

ASSISTED LIVING FACILITIES  
RESIDENTS' AND RELATIVES'  
PREFERENCES FOR FAMILY ACCESS  
TO THEIR MEDICAL AND PERSONAL  
INFORMATION

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by  
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The undersigned, appointed by the dean of the Graduate School, have examined the thesis entitled

ASSISTED LIVING FACILITIES RESIDENTS' AND  
RELATIVES' PREFERENCES FOR FAMILY  
ACCESS TO THEIR MEDICAL AND PERSONAL  
INFORMATION

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and hereby certify that, in their opinion, it is worthy of  
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# ASSISTED LIVING FACILITIES RESIDENTS' AND RELATIVES' PREFERENCES FOR FAMILY ACCESS TO THEIR MEDICAL AND PERSONAL INFORMATION

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## ABSTRACT

The purpose of this study is to explore privacy preferences of elderly residents and their relatives at assisted living facilities. In the past year, there has been a large increase in the interest and concept of accessing medical information as a right for every American. The Health Information Technology for Economic and Clinical Health Act (HITECH Act) as well as the Office of National Coordinator for Health IT's Nationwide Health Information Network (NHIN) project are prime examples of this increased awareness and interest. This pilot study focuses on just the privacy access rights for family access. To explore this, a structured interview questionnaire was created and administered to 12 participants, 10 of whom were residents at two assisted living facilities and two of whom were relatives of residents. The most interesting result was that some residents understand "access" to mean that the person accessing the information can also act upon that information. An actionable discovery is that illness has a huge impact on how often the participants wanted to review their access preferences, as well as what their preferences are. Further study is required to fully explore these findings.

# CHAPTER 1

## INTRODUCTION

Privacy is a major concern and is very important to most people in any society (Chhanabhai & Holt, 2007; Menkes, Hill, Horsfall, & Jaye, 2008; Willison, et al., 2007). Like privacy, confidentiality is very important and if it is not guaranteed, many patients will choose to withhold information or refrain from seeking health care (Bolton Research Group, 2000; Carlisle, Shickle, Cork, & McDonagh, 2006; Courtney, 2008; Goodwin, Courtney, Kirby, Iannacchione, & Manley, 2002; Morin, et al., 2005; Sankar & Jones, 2005; Whiddett, Hunter, Engelbrecht, & Handy, 2006). However, very little research has been conducted on understanding the patient's perspective regarding privacy, confidentiality, or who can access their medical information. This study's objective is to explore the subset of the bigger picture of patient perspective, which is the topic of family access preferences. This study focuses on a very narrow issue of the elderly patient's preferences for family access to medical information. Everyone has unique, individualized, and highly subjective preferences for who should have access to their information. However, it is the hypothesis of the researcher that elderly persons will have a more similar set of access preferences for their family members despite the subjective nature of preferences.

As the push for more electronic based data continues, the right to express their preferences and control who can access data will become increasingly important ("Americans Concerned About Safety, Accuracy of Electronic Health

Records: Survey," 2007; Bernheim, et al., 2006; Goodwin, et al., 2002; Pyper, Amery, Watson, & Crook, 2004; Wiljer, et al., 2006). Evidence of increased attention to patient's rights can be seen in Federal projects such as the Nationwide Health Information Network (NHIN) and its software implementation; the Federal CONNECT. NHIN is "a set of standards, services and policies that enable secure health information exchange over the Internet" (AHRQ\_NRC, 2010). The Federal Connect software is the technical software that allows that secure transmission and one part of several core policies of the NHIN that is part of the consumer preferences service.

When patients are given power and responsibility for their care, they become consumers (Eysenbach, 2000). One set of the policies defined by NHIN focuses on consumer preferences. The *Consumer Preference Requirement Document* (CPRD), currently in draft stage, focuses on organizing efforts to provide appropriate protection and security of information within constraints of the consumer driven set of individualized preferences (*Consumer Preferences Draft Requirements Document*, 2009). The draft explains, "Without appropriate protections, consumers may be less willing to participate in information exchange and the benefits of an electronically enabled healthcare delivery system may not be fully realized." This study began with that statement and developed into the specific issue of family access preferences without being as granular as the CPRD is proposing. The CPRD focuses on allowing the patient to control down to the individual level, while this research study focuses on the overall categories of different family members.

This study began with a review of family access preferences. Several studies were discovered showing evidence that the elderly have an interest in what information is recorded about them, as long as their family has access to that information (Alexander, et al., 2008; Demiris, Hensel, Skubic, & Rantz, 2008; Demiris, Oliver, Dickey, Skubic, & Rantz, 2008). These studies discuss the installation and use of “smart home” sensors in the participant’s assisted living facility apartments. They are designed to record the motion that occurs in a given room and that information is aggregated into a database to be used by researchers. The purpose is to detect the declining health of residents in order to prevent events such as falls and the resulting hospitalizations.

The participants’ willingness to allow “smart home” technology to be installed and their apparent enthusiasm seemed to express their desire to share the collected information with their family. This begs the question: “How much do they want to share with their families?”

We began to explore this question by becoming part of the “smart home” research team (“Center for Eldercare and Rehabilitation Technology,” 2010). During the initial stages of development this team developed a small electronic medical record (EMR) designed to allow the nursing staff to manage medical data about the residents. The creation of the EMR was the first step in integrating medical data with the sensor databases described above. However, the EMR’s target audience was the nursing staff, not residents or family members. There was a missing link that prevented residents’ or their families’ easy access the EMR’s content. This research team also has very little literature

to help guide the development of an EMR that allows nurses, other medical providers, residents, and relatives of the residents to access the same information but at 'appropriate' access levels. To help address this limitation, in this study, we decided to focus on family access to medical and other sensitive information.

## CHAPTER 2

### RELATED LITERATURE

Goodwin (2002) and Courtney (2008) defined *confidentiality* as the conditions under which private information is shared, while *privacy* is the desire to limit disclosure. Everyone has the right to privacy and they are demanding more of it; however, the increase in technology is threatening to erode that privacy (Katz & Rice, 2009; Whiddett, et al., 2006). Despite these concerns, many people believe that the benefits of technology outweigh the potential risks (Chhanabhai & Holt, 2007; Mohd Rosli, Taylor, Knott, Das, & Dent, 2009; Wiljer, et al., 2006). For the list of perceived risks, see Table 2. Despite the importance of these topics, very little research has been conducted on understanding patient's perspectives. There are over six thousand research papers on other perspectives, such as legal, administrative, and physician preferences (Whiddett, et al., 2006). The patient perspective will be an increasingly important issue as the health care industry becomes more technologically integrated (Mulligan & Braunack-Mayer, 2004).

A search for related literature was performed in Medline (1950-Present), the Cumulative Index of Nursing and Allied Health Literature, CINAHL, (1982-Present), the EI Compledex\*Plus in Ovid (1987-Present), SCOPUS (Full Database) and PsycINFO (1987 to July Week 4 2009). Each database required an individual custom search (Appendix A) but the important terms are as follows:

- ("Privacy and Confidentiality" OR "Access to Information" OR "Confidentiality" OR "Anonymity") AND
- ("Medical Informatics" OR "Health Informatics" OR "Informatics" OR "Computerized Patient Record" OR "Patient Record Systems" OR "Medical Records Systems, Computerized") AND
- ("Attitude" OR "Patient Attitudes" OR "Attitude to Health" OR "Attitude to Computers" OR "Health Knowledge, Attitudes, Practice " OR "Patient Accept\*" OR "Patient Prefer\*" OR "Preference")

Studies were limited to journal articles about the patient's perspective (instead of physician or other parties' perspective). One database was unable to limit to journal articles and it returned conference papers. Conference papers were excluded because only one of the databases held conference papers (consistency across databases) and conference papers are often limited in size, thus fewer details of the experiments could be provided. These were removed during the review process. Studies not written in English were excluded, as well as any study published prior to 1995. Any study prior to 1995 would not focus on the electronic element that affects the modern topics of privacy and confidentiality. The following criteria were used, in order of exclusion:

1. The article was a conference paper.
2. The article's perspective was not that of the patient.
3. The topic of the article was not about confidentiality, privacy, or a discussion about patient's concern about access to their personal health information (PHI).

