consisting of the consent choices and medical histories of 18208 patients in Western New York over a period of 3 years. To address the heterogeneity among patients and the consequential impact of their individual differences on their consent choices, we also develop a Bayesian approach which results in much more precise estimates of individual preferences. Our results indicate that the severity and type of the medical conditions together jointly affect the consent choices of patients. The findings of this research have significant implications for targeted marketing interventions by HIE firms in securing adequate levels of consent from patient populations that would otherwise have not consented; such interventions are essential, leading to enhanced cost-effectiveness of healthcare services using HIE systems.

## **1. Introduction**

Healthcare expenditures constitute a major part of the structural deficit in the US federal budget (Chernew et al. 2010). The US spent 17.9 percent of its GDP on healthcare in 2010, more than any other country in the world (Baicker and Skinner 2011; Martin et al. 2012). Despite the \$2.6 trillion of expenditure, the quality and efficiency of the US healthcare ranked last when compared to

Britain, Canada, Germany, Netherlands, Australia and New Zealand (Baicker et al. 2010). As a result, a concerted national effort to reform healthcare using information technologies with a focus on reducing costs and increasing quality of service is well under way (Menon et al. 2000; Casalino et al. 2003; Aron et al. 2011; Buntin et al. 2011). The recently enacted Health Information Technology for Economic and Clinical Health Act (HITECH) requires all medical records to be in standardized digital forms by 2014 (Blumenthal and Tavenner 2010). One of the principal objectives of this act is to set up Health Information Exchange (HIE) platforms through which providers can access medical data in a timely and cost-effective manner (Sipkoff 2010). The financial savings through full implementation of HIE platforms nationwide is estimated to be over \$77 billion per year (Walker et al. 2005; Frisse and Holmes 2007).

Federal and state laws mandate HIE platforms to obtain patients' permission before sharing their medical records (Terry 2012). 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. Increasing the number of patients who fully or even adequately consent will directly affect the value of the HIE platform to its members by increasing the number of accessible medical documents.

The traditional models of privacy calculus (Dinev and Hart 2006) and evaluation of costs and benefits of disclosing personal information (Culnan and Armstrong 1999) may not be suitable to explain the patients' decisions in disclosing their medical information since (1) there may be a high degree of emotional involvement in patients' decision making processes and thus they may not necessarily be considered as pure rational agents; and (2) in comparison with personal or financial information, compromising sensitive medical information may have much more severe consequences for patients (Hodge Jr et al. 1999; Anderson and Agarwal 2011).

Although there are a few studies on patient privacy (see Anderson and Agarwal 2011; Appari and Johnson 2010 for a systematic literature review of privacy in healthcare), all of them are based on either survey data or focus groups rather than actual longitudinal observations of patient privacy decisions and hence their conclusions are limited to outcomes that are perceptible to community members. The observation of actual patients' decisions on disclosing their personal information becomes even more important in the context of healthcare. Prior research indicates that medical conditions affect individuals preferences (Loewenstein 2005) and since individuals are not aware of their future medical conditions and emotional status, the survey responses collected at a single point of time may not necessarily reflect the actual decisions that individuals make when faced with emotional pressure of severe medical hardships over time.

HIE is a fairly new phenomenon that has emerged recently and thus it is not surprising that theory development in patient privacy in the context of HIE is still in its infancy. Given the unique factors affecting patients' decisions on disclosing medical information and their profound influence on the proposed value of HIE platforms (Yaraghi et al. 2012, 2013), a more comprehensive understanding of patient privacy concerns is warranted. In this research, we bridge these gaps by designing a model of medical privacy which takes the patients' medical conditions into account and provides empirical insights by analyzing an extensive database of consent choices of 18208 patients. This database is provided by HEALTHeLINK – the Regional Health Information Organization in Western New York – and in addition to consent choice, includes the patient demographics and medical history of the patients over a period of three years.