Item number three (confidentiality, privacy, or concerns) was not separated into separate criteria because it would narrow the literature review too much and the purpose of the study would be lost. Given the limited number of articles focusing on the patient perspective, the literature search was not limited to the elderly (65 years or older), which would have resulted in only two articles

being relevant given the inclusion and exclusion criteria. In addition to the small number of possible articles that would pass a more narrow inclusion criteria, it is important to understand how patients from a wide range of ages view the topic because the relatives for the study can potentially come from any age group, 18 to 89. The details of the papers were categorized into the following focuses:

- Discuss patient concerns
- Family access discussed
- Patient access to their medical data
- Discussion about who should have access to their medical data
- Discussed confidentiality or privacy

The literature search uncovered 284 unique articles. After reviewing the title and abstract, 80 articles met inclusion criteria. Most articles excluded did not present the article's topic from the patient's point of view (n = 137). Fifty-five articles were not journal articles and they were excluded immediately. Then the full text was reviewed against the same criteria. As expected, more articles were removed because they did not focus on confidentiality, privacy, or it did not discuss patient concerns (n=39). The result was 30 relevant articles that are outlined in Table 1.

## 2.1 RESULTS

Interestingly, none of these articles was published before 2000. Twenty-six of the articles discuss patient concerns about various confidentiality or access issues. Three articles discussed patient's views about their family members having access to their medical data. More articles (n = 19) discussed who should have access other than family members, such as doctors, nurses, and staff. The

literature separated the topic of self access to patients' own private information (n=10). Eight articles discuss the topic of allowing identifiable or non-identifiable medical data to be used for research purposes. Almost all articles (n=24) discussed patients' views and understanding about confidentiality and/or privacy. Confidentiality and privacy are commonly interchangeable in the literature and they are treated as the same topic for the purposes of this literature review (Courtney, 2008).

*Table 1: Literature Review Characteristics*

Author / Year	Study Design / Sample (response rate)	Patient Concerns	Family Access	Patient Access to File	Who can Access Info	Confidentiality or Privacy
"Americans Concerned About Safety, Accuracy of Electronic Health Records: Survey", 2007	Study Sample Size N/A	Yes	No	Yes	Yes	No
Baker et al., 2003	Editorial	Yes	No	No	No	Yes
Barrett et al., 2006	Survey 2872 responded (62%)	Yes	No	No	Yes	Yes
Bernheim et al., 2006	Questionnaire 392 responded (73%)	Yes	No	Yes	No	Yes
Bolton Research Group, 2000	Questionnaire 862 responded (82%).	Yes	No	No	Yes	yes
Brenner, 2003	Questionnaire 235 patients	Yes	No	Yes	No	No

*Table 1: Literature Review Characteristics (Continued)*

Author / Year	Study Design / Sample (response rate)	Patient Concerns	Family Access	Patient Access to File	Who can Access Info	Confidentiality or Privacy
Carlisle et al., 2006	Interview 9 males and 11 females	Yes	Yes	Yes	Yes	Yes
Chhanabhai et al., 2007	Survey 300 responded (75%)	Yes	No	No	No	No
Courtney, 2008	Focus Groups 11 Nursing Home Residents	Yes	No	No	No	No
Flynn et al., 2003	Survey 80 patients	Yes	No	No	Yes	Yes
Garcia-Sanchez, 2008	Questionnaire 62 responded (62%)	No	No	No	Yes	Yes
Goodwin et al., 2002	Questionnaire 92 patients	Yes	No	Yes	Yes	Yes
Kass et al., 2003	Interview 597 respondents	Yes	No	No	Yes	Yes
Katz et al., 2009	Survey 1404 respondents	Yes	No	No	No	No
Marshall et al., 2000	Survey 185 family members and 64 patients	No	Yes	No	Yes	Yes
Menkes et al.,	Interview 32 patients	Yes	Yes	Yes	Yes	Yes
Mohd Rosli et al., 2009	Cross Sectional 270 patients and 92 staff	Yes	No	No	No	Yes

*Table 1: Literature Review Characteristics (Continued)*

Author / Year	Study Design / Sample (response rate)	Patient Concerns	Family Access	Patient Access to File	Who can Access Info	Confidentiality or Privacy
Morin et al., 2005	Interview 30 elderly patients	Yes	No	Yes	No	No
Mulligan et al., 2004	Literature Review	Yes	No	No	No	Yes
Ogden et al., 2005	Questionnaire 324 responded (40%)	No	No	Yes	Yes	Yes
Porteous et al., 2003	Questionnaire 12 patients, 31 non-patients	Yes	No	No	Yes	Yes
Pyper et al., 2004	Questionnaire 100 patients	Yes	No	Yes	Yes	Yes
Sankar et al., 2005	Interview 85 women	Yes	No	No	No	Yes
Schers et al., 2003	Questionnaire 644 responded (74%)	Yes	No	No	Yes	Yes
Stone et al., 2005	Interview 20 patients, 15 non-patients	Yes	No	No	Yes	Yes
Tracy et al., 2004	Focus Groups 8 urban professional, 7 immigrants, 6 health advocates, and 7 Elderly	Yes	No	No	Yes	Yes
Whiddett et al., 2006	Questionnaire 203 responded (77%)	Yes	No	No	Yes	Yes

*Table 1: Literature Review Characteristics (Continued)*

Author / Year	Study Design / Sample (response rate)	Patient Concerns	Family Access	Patient Access to File	Who can Access Info	Confidentiality or Privacy
Wiljer et al., 2006	Questionnaire 43 patients and 7 staff	No	No	Yes	No	Yes
Willison et al., 2003	Survey and Interview  17 were interviewed and 106 completed a survey	Yes	No	No	Yes	Yes
Willison et al., 2007	Interview  1,230 responded (58%)	Yes	No	No	Yes	Yes

## 2.2 PATIENT CONCERNS

Privacy and security are primary concerns of all patients according to some of the studies that identities theft of data and hackers as some of the main concerns (Chhanabhai & Holt, 2007; Courtney, 2008; Katz & Rice, 2009; Porteous, Bond, Robertson, Hannaford, & Reiter, 2003). Chhanabhai & Holt (2007) found that 68% of respondents were worried about malicious software and 70% expressed concern about information leaks due to weak security. Forty percent say that this would be even more of a concern if electronic health records are used instead of paper records. The aged population is less concerned about security and confidentiality, possibly due to their lack of understanding (Morin et al., 2005).

Patient concerns about privacy, confidentiality, and access to their medical records focuses on the list found in Table 2, with unauthorized access and the use of their medical data against them being the strongest worries (Chhanabhai & Holt, 2007; Flynn, Marcus, Kerber, & Alessi, 2003; Porteous et al., 2003).

*Table 2: Common Concerns Expressed by Patients*

<ul style="list-style-type: none"> <li>• Sharing or disclosure of medical information without knowledge of the disclosure</li> <li>• Unauthorized access</li> <li>• Vendor access to medical data</li> <li>• Unwarranted disclosure leading to medical data being used against the patient</li> <li>• Insurance companies or employers gaining access to their medical data</li> <li>• Medical data being used for commercial gain instead of research knowledge.</li> <li>• Increase in medical errors due to the introduction of the computer into the communication exchange</li> <li>• Erosion of existing privacy rules</li> <li>• Losing or lacking the ability and right to control the use of their medical data</li> </ul>
<p>Source: (Chhanabhai &amp; Holt, 2007; Flynn, Marcus, Kerber, &amp; Alessi, 2003; Garcia-Sanchez, 2008; Kass, et al., 2003; Menkes, et al., 2008; Mohd Rosli, et al., 2009; Morin, et al., 2005; Porteous, Bond, Robertson, Hannaford, &amp; Reiter, 2003; Pyper, et al., 2004; Sankar &amp; Jones, 2005; Willison, Keshavjee, Nair, Goldsmith, &amp; Holbrook, 2003)</p>

There was also a lot of concern about medical data and the use of the Internet (Bernheim, et al., 2006; Pyper, et al., 2004). Most research found that between 70% and 80% of respondents classified themselves as Internet users, but only 40% used the Internet as part of daily life (Brenner, 2003; Chhanabhai & Holt, 2007). Despite the security worries about obtaining medical information via the Internet, most respondents would be willing to accept it, because they believe that the benefits outweigh the perceived risks (Pyper, et al., 2004).