Considering the unique characteristics of HIE platforms and the existing lacunae in the literature, the objectives of this work are to build an interpretive theory of patient consent choices in the HIE context and investigate the drivers of consents by analyzing the actual decisions made by patients

with regards to their medical privacy in disclosures in a HIE. We also study the effects of patient-physician interactions and the socioeconomic status of patients on their consent choices. Our results indicate that the type and severity of the medical conditions as well as the socioeconomic status of the patients together impact their disclosure behaviors on HIE platforms.

This paper is organized as follows. Section 2 reviews the relevant literature and presents our research model. Section 3 introduces the dataset and discusses the operationalization of the model constructs. The analysis results are presented in section 4. We conclude the paper and present directions for future research in section 5.

## **2. A Conceptual Model of Consent Drivers**

Mancilla and Biedermann (2009) discuss trust as an important factor for increasing the patients' support in using digitized medical documents. Rohm and Milne (2004) conclude that the patients will indicate greater concern and perceived risk in instances where they do not trust the organization to use their personal information fairly. The study of Willison et al. (2007) on patient concerns about sharing their medical records with researchers also shows that the level of patients' trust to different organizations varies significantly. The patient-physician interaction and provision of sufficient information to patients is shown to help their decision making process and improve the level of adherence to medical recommendations (DiMatteo 1997; Mazur and Hickam 1997). Physicians, as an important source of seeking advice about joining HIE, can have a significant role in building patients trust in HIE platforms. Since physicians have considerably different attitudes toward HIE and its inherent privacy risks (Wright et al. 2010), they offer different advices and their patients will provide consent to sharing their medical records on HIE platforms accordingly.

*H1: The physicians with whom the patients interact the most, will affect the decision of the patients on disclosing their medical records on HIE platforms.*

Kam and Chismar (2006) synthesis the previous studies on patient privacy and conclude that self-disclosure is affected by patient perceptions of privacy, context sensitivity, and the information value of content and feedback. Building on their findings, we argue that the type of the diseases determine the sensitivity of the associated medical records and the severity of the diseases, is associated with the value of the information content and feedback for the patients. It is more likely for the patients with severe medical conditions to seek enhancement in the quality of their healthcare by providing consent to sharing their medical history. In other words, the value of medical information and the feedback the patients receive by sharing that will be much higher when the patients are in a sever medical condition.

*H2: The patients' type of disease will affect the decision of the patients on disclosing their medical records on HIE platforms.*

*H3: The patients' severity of disease positively affects their decision to disclose their medical records on HIE platforms.*

### **3. Analysis of Consent Behaviors**

In the following discussion, we first describe the datasets used and then develop the multinomial logit model.

#### **3.1. Data Sets**

We employed two databases provided by HEALTHeLINK, the RHIO in western New York. The first database consists of the consent choices that patients have made when asked about their preferences of sharing their medical records on the HIE system. This dataset also includes the age and gender of each patient. The second dataset is the HIE access log files and shows the access trend of all the HIE members to the medical records of the patients over the last three years. This dataset indicates the date, number and type of the tests that different medical specialists have either

accessed or ordered for each of the 18208 patients. Even if patient do not provide consent to sharing his/her medical records on HIE, although his/her records will not be accessible through HIE, we still can identify the date, number and type of the tests that were ordered for him/her.

After merging the consent type data set with the HIE data set, we will have a new data set which includes the age, gender, consent type and the medical history of 18208 patients. The patients' consent is categorized into 3 groups denoted as Y (*Full Access* granted to the entire medical record), E (*Limited Access* granted to the entire medical record in case of emergency) and N (*No Access* granted to the medical record). Using these HIE datasets, we clustered each of the patients based on three different clustering schemes. Each of these schemes is described below.