## 2.3 PRIVACY AND CONFIDENTIALITY

Privacy may be the primary worry, but patients view confidentiality as the most important part of their medical information and of patient-doctor communication (Baker, Reifsteck, & Mann, 2003; Menkes, et al., 2008). This is more important when it comes to young people, because their age (under 18 years of age) is when they begin to want freedom from their parents and more privacy (Carlisle, et al., 2006). While no evidence from the literature exists, the elderly may have the opposite view where they prefer to share with their family. Eighty-five percent of patients said that doctors and hospitals were trustworthy to maintain confidentiality (Morin, et al., 2005; Willison, et al., 2007). This trust is the core of all consultations between patients and their doctors (Bolton Research Group, 2000; Carlisle, et al., 2006; Chhanabhai & Holt, 2007; Courtney, 2008; Goodwin, et al., 2002; Kass, et al., 2003; Marshall & Solomon, 2000; Menkes, et al., 2008; Morin, et al., 2005; Sankar & Jones, 2005; Stone, Redsell, Ling, & Hay, 2005; Tracy, Dantas, & Upshur, 2004; Whiddett, et al., 2006; Willison, et al., 2003).

Morin (2005) says that major harm is a possibility when confidentiality is compromised. Patients who think that confidentiality is not or will not be upheld will often withhold vital information such as HIV status, sexual status, and other conditions that are of a sensitive nature (Bolton Research Group, 2000; Carlisle, et al., 2006; Chhanabhai & Holt, 2007; Courtney, 2008; Goodwin, et al., 2002; Morin, et al., 2005; Sankar & Jones, 2005; Whiddett, et al., 2006).

## 2.4 ACCESS TO MEDICAL DATA

As technology increases the ability to quickly and easily share medical records electronically, many believe that it will reduce the number of medical mistakes and prevent duplicate procedures, improve the management of patients and their conditions, and improve communication between all parties in the process of managing patients ("Americans Concerned About Safety, Accuracy of Electronic Health Records: Survey," 2007; Bernheim, et al., 2006; Mohd Rosli, et al., 2009; Mulligan & Braunack-Mayer, 2004; Wiljer, et al., 2006).

With the ability to transmit records electronically, patients are increasingly wanting to access their own medical data ("Americans Concerned About Safety, Accuracy of Electronic Health Records: Survey," 2007; Goodwin, et al., 2002; Menkes, et al., 2008; Mohd Rosli, et al., 2009). Goodwin (2002) found that 89% of the study's patients correctly believed that they could take a copy of their records home, which is a legal right outlined in the HIPAA regulations. As more patients realize that they have this right, they will begin to demand access from where ever and whenever they want to access it (Mohd Rosli, et al., 2009).

Since the purpose of sharing a medical record is exactly that, to share, it would be expected that patients will becoming increasingly concerned about who has access to their records. Surprisingly, they assume that their doctors or general practitioners are the gate-keeper who control and delegate access rights (Bolton Research Group, 2000; Morin, et al., 2005; Schers, Van Den Hoogen, Grol, & Van Den Bosch, 2003). Nearly everyone (about 97%) in several studies agreed that their primary doctors should have full access to their medical

records, while other health care professionals should not have full access ("Americans Concerned About Safety, Accuracy of Electronic Health Records: Survey," 2007; Goodwin, et al., 2002; Mohd Rosli, et al., 2009; Porteous, et al., 2003; Schers, et al., 2003; Wiljer, et al., 2006). In contrast to these studies, very few (14%) felt that the reception staff should have access to their record (Bolton Research Group, 2000; Ogden, Jones, Seed, & Durbaba, 2005).

As the ability to share records increases, patients would like to share their records not only among health professionals, but also with their families (Marshall & Solomon, 2000; Tracy, et al., 2004). Patients prefer to be consulted before allowing non-providers to gain access to their data. When deciding who should have access and to what kind of information, patients make their decisions based on three guidelines: 1) Information being accessed; 2) Recipient of the access; 3) Identity protection ("Americans Concerned About Safety, Accuracy of Electronic Health Records: Survey," 2007; Courtney, 2008; Kass, et al., 2003; Schers, et al., 2003; Stone, et al., 2005; Whiddett, et al., 2006; Willison, et al., 2003).

The goal of the study is to collect patient preferences irrespective of any potential legal barriers, administrative barriers, or technical limitations which could affect adherence to those preferences. Examples of barriers would be what is legally allowed by law, such as HIPAA, or what is considered acceptable given the culture of the host organization. In other words, the goal is to collect pure subjective data from the patients with it unfiltered by what is realistically possible. The end result of the study is to add to the available knowledge with a

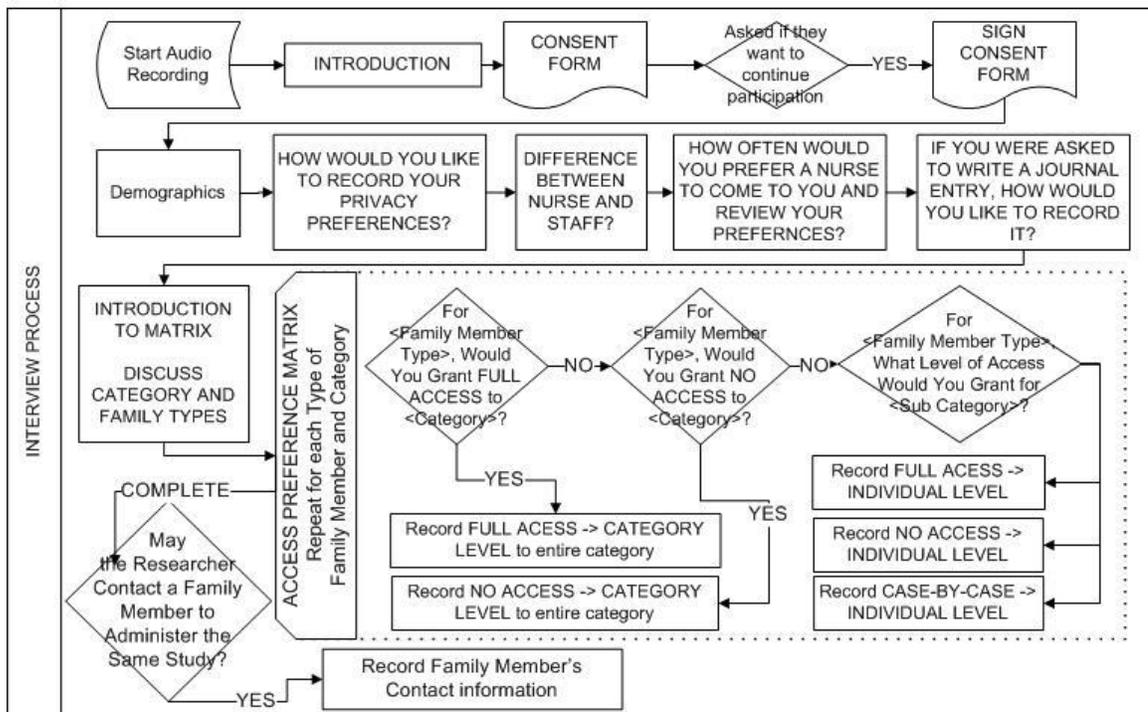
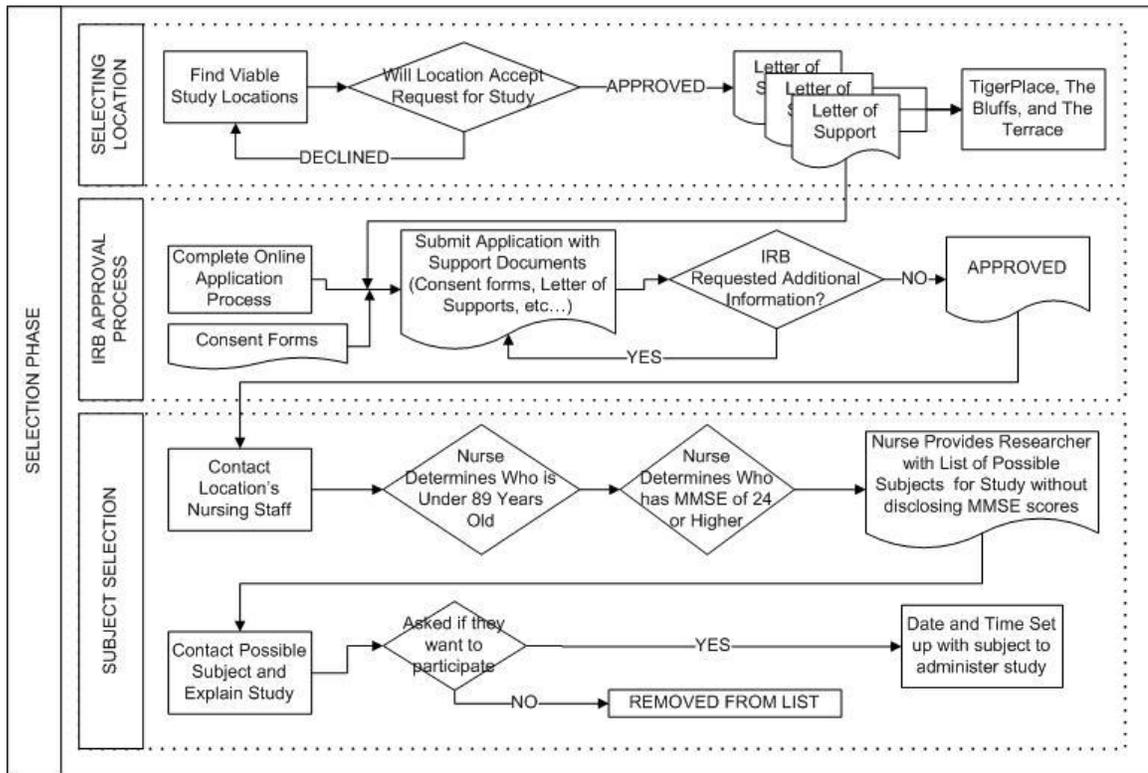
recommendation for a set of default access rights that patient-centered software applications could implement.

## CHAPTER 3

### METHODOLOGY

Given the fact that very little literature exists on the topic, this study was undertaken as an exploratory pilot study with up to 12 residents of two assisted living facilities and up to 12 relatives related to those residents. The design of the study was built on the few predecessors discovered during the literature search. Confidentiality of this study's records, such as participant identifiable information, has been strictly maintained through the University of Missouri Institutional Review Board process which included using coded identifiers that were maintained separately from the participants' identifiable information, which is used for administrative purposes only. In addition, the names of individuals interviewed are not identified on any part of the research, including the final report, presentations, and publications. Figure 1 below shows the overall process from selecting a location to administering the study. The methodology explanation follows that work flow.

Figure 1: Selection Phase and Interview Process



### 3.1 PILOT INTERVIEWS

One individual from Bluff Creek Terrace, who was over 88 years of age, offered him/herself as a practice interview participant, since he/she was curious about the study. This person's responses are not included in the study results, but did help identify and clarify several parts of the data collection script, which can be found in Appendix C. The biggest improvement was in the reduction of the Matrix Introduction section (Figure 1). Originally, the Matrix Introduction included a large discussion about the difference between the last three questions and the section being introduced. Then the original script would confirm that the subject was more comfortable with electronic or paper based activities. Based on that, the researcher would 'frame' the purpose of the matrix. If they are electronic based, then the matrix would mean a 'default' access matrix to be used by a computer. If they were paper based, then it could be used as a 'default' setting for the nurses to use when someone calls or walks into the facility, such as an adolescent grandchild wanting to contact their grandparent. This was removed because it took too long to have to re-explain the 'framing' several times with no satisfactory understanding by the individual.

On the other hand, the other two pilot interviews, which came before the one described above, identified the 'need' for those sections. Without framing the question, one stated "this interview is useless unless I know what it can be used for other than a paper," while the other stated something similar. Given that the primary target were elderly, the decision was made to remove the section since the other pilot interviews were performed on one male and one female who

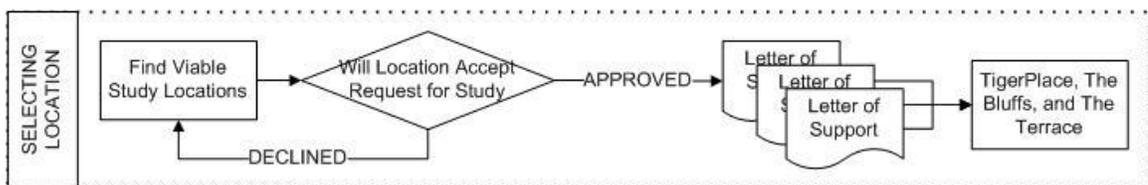
were aged 50-64. This would be the expected age group of children of the residents at the study locations.

During all three pilots, the family categories were a major area of discussion. One outcome was that the original category of “legal guardian” was changed to “power of attorney.” As one pilot participant pointed out, “legal guardian” is often a court-appointed person who can override all preferences of the ward. As he/she put it, "I make the choice" when it comes to power of attorney.

An interesting concept arose during the interviews when discussing adolescents, those who are under the age of 18. That is why two of the pilot interview subjects said that adolescents should not have access to the subject's medical information. One of the pilot subjects explained that access equals burden. The burden of knowing means the burden of having to act on that information. "They cannot make legal decisions so why should they have access to [my] medical" information?

### 3.2 STUDY LOCATION

*Figure 2: Location Selection*



Locations for the study were challenging to identify and secure. The original location selected was Lenoir Retirement Community, which has the full

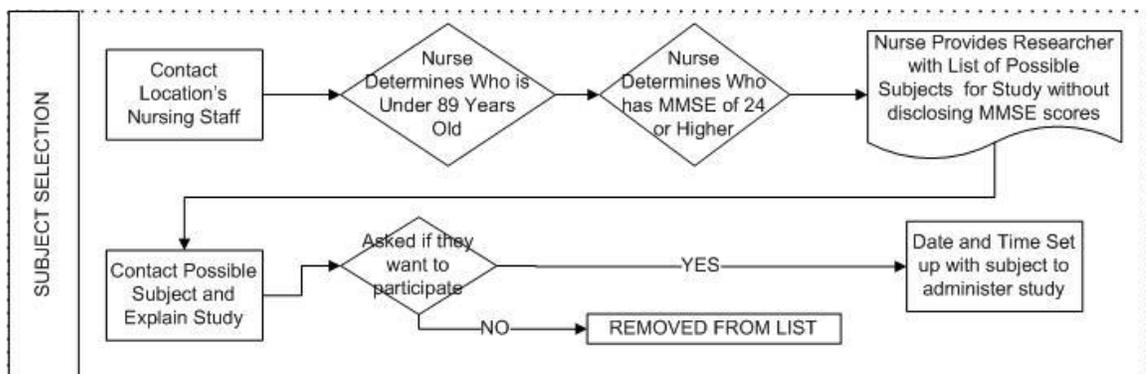
spectrum of care from assisted living facilities to full staffed nursing homes. However, Lenoir could not accommodate my research, due to the number of research projects already being done there. The primary investigator of the TigerPlace sensor study, who was also an expert in long term care, was able to connect me with three assisted living facilities: The Bluffs, Bluff Creek Terrace, and TigerPlace. All three agreed to allow me to recruit from their facilities and supplied letters of support (Figure 2), which were used in the Institutional Review Board (IRB) approval process.