### ***3.1.1. Clustering Based on Medical History***

We logically expect the type of the diseases of the patients to affect their privacy concerns. The type of the medical specialties of the doctors whom a patient visits can shed considerable light on the type of the disease and illness that he/she has. There are 71 different medical specialties in our data set. The number of interactions between every patient and each of these different specialties is documented in a matrix of 18208 rows and 71 columns. Each cell of this matrix represents the number of times that the corresponding patient and specialty group of the cell have interacted. We used this matrix to apply Ward clustering method and group the patients into 5 different clusters. Although it is very hard to come up with a specific definition of these clusters (due to the large number of members in each cluster, we cannot ask experts to name the clusters), we know that the medical history of the patients in each cluster is significantly different from those in other clusters. Table 1 shows the number of patients in each medical cluster.

<b>Cluster</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
# Observations	2813	2610	1002	3662	8121

*Table 1: Number of patients in each medical cluster*

### **3.1.2. Clustering Based on Practices (geographical location of the patients)**

The geographical location of the patients can be correlated with other latent variables such as socioeconomic status of the patients and their awareness about the benefits of HIE which in turn will affect their privacy concerns. Since we do not have access to the location data of the patients, we may assume that the location of the practices in which they have been treated is highly correlated with the patients' location and thus clustering patients based on the practice that they have visited provides some insights about the location of the patients.

Based on HIE usage data set, we have created a 18208 by 311 matrix in which the rows represent patients and the columns represent the number of interactions of every patients with each of the 311 practices in the HIE system. Ward clustering method is used to cluster these patients into 5 different groups. Table 2 represents the number of patients within each cluster

<b>Cluster</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
# Observations	1839	1831	1873	907	11758

*Table 2: Number of patients in each location cluster*

### **3.1.3. Clustering Based on Physicians (Personal interaction of physicians and patients)**

Different physicians may have different tendencies toward HIE and will convey their beliefs about HIE to their patients. The recommendation of physicians can be a strong factor for patients in their decision about giving consent. Based on HIE usage data set, we created a 18208 by 1275 matrix in which the rows represent patients and the columns represent the number of interactions of every patients with each of the 1275 members of the HIE system. This matrix is then used to apply Ward clustering method and group patients into 2 clusters based on the physicians with whom they have interacted the most. The appropriate number of clusters are identified based on criteria such as

Pseudo F Statistic and Cubic Clustering Criterion. The number of patients within each of the two clusters is presented in table 3.

<b>Cluster</b>	<b>1</b>	<b>2</b>
# Observations	3121	15087

*Table 3: Number of patients in each physician cluster*

### **3.1.4. Other Variables**

We have also identified the number of lab and radiology reports and hospital transcriptions of each patient as well as the number of days between his/her first and last visit. The severity of the health status is calculated as the total number of the tests divided by the period between the first and the last visit. The descriptive statistics of these variables are shown in table 4. Figure 1 presents the research model constructs and the relationships between them.

<b>Variable</b>	<b>Mean</b>	<b>Std. deviation</b>	<b>Min</b>	<b>Max</b>
Radiology test	1.3631570	1.9589998	0	32
Lab tests	3.2958203	6.9999949	0	84
Hospital transcriptions	0.0344373	0.3129811	0	15
All tests	4.6934146	7.1430228	1	88
Age	53.6021310	19.1332421	0	103
Days on HIE system	60.7183501	121.8536899	1	913
Severity	1.1087358	1.3451496	0	24
Gender (=1 if female)	0.7065964	0.4553343	0	1

*Table 4: Descriptive statistics of other variables*



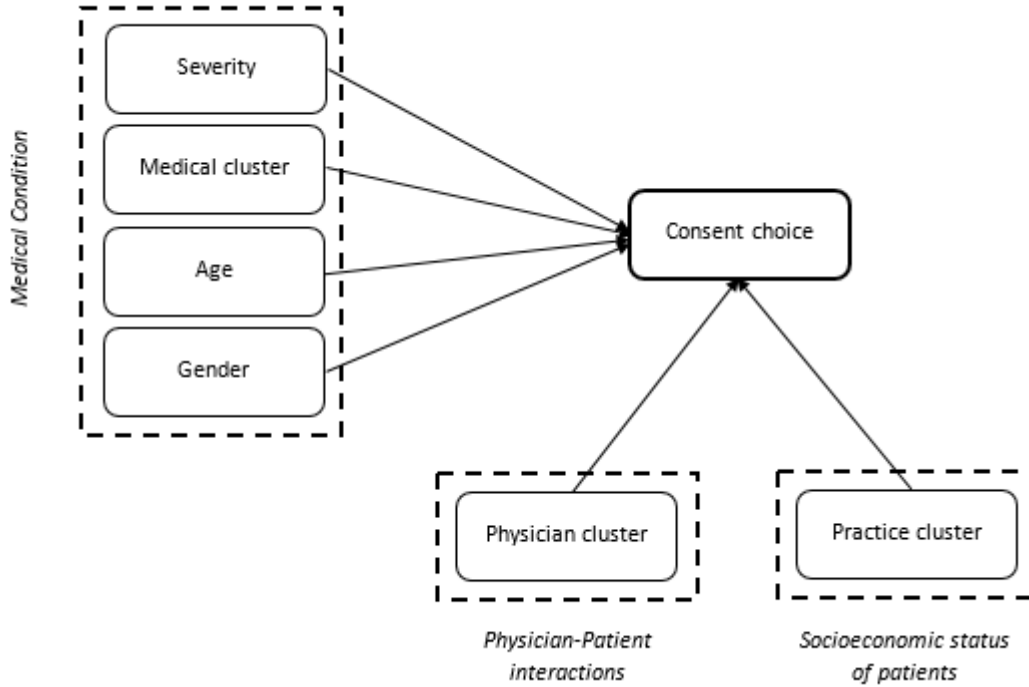


Figure 1: The conceptual research model

### 3.2. Multinomial Logit Model

Multinomial logit models are often used to analyze the data sets in which the response variable is a categorical variable and the choices cannot be sorted in any specific order. In our context, the response variable is the consent type which can have any of the three choices, Y, E and N. We analyze these choices as nominal variables which no preference can be given to any of them and thus are not ordinal. Consider a patient who chooses consent type  $j \in \{Y, E, N\}$  among  $m = 3$  alternatives. Let  $\pi_{ij}$  be the probability that the patient  $i$  choose alternative  $j$  and  $\mathbf{X}_i$  represent the characteristics of patient  $i$ . Patient  $i$  will choose consent type  $C_{ij}$  among a set of possible choices  $j = \{Y, E, N\}$  according to a multinomial distribution with parameters  $\pi_{ij} = \{\pi_{iY}, \pi_{iE}, \pi_{iN}\}$  in which the probabilities are a function of patient specific covariates  $\mathbf{X}_i$

The relationship between  $\mathbf{X}_i$  and  $\pi_{ij}$  can be defined through a logit function

$$\log\left(\frac{\pi_{ij}}{\pi_{ij^*}}\right) = \mathbf{X}_i' \beta_j$$

In which  $j^*$  is the baseline choice and  $j^* \neq j$

$$\frac{\pi_{ij}}{\pi_{ij^*}} = \exp(\mathbf{X}_i' \beta_j)$$

Since  $\sum \pi_{ij} + \pi_{ij^*} = 1$  then

$$\pi_{ij^*} + \sum_{j \neq j^*} \pi_{ij^*} \exp(\mathbf{X}_i' \beta_j) = 1$$

$$\pi_{ij^*} = \frac{1}{1 + \sum_{j \neq j^*} \exp(\mathbf{X}_i' \beta_j)} = \frac{\exp(\mathbf{X}_i' \beta_{j^*})}{1 + \sum_{j \neq j^*} \exp(\mathbf{X}_i' \beta_j)}$$