The Bluffs were unable to find anyone who met the inclusion criteria. Most residents were recruited from TigerPlace, because Bluff Creek Terrace only had a few candidates who were under the 89-years-of-age inclusion requirement. The remaining locations were very different in population as well as the number of existing research studies. As mentioned, TigerPlace has a strong technical background, starting in 2004, with the Sensor Study and other technologies, such as electronic medical records, motion sensor networks, video sensor networks, and the web applications to integrate these networks (Alexander, et al., 2008; Center for Eldercare and Rehabilitation Technology," 2010; Demiris, Hensel, et al., 2008; Demiris, Oliver, et al., 2008; Rantz, et al., 2010; Skubic, Alexander, Popescu, Rantz, & Keller, 2009). The Bluff Creek Terrace has very little research technology in progress but this is important diversity to express in the research. Due to this difference of culture, perception of technology could be a major influence on the participants of this study.

### 3.3 CRITERIA

The inclusion criteria for both relatives and residents are: must be between the ages of 18 and 89; and must be able to make decisions for them self. The criteria were approved by the Institutional Review Board (IRB) at University of Missouri. The age was determined by the IRB special protection for anyone under the age of 18 and Health Insurance Portability and Accountability Act (HIPAA) additional requirements for anyone over the age of 89 (NIH, 2010). The age range is wide because the relatives can be of any age. The criteria they requested strict explanation of how to determine that an individual was able to make decisions for themselves (Figure 3). This request was answered by requiring a Mini-Mental State Exam (MMSE) score of each resident be 24 or higher. It also required that the nursing staff verify that the residents meet both criteria and provide the researchers with a list of candidates. The list did not contain the resident's MMSE score and this was done through the nurses in order to protect their HIPAA Personal Health Information (PHI) data.

*Figure 3: Subject Selection*



The interviews were conducted in person with the residents of the two facilities themselves and via telephone with the relatives of the assisted living residents. The relatives were recruited through the residents, who were asked for verbal permission to contact the relative of their choice. The residents were recruited through the facilities' nursing offices. To inform the potential participants, each one was provided with some background of this research study topic, the purpose of the study, and an explanation of how their identity would be protected. If they were interested, then a time was set up to thoroughly inform the subject of the study and administer it. The formal consent form was reviewed with the patient on the day the study was administered because the study is a one-time only meeting and the researcher felt it would be more effective due to the age of the subjects. Upon request, the study would be rescheduled if they wanted time to share the consent form with a relative.

### 3.4 STUDY DESIGN

The study methodology included conducting structured interviews. This style of interviewing allows for an in-depth interview on the topic, while also following a data collection script (Appendix C) similar to a survey. During each question, omitting demographics, each participant was encouraged to share why they answered the way they did. This "and why did you answer that way?" technique pulls out additional qualitative data that enhances the value of this exploratory pilot study.

Structured interview was chosen because of its flexibility. It allows for the open-endedness of an interview but the structure of a survey. The other option considered was focus groups. The main reason focus groups were not used was the nature of privacy. To discuss privacy, the subjects would require privacy. Also, focus groups are conducted using open ended questions that provide a broad and possibly unpredictable results (Krueger, 1994, pp. 17-20).

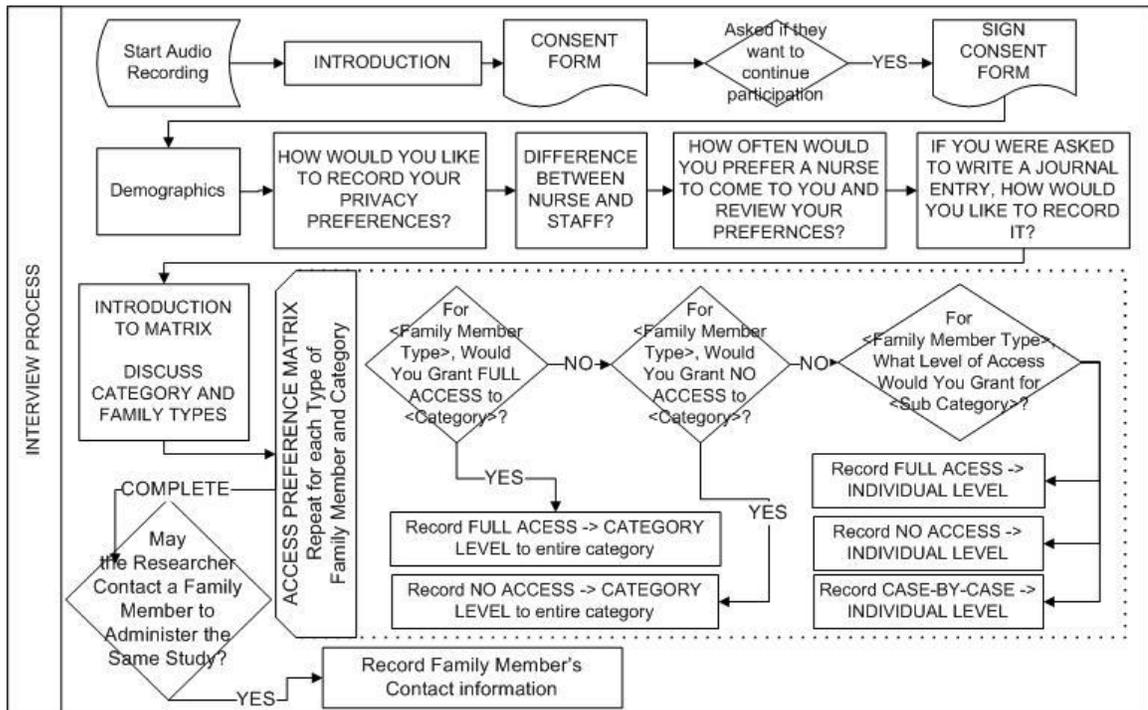
The interviews took approximately 30 minutes to 1 hour, with no known risk to participants, and were read from a data collection script. The script ensured that each interview was consistent and created a standard platform to compare responses. The pilot interviews were effective in identifying key areas of potential confusion. The problem areas identified were either restructured or additional explanation was added to the script. The only potential 'risks' to participants might have been discomfort and/or confusion about questions that could be misunderstood.

Goodwin (2002) discovered that privacy, confidentiality, and security were used interchangeably. Since privacy is defined as the desire to limit disclosure of information, this study restricted its terminology to 'privacy' only (Courtney, 2008; Goodwin, et al., 2002). Besides the possible confusion, the term confidentiality was not used because this study does not discuss the condition under which private information is shared.

### 3.5 INTERVIEW PROCESS

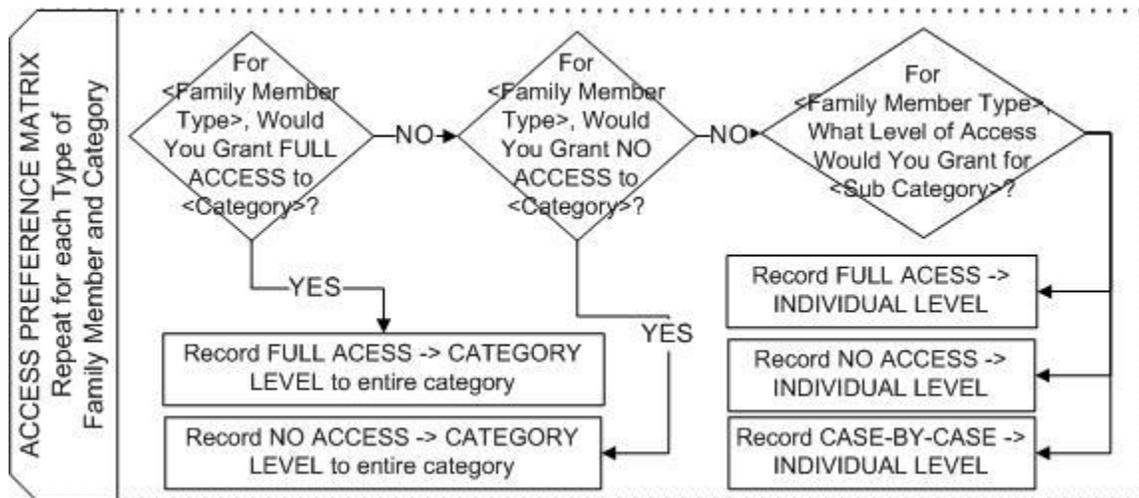
The questionnaire was split into three sections: 1) Demographics, 2) Communicating Preferences and 3) Preference for Family Access to patient health information. A complete list of questions can be found Appendix B. Figure 4 (above) outlines the interview process from beginning to end. There were seven typical demographic questions. There were three 'how to' questions about recording access right preferences. The first 'how to' question had a secondary question, supported by the literature review, exploring if subjects saw a difference nurses and staff members when it comes to medical information (Bolton Research Group, 2000). This was followed by a series of repeating questions that asked about the preference itself per type of family. Each series could be between three and nineteen questions. The response was arranged in a matrix of categories of information on the horizontal and the type of family member on the vertical (Table 3). The categories of information were heavily influenced by Alexander, G., et al. (2008), Morin, D., et al. (2005), and Schers, H., et al. (2003).

Figure 4: Interview Process



The categories are medical, personal profile, and sensitive contact information. Medical information is relatively self explanatory. It consists of medications, illness, treatment plans, and reports about mental health and events such as falls and hospitalizations. The topic of “*Social and Mental Difficulties Such as Memory Problems or Depression*” is a sub-category that concerned the researchers. As such, it was made clear that the research is not asking if they have difficulties, but is asking about the type of information. The personal profile category focuses on the behaviour of the person. In an assisted living facility, the collection of such information, especially social activity, is very important as it can be an indicator of overall health (Alexander, et al., 2008; Demir, Hensel, et al., 2008). The last category is contact information and it is split to investigate if phone number is important enough to separate.

Figure 5: Matrix Work Flow



Due to the number of possible questions that could happen within the matrix (Table 3), the study was divided into the three categories. Figure 5 shows the work flow that is repeated for each category and each family member type. The participants were asked if they would grant full access to the category. If they answer no, then they were asked if they would grant no access to the entire category. If they responded no again, then the researcher would ask what level of access for each sub-category, such as medications or present illnesses. The three access categories are Full Access, Case-by-Case, and No Access. Case-by-Case is a special category that would require the patient or resident to be contacted with each request for information. For example, a sibling calling into the facility asking about their relative's current illness would require a nurse asking the resident if it is ok to discuss their condition with the sibling.

Table 3: Categories of Information and Types of Family Members

	Medication (Current or Previous)	Present illnesses	Past illnesses	Scheduled Appointments	Treatment or Service Plan (While At Hospital)	Discharge Plans (Once You Are Out of Hospital)	Events such as Falls and Hospitalization	Social and Mental Difficulties Such as Memory Problems or Depression	Smoking Habits	Alcohol Usage	Social Activity, such as Travel Habits	Contact Information - Phone #	Home and Other Contact Details
	Medical Information							Personal Profile			Sensitive Contact Info.		
Self													
Spouse													
Former Spouse													
Parent of Resident													
Sibling													
Adult Child													
Adult Grandchild													
Adolescent Grandchild													
Power of Attorney Holder													
Others:													

## CHAPTER 4

### RESULTS

As mentioned before, the number of willing participants was limited due to the age restriction and the small number of available facilities. Between the three locations, only ten residents could be found, none of whom were at The Bluffs. The nursing staff at the Bluffs explained that their population of residents did not meet the inclusion criteria of MMSE score of 24 or higher, so they were not included in the study. Seven residents came from TigerPlace and three were from Bluff Creek Terrace. I observed that the facilities' populations were very different, with TigerPlace having more active/mobile residents who participate in research more often than Bluff Creek Terrace residents. Despite the differences, both populations' responses were very similar.

Residents' response to the request to contact a relative was very similar. Six out of ten residents gave permission for a relative to be contacted. The primary reason residents gave for declining to provide access to a relative was that their relatives were very busy and they did not want them to be disturbed. As subject 1010 explained, "I would not obligate someone else's time." Only two of the relatives responded to the request and participated in an interview, which severely restricts the ability of their results to be generalized to a larger population. A possible third relative was scheduled but the researcher was unable to contact the relative on the agreed upon date. Another relative was finally contacted but would not participant in the study. The primary reason was

that her relative (the resident) had not mentioned the study to her. "I am an attorney and you say you talked to her [my relative] but I will require written proof before I tell you anything." Due to the time constraints of the study, this request was not possible. The last two relatives could not be contacted after several attempts.

When reading the consent form, subject 1009 read the form very closely. A second individual requested additional time to review the consent form with their family member. Sadly this individual was ultimately unable to participate in the study because they had difficulty remembering to discuss the project when their relative visited once a week. Subject 1017 waved his right to be read the consent form because he had just gone through that process the day prior on another study. The average time for the introduction and reading the consent form was 4 minutes and 49 seconds. The average time increases to 5 minutes and 13 seconds when outliers are removed. The average time to administer the entire study was about 25 minutes with one outlier taking 42 minutes to complete.

## 4.1 DEMOGRAPHICS

*Table 4: Categories of Information and Types of Family Members*

Gender	7 Females 5 Males
Age	2 age 50 to 64 1 age 65 to 74 9 age 75 to 89
Race	12 White
Education	5 College 5 Graduate/professional 2 High school
Marital Status	8 Widowed 3 Married 1 Single
Relationship	10 Residents 2 Children of Residents

There were seven female and five male participants. Two of the residents were age 50 to 64, one was between 65 and 74, and the remaining nine were age 75 to 89. This is very close to the national average which states that 74% of assisted living facility residents are female and the average age is 86.9 years old (National Center for Assisted Living, 2010b). Due to the demographic characteristics of both locations, all of the participants were white, non-Hispanic. The study population was rather well educated with two having high school diplomas, five having a college degree (bachelor degree), and five having a graduate or professional degree. Not surprisingly, most were widowed, with one being single/never married and four were currently married. One resident had a spouse with a severe ailment, which all but classified the resident as a widowed person, even though they were categorized as married for this study. The two

participants, who were children of two residents that participated in the study, live in private houses, while the residents live in the assisted living facilities.

## 4.2 HOW TO RECORD PREFERENCE

These questions ask how and how often the participant would like to record their preference for who accesses personal health information. This section took on average 5 minutes with a range of 2 minutes and 20 seconds to 12 minutes and 42 seconds. The upper range was an outlier because subject 1009 had a difficult time understanding the idea of 'how to record'. The subject kept thinking that the researcher was asking if the researcher or someone, such as a nurse, was asking permission to gain access to their medical information. The participant also seemed confused about why the questions were being asked since they "had no secrets to hide and would share with anyone." The second highest time was eight minutes.

### 4.2.1 HOW WOULD YOU RECORD YOUR PRIVACY PREFERENCES?

*Table 5: How Would You Like to Record Your Privacy Preferences?*

2	Fill out your preferences on computer
4	Fill out a paper form and give it to a nurse
6	Verbally instruct a nurse or care provider of your preference

Half stated that they would want to record their preferences by verbally instructing a nurse or care provider of their preferences. Four of the subjects stated they would prefer to fill out a paper form and give it to a nurse. The last two stated they had a preference for computer based recording of their records.

Several subjects had difficulty understanding that this question was about their preferences, not the researcher's, and they were unable to understand what they would be recording. Subject 1004 stated "whatever you need to do your research" and subject 1009 said "anyway you want to record it." For the subjects having difficulties understanding what was being recorded, the researcher had to state "If you had 100 people you wanted to allow access to your medical information, how would you like to record who can see what kind of information?" With this reframing, they were able to answer. Also, one of the relatives was confused between answering with their personal preference or what they think their relative in the facility would prefer. During this section of 3 questions, this participant, subject 1012, would flip between "what I would" and "what my mother would". When this happened, the researcher would confirm that it was their preference and not their perception of their parent's preference.