Considering the consent type Y as the default choice ( $j^* = Y$ ), we estimate two sets of regression coefficients, one for preferring consent type E over Y, and one for preferring consent type N over Y. In other words,  $\beta_1, \dots, \beta_m$  are  $m$  vectors of unknown regression coefficients and by setting  $\beta_m = 0$ , the other remaining coefficient ( $\beta_k$ ) represent the effects of the  $\mathbf{X}$  variables on probability of choosing alternative  $k$  over the alternative  $m$ . In our context, we consider the consent type Y as the default choice ( $\beta_Y$ ) and investigate the effects of variables such as age, gender and medical history on the probability of choosing other two types of consent (E, N) over the default consent type (Y).

#### 4. Results

Table 5 presents the overall effect of the model variables on the choice of consent. The null hypothesis is that there is no relationship between the predictor variable and the consent choice.

According to the results in table 6, all of the variables are affecting the patients' consent choice except the doctor cluster.

Source	Chi-Square	Pr > ChiSq
Age	2465.75	<.0001
female	191.43	<.0001
medicalcluster	43.17	<.0001
practicecluster	53.65	<.0001
doctorcluster	3.60	0.1653
severity	46.63	<.0001

*Table 5: Maximum likelihood analysis of variance*

In table 6, the maximum likelihood estimates of all the above variables in the two regression equations (for consent type E and N) are presented. Two models were defined in this multinomial regression: one relating consent type E to the referent category, consent type Y, and another model relating consent type N to Y. The model number indicates to which model an estimate, standard error, chi-square, and p-value refer. Our consent type category 1 is E, so model 1 corresponds to the E relative to Y model and model 2 corresponds to the N relative to Y model. The standard interpretation of the multinomial logit is that for a unit change in the predictor variable, the logit of outcome m relative to the referent group is expected to change by its respective parameter estimate (which is in log-odds units) given the other variables in the model are held constant. We discuss and interpret the results for each model separately below.

#### **4.1. Preference of Consent Type E Relative to Y**

*Age:* If a patients' age were to increase by one year, the multinomial log-odds for preferring consent type E to Y would be expected to decrease by 0.0428 unit while holding all other variables in the model constant.

Parameter	Preferring consent choice E to Y				Preferring consent choice N to Y			
	Estimate	Standard Error	Chi-Square	Pr > ChiSq	Estimate	Standard Error	Chi-Square	Pr > ChiSq
Age	<b>-0.0428</b>	<b>0.00104</b>	<b>1707.76</b>	<b>&lt;.0001</b>	<b>-0.0571</b>	<b>0.00187</b>	<b>928.34</b>	<b>&lt;.0001</b>
Female	<b>-0.4972</b>	<b>0.0554</b>	<b>80.67</b>	<b>&lt;.0001</b>	<b>-1.1484</b>	<b>0.1009</b>	<b>129.64</b>	<b>&lt;.0001</b>
Severity	<b>-0.1048</b>	<b>0.0252</b>	<b>17.33</b>	<b>&lt;.0001</b>	<b>-0.3793</b>	<b>0.0667</b>	<b>32.36</b>	<b>&lt;.0001</b>
Medical cluster 1	<b>-0.2538</b>	<b>0.0783</b>	<b>10.50</b>	<b>0.0012</b>	<b>-0.6375</b>	<b>0.1522</b>	<b>17.55</b>	<b>&lt;.0001</b>
Medical cluster 2	0.0111	0.0740	0.02	0.8813	0.1109	0.1298	0.73	0.3927
Medical cluster 3	<b>0.2089</b>	<b>0.1057</b>	<b>3.90</b>	<b>0.0482</b>	<b>0.6131</b>	<b>0.1701</b>	<b>12.99</b>	<b>0.0003</b>
Medical cluster 4	0.1004	0.0716	1.97	0.1610	0.0935	0.1317	0.50	0.4778
Location cluster 1	-0.0904	0.0986	0.84	0.3593	-0.0103	0.1666	0.00	0.9508
Location cluster 2	-0.1543	0.0927	2.77	0.0959	-0.2579	0.1615	2.55	0.1103
Location cluster 3	<b>-0.1604</b>	<b>0.0837</b>	<b>3.68</b>	<b>0.0552</b>	<b>-0.7118</b>	<b>0.1640</b>	<b>18.84</b>	<b>&lt;.0001</b>
Location cluster 4	<b>0.4137</b>	<b>0.1113</b>	<b>13.81</b>	<b>0.0002</b>	<b>1.0310</b>	<b>0.1838</b>	<b>31.46</b>	<b>&lt;.0001</b>
Physician cluster 1	0.00748	0.0544	0.02	0.8908	0.1921	0.1013	3.60	0.0579