When reviewing why residents chose their answers, those who stated the preference for verbal instruction gave no explanation other than that it is "my preference". Half of the subjects did state that they were unable to write due to their illnesses. Subject 1013 stated that they would prefer using a computer because there would be "less chance of being lost than paper" and "less chance of misunderstanding than verbal instructions." Several subjects cited the same reason for choosing paper. Subject 1003 stated that paper was "more permanent" than verbal or electronic formats while subject 1010 states that verbal is "subject to interpretation and when you write it down, there is no interpretation." Also, many of the participants discussed that they were

uncomfortable with computers. "Well that's the simplest way, I don't do the computer" explained subject 1007 whom chose to write down their preference.

#### 4.2.1.1 IS THERE A DIFFERENCE BETWEEN NURSE AND STAFF?

Since the literature review pointed out that some patients make a distinction between staff and a medical professional accessing their information. This study included two options to this question to explore the topic more in depth: verbally instruct a nurse/care provider; or verbally instruct a staff member. Bolton Research Group (2000) reported that 68% of their respondents said that office and reception staff should not have access to their medical information. To explore if the same preference would be present for collecting information, the residents were asked if they see a difference between the two types. The researcher of this study assumed that most residents would not see a difference, since all the staff members at the assisted living facility would already be working closely with them.

*Table 6: Is There a Difference Between Nurse and Staff?*

2	No difference
4	Discussed some difference
6	No Response

Half of the respondents had nothing to say on the matter and simply moved on to the next question. Two of the subjects stated that they either didn't see a difference or "it does not matter." The last four did see a difference and the reason centered on occupational responsibilities or the ability of nurses to understand the medical information. Subject 1001 said that nurses are "bound

by legal obligations". "Nurses are subject to confidentiality because of her profession than a staff member here would not be," as subject 1010 explains. They go on to state that "most nurses are bound by HIPAA regulations while staff is not." This could mean that there is a lack of education about patient's rights and the legal requirements of facilities that hold medical data. Subject 1012 stated that they would prefer medical nurses because "they have all the adequate information and can make correlations." "Nurses have a better understanding of your medical [information]", but subject 1017 continued by saying "I have a preference but I would not preclude staff.

#### 4.2.2 HOW OFTEN WOULD YOU PREFER A NURSE TO COME TO YOU AND REVIEW YOUR PREFERENCES?

*Table 7: How Often Would You Like to Review Your Preferences?*

3	Once a Quarter
4	Twice a Year
5	Annually

When asked why they choose that answer, five that stated once a year or twice a year explained that things were not likely to change or would never change. Three subjects stated that it "does not matter" how often they were asked. The two relatives answered that they saw the nurse asking for a review as a reminder that it is an option. This would allow them to be proactively involved in their own privacy.

#### 4.2.2.1 HEALTHY VS UNHEALTHY

Three of the subjects explained that their answer "depends on the condition you're in". All of the subjects were in good health and decided to answer the question in their 'healthy' state. Subject 1017 stated that "if I had a health issue, then as often as needed. Once a month." Subject 1001 explained that "if I became ill and [I] want to limit access to one child only, would that be possible?" They explained that "one has better common sense over the other one" and "I know these things can get complicated," thus one can handle it while the other may not.

#### 4.2.3 IF YOU WERE ASKED TO WRITE A JOURNAL ENTRY

The participants were allowed to choose more than one answer to this question. Half of the subjects only gave one answer with five more choosing two. Only one subject had a lot to say and chose four options. The breakdown of the results can be found in Table 5. One subject stated that they had no time to write and would not write a journal entry. If they were required to do it, they "would do it half heartedly."

*Table 8: Responses for "If You Were Asked to Write a Journal Entry"*

# of responses	Option
3	Write it down and give it to the researcher
4	Type it into the computer
2	Verbally dictate into a recording device
3	Verbally tell a nurse, care provider, or staff member, who records it
3	Verbally tell a researcher, who records it
3	Verbally tell a family member, who, on your behalf, records it

1001 stated that "as long as I am able" I want to write it down, also "by the time you transfer it through too many people, it [the message] can be lost." Subject 1009 stated that their journal would be "boring" but would write it down since they would not "want to have someone else take the time to write it down" for them. As discovered in the previous question, subject 1012 explained that their answer "depends on your health." They would prefer to type it into a computer because "I can do it in my own time frame", but if they were ill, they would "record it verbally into a dictation device." Subject 1017 stated that their choice of typing it into a computer "just makes sense" and they simply "prefer it when they are able to use a computer."

Several subjects explained that they are unable to write well and that was a huge factor in choosing to verbally tell someone or to use a recording device. Common reasons for verbally discussing their day were: "[It] just makes sense to do it [this way instead of doing it] more than once" (subject 1003); "It seems logical to me" (subject 1017); and "It does not really matter" (subject 1011). Subject 1013 choose to discuss with their family because it is a way to "remind or bring to the attention of a health care provider [of my preferences] in case I can't."

#### 4.3 LEVEL OF ACCESS

The level of access is the largest section of the study as it can produce a recommended default access matrix for electronic applications that plan to share information with family members of the patient. Access for use in this study, is

the formal permission granted to an individual or category of people who would like to see or interact with the subject's data. As Figure 4 outlines, this section consisted of the introduction of family types and information groups followed by the repetitive loop (Figure 5) of the matrix (Table 3). After the third pilot interview, the set up section was reduced, because it originally took ten minutes to set up and the amount of new information being introduced made it difficult for the subject to fully understand the content being introduced. After the restructuring, it reduced the set up time to an average of three and a half minutes. It consisted of introducing the types of family members, the discussion of which family members do not apply to the subject, and then introducing the categories of information, see Table 3 for a breakdown of the categories. When a subject showed signs of not understanding something, care was taken to explain the item in more detail. In those cases, subject 1017 said would say "well, let's just try this and we will figure it out as we go along." The hardest part for these individuals was the idea of *choosing* the level of access for different people.

The second half of this section took on average eight minutes with two individuals taking 16 minutes. One of the 16-minute participants had a lot to say, while the other had a great deal of difficulty understanding the questions, but also had a lot to say once they understood it. This individual was hard of hearing, which made it difficult to communicate. The aggregated results can be found in a ten by thirteen matrix in Appendix D. Personal, spouse, adult children, and power of attorney holder access were fairly wide open and granted full access.

Several participants did not have children and/or grandchildren; however, these individuals considered stepchildren or nieces/nephews as their family and substituted them as children. Only one subject chose not to have personal access to their personal profile and contact information. Subject 1009 states "I already lived it" and "it's unnecessary to have access to it." Another subject, 1001, discussed that the reason they want access to their personal medical information is to ask the "Now, why did that happen" question because "I would like to understand it, I was a nurse." They continued by stating "can I do anything about it is the real question... [you] can't act like it's not there if it displeases you."

Given that most of the participants are widowed, the researchers asked if they would like to answer the family type of spouse as they would if their partner was still with them. Only three subjects declined to answer because it either brought up memories or they felt it was not important. Only one subject had a former spouse and they choose not to discuss the category. All but two subjects responded to personal, spouse, and children access questions as "I am an open book" or "I have nothing to hide." This openness also extended from the children to their parents. No resident answered the questions about parents but the children granted full access rights to their parents. "Sometimes it is as useful for an adult to also know the medical information of the child as it is useful for the child to know about their parent", explained subject 1013.

The most striking variation of responses can be found in the categories of adult and adolescent (less than 18 years of age) grandchildren or great grandchildren. For those participants that these categories apply to, they were

willing to share their personal profile and contact information. The only exception is the two subjects who would not grant access to their personal profiles for individuals under 18 because "I don't think they would be interested." The access rights to medical information for adult grandchildren were full access with only one subject being the exception by granting a case by case access. Subject 1017 explained that they would be willing to allow access to current illness information but not "the whole medical history." This built upon their explanation of case-by-case access to siblings. "If I had a medical illness, then I would want to share it, otherwise they do not need to know it." The responses shifted when discussing adolescent grandchildren.