*Table 6: Analysis of Maximum Likelihood Estimates*

*Gender:* This is the multinomial logit estimate comparing females to males for preferring consent type E relative to Y, given the other variables in the model are held constant. The multinomial logit for females relative to males is 0.4972 unit lower for preferring consent type E to Y, given all other predictor variables in the model are held constant. In other words, females are less likely than males to prefer giving consent type E to Y.

*Medical history (disease type):* The multinomial logit for patients who are grouped in medical cluster 1 relative to those who are grouped in medical cluster 5 is 0.2538 unit lower for preferring consent type E to Y, given all other predictor variables in the model are held constant. In other words, the patients in medical cluster 1 are more likely to choose consent type Y rather than E.

The multinomial logit for patients who are grouped in medical cluster 3 relative to those who are grouped in medical cluster 5 is 0.2089 unit higher for preferring consent type E to Y, given all other predictor variables in the model are held constant. In other words, the patients in medical cluster 3 are more likely to choose consent type E rather than Y.

Medical clusters 2 and 4 have no significant effect on patients' choice of consent type.

*Practice cluster (geographical location):* The multinomial logit for patients who are grouped in practice cluster 3 relative to those who are grouped in practice cluster 5 is 0.1604 unit lower for preferring consent type E to Y, given all other predictor variables in the model are held constant. In other words, the patients in practice cluster 3 are more likely to choose consent type E rather than Y. The multinomial logit for patients who are grouped in practice cluster 4 relative to those who are grouped in medical cluster 5 is 0.4137 unit higher for preferring consent type E to Y, given all other predictor variables in the model are held constant. In other words, the patients in practice cluster 4 are more likely to choose consent type E rather than Y. Practice clusters 1 and 2 have no significant effect on patients' choice of consent type.

*Doctor cluster (personal interaction of patient and physician):* Doctor clusters have no significant effect on patients' choice of consent type.

*Severity:* If a patients' severity of illness were to increase by one unit, the multinomial log-odds for preferring consent type E to Y would be expected to decrease by 0.1048 unit while holding all other variables in the model constant. In other words, when the health status of the patients is deteriorating, they are more likely to prefer consent type Y to E.

## **4.2. Preference of Consent Type N relative to Y**

The factors that affect the preference of choice E to Y are having the same effect on preference of choosing consent type N to Y. In summary, the older patients are more open in sharing their documents and the sicker a patient is the more likely it is to give full consent rather than limited or No consent at all. The patients in medical cluster 1 are less likely to give consent type N while the ones in medical cluster 3 are more likely to give no consent. Similarly, the patients in practice cluster 3 are less likely to give consent N while the ones in practice cluster 4 are more likely to give no consent.

## **5. Discussion**

To the best of our knowledge, this work is the first attempt to investigate the patients' privacy and their decision to disclose medical information on HIE platforms by analyzing a large dataset of actual consent choices and detailed medical history of the patients. Our results indicate that age and gender as well as medical conditions of patients is affecting their choice of consent. These findings can be of interest to HIE platforms in designing targeted marketing strategies to attract the patients whom otherwise would have not given consent and thus increase the value of their platform for their current and future members.

We are currently developing hierarchical Bayesian market choice models of consent choice. The Bayesian approach enables us to emphasis on the individual differences among patients. Classical models do not allow the estimation of individual-level parameters. For example unless implemented through a conditional likelihood approach, the random coefficient models can only estimate the hyper-parameters. Even models of heterogeneity often restrict heterogeneity to a

limited subset of parameters such as intercept. The drivers of patients' consent decision can be better understood if we allow differences in not only intercepts, but also slope coefficients.

Since there is a very small percentage of patients with limited consent types, responding to individual level differences becomes even more important. To efficiently design targeted interventions for increasing the level of full consents, we should use a method which describes the uncertainty in patient-level estimates. By estimating the responses at individual level, we can estimate the population response by aggregating the individual level responses. This method will lead to much more precise estimates of the population response.

To address heterogeneity, fixed effects methods in which some of the model parameters are considered fixed across all or at least a subset of individuals are proposed (Currim 1981; Guadagni and Little 1983; Kamakura and Russell 1989). Although we have a data set of over 18000 patients, the individual level information about each of these patients is very scarce. This scarcity renders the use of fixed-effects approach to heterogeneity. Even if there was an ample amount of data about individual characteristics, it is implausible to assume that heterogeneity is fully captured by intercepts (Rossi and Allenby 1993).

An alternative approach is to use a random effects model in which individual patient level parameters are viewed as draws from a super population. This method estimates the parameters' distribution over the population but still is not able to provide individual level parameter estimates (Chintagunta et al. 1991) and thus is not suited for inferences about individual level effects.

In the Bayesian approach, we will first assign a general prior distribution to model parameters based on the assumption that the population is homogenous and there is no difference in model parameters among individual patients. Through the Bayesian process, the prior distribution will be

updated by observing the behavior of each of the patients at individual level. In other words, if patient  $i$  can choose among  $j \in \{Y, E, N\}$  alternatives according to a multinomial distribution with probabilities  $\{p_{iY}, p_{iE}, p_{iN}\}$  in which the probabilities are linked to patient characteristics through a standard logit model as  $p_{ij} = \frac{\exp(x_i' \beta_j)}{\sum_{j^*} \exp(x_i' \beta_{j^*})}$ , then the likelihood of model parameters vector  $\beta$ , given the observed choices for patient  $i$  over a period of  $T$ , can be defined as  $\ell_i(\text{Data}_i | \beta) = \prod_{t=1}^T \prod_{j=1}^J p_{ijt}^{I(C=j)}$  where  $I(C = j) = 1$  if the patient chooses consent type  $j$  and  $I(C = j) = 0$  otherwise. If we assume  $\pi(\beta)$ , a prior distribution for the vector of model parameters  $\beta$  based on the aggregate level estimations, we can form a posterior distribution for patient level parameters through the simple Bayesian process such that  $p_i(\beta | \text{Data}_i) \propto \pi(\beta) \ell_i(\text{Data}_i | \beta)$ .

The critique to Bayesian approach is its ambiguity in defining the prior distributions. We will address this by defining the prior distribution as a multivariate normal distribution with mean  $\bar{\beta}$  and covariance proportionate to  $\Sigma$  based on the pooled maximum likelihood estimation of model parameters (McCulloch and Rossi 1991). The use of normal approximation for multivariate logit models is justified by Zellner and Rossi (1984). Prior to the invention of Markov chain Monte Carlo methods, the posterior distribution had to be analytically arrived at by multiplying the prior distribution by likelihood function. The emergence of Monte Carlo Markov Chain (MCMC) simulation methods has eliminated the need to tedious analytical derivation by substituting it with a set of repetitive calculations that, in effect, simulate draws from this distribution (Allenby et al. 2005). We are currently pursuing the research in this venue.



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