As discovered during the pilot interviews, many of the subjects would agree that adolescents "are too young and they don't need to know", as subject 1003 discussed. Only two participants stated that they would grant full access to their medical information. Subject 1006 explained "at my age they will not be able to participate so sure [they can have access]." Another subject said that when it comes to adolescents, as well as adult grandchildren, if there is "a need to know, I would grant that." An interesting conversation developed with subject 1001, who was concerned with "can they deny me anything that I want?" Also, "I don't think they should be able to cancel any of my appointments. Can they?" This concern about "access" equalling "right to act" was first identified during the pilot interviews. Despite the clear explanation during the introduction component of the study, this participant was very concerned about this issue. Subject 1013 however stated they had "very little concern about family having full access to my

information. My concern would be insurance companies gaining access to my medical information." This concern is aligned with what was discovered during the literature review which states that patients are concerned about the insurance companies or employers gaining unauthorized access to their medical records (Chhanabhai & Holt, 2007; Garcia-Sanchez, 2008; Willison, et al., 2003).

## CHAPTER 5

### DISCUSSION

The main goal of this study was to explore the concept of family access preferences at assisted living facilities. As identified in one of the pilot interviews and mentioned by several subjects, many participants viewed access to patient health information as the right to act on the information. This is an important detail which might erode the independent living of residents at assisted living facilities. It was clear that most of the residents had healthy family lives, which reflected an "open book" family access preference. The "open book" view is different than what Carlisle (2006) found among adolescent subjects. The young people prefer to limit access as it is a sign of their developing maturity. Subject 1010 explained what they counted family as: "members of my family does not mean cousins and so forth. It is my immediate family. So that would mean my siblings and my children and grandchildren." However, despite the healthy family life, once they become ill, such as a major change in their ability to live independently, three participants expressed a desire to change their access rights preferences. It might be worthwhile to explore this in more depth in future studies.

Another major finding, but not a surprising one, is that most elderly participants preferred to verbally discuss their preferences. Part of this stronger preference is due to the physical inability to write. When the resident is well educated, thus understand the legal system, or when the resident becomes ill

enough, they prefer paper-based records instead of verbal instruction. This is because paper does not require interpretation. Relatives on the other hand are more inclined to work with a computer. One reason may be comfort level while another reason might be the busy lifestyle (compared to residents) and computers are more convenient. Given the small number of relatives and the education level of the relatives, it is difficult to generalize these statements.

An interesting discussion point is that the participants saw a difference between staff members and medical professionals. This is in line with previous studies, such as Bolton Research Group (2000). However, in the assisted living facility environment, this difference is not enough to restrict residents to working exclusively with medical professionals. Some participants, such as subject 1001, discussed staff members as the legal side of the institution while nurses were the medical.

Despite the limitation of the study, several opportunities were identified for the facilities involved, as well as perhaps all assisted-living facilities. Residents of these facilities understand that access to their medical information is restricted, but the idea of personally controlling that access is not well known. This means that educating the residents and their relatives about their privacy rights can lead to better informed and engaged members of the facility. TigerPlace is unique in this sense, because they are already highly active in research projects and this means greater opportunity to teach.

However, it appears that the regulations, such as HIPAA, are not well understood by residents. An education program to introduce and explore privacy

rights and privacy regulations would benefit the organizations. This benefit could increase trust in the facility by both residents (who already have a high level of trust) as well as their relatives. Also, this activity would be in line with several federal programs being launched. On March 29th 2010, the Department of Health and Human Services announced a \$26 million dollar grant to a public relations firm to educate the public about their privacy and security rights (Mosquera, 2010). While this research study does not include security, it is right in line with the privacy aspect of the grant.

In addition to education, assisted living facilities should review their policies about privacy. If they have not already done so, they should review their HIPAA related policies to reflect recent changes. The more important policies that should be enacted are those that require mandatory evaluation of access rights. These rights should be reviewed once a year, at least, with a clause that reduces the period between reviews to every three months when the patient is seriously ill. Besides having an up-to-date access list, this activity would re-enforce that the facility takes privacy seriously, remind the residents that they have the right to their information, and allow the nursing staff to interact with the resident, thus possibly discovering a change in condition.

The suggested next step would be a similar study that explores the resident's perception of the different terms of privacy, confidentiality, security, and trust. What do these terms mean to the subjects as well as how do they perceive their importance when determining the level of access to their family members? As previously identified, privacy is extremely important to

establishing and maintaining trust. Can the same be stated for confidentiality or security?

## 5.1 LIMITATIONS

This exploratory study is small but the responses were consistent among all the participants. The small number was a major limitation as well as the age restriction and the limited number of acceptable locations. For example, one location had no more than 20 residents with only three of them meeting the qualification criteria. This location is unusually small given that the average facility has 54 units (National Center for Assisted Living, 2010a). Also, the low acceptance rate for relatives of the residents who participated is a major consideration.

Any future studies would require a substantially larger number of residents and locations, as well as possible inclusion criteria of mandatory relative participation. An increased number of locations would also capture a more ethnically diverse perspective and educational background, because this study included only White, non-Hispanic participants and an overall well educated subject population. Another limitation is that the concept of what is privacy, confidentiality, security, trust, and HIPAA could not be explored.

A major limitation of the study tool (Appendix B) was the introduction of the matrix. This introduction discussed the categories of information and the different types of family members. The limitation was the way the topics were introduced and the participants wanting to know the point of the introduction. To

adapt and answer their questions, the researcher would give an example of the process (Figure 5). This was not very successful since they would often answer the example.

## 5.2 RECOMMENDATIONS

This small study presents several key recommendations that can be used regardless of its implementation, electronic or policy based. The most important recommendation is to ask the patient about their preferences, thus they should be involved with taking care of their own privacy. If they are not actively involved then they may assign full access to family and assume that that access is the right to act on the information. The next recommendation would be that these preferences should be reviewed by the patient with a nurse at least once a year if the patient is healthy and every three months if they are ill. Revisiting the preferences is important for the elderly since their condition can change rapidly, but this is also important for the younger population.

The last set of recommendations are default access levels for different types of family members. These should be used as a starting point to get the patient involved with their own privacy and not as *the* access levels. Also, these default levels do not reflect the preference towards specific family members. For example, the older child should have access but the younger one should not because of family tensions.

The patient themselves, their spouse, and power of attorneys should have full access to all information since these are the individuals that will make most of

the medical decisions. Adult children and grandchildren should have full access to the patient's information because they are often strongly involved with the patient's major decisions. Most of the time, the power of attorney holders are the children themselves. For the residents who had no family, they treated nieces and nephews in the same way they would their children. Siblings and adolescent family members should have case-by-case access. Adolescents should have restricted access because they may not have the maturity to understand the information and they would not legally be allowed to act on behalf of the patient. Siblings should have restricted access because of the wide variation of family relations.

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# APPENDIX

## APPENDIX A: LITERATURE REVIEW DATABASE QUERIES

*Table 9: CINAHL 2002-2009  
Accessed July 16th 2009*

1	(MH "Privacy and Confidentiality+") OR (MH "Access to Information+")
2	(MH "Medical Informatics") OR (MH "Health Informatics") OR (MH "Computerized Patient Record") OR (MH "Patient Record Systems+")
3	(MH "Patient Attitudes") OR (MH "Attitude to Health+") OR (MH "Attitude to Computers") OR (MH "Health Knowledge")
4	1 AND 2 AND 3
5	limit 4 to English language AND yr between 2002 AND 2009

*Table 10: Ovid Ei COMPLENDEX\*PLUS 1980 to June 2009  
Accessed July 16th 2009*

1	Information dissemination/ OR Data privacy/
2	Health Care/
3	patient.mp
4	1 AND 2 AND 3
5	Limit 4 to yr="1995-2009"
6	Limit 5 to English language

*Table 11: Ovid MEDLINE 1950 to Present  
Accessed July 16th 2009*

1	exp Access to Information/ OR exp Confidentiality/
2	exp Attitude to Computers/ OR exp Attitude/ OR exp Health Knowledge, Attitudes, Practice/
3	exp Patient Acceptance of Health Care/
4	exp Medical Records Systems, Computerized/ OR exp Informatics/ OR exp Medical Informatics/
5	1 AND 2 AND 3 AND 4
6	limit 5 to (English language and yr="1995 - 2009")

*Table 12: Ovid PSYCINFO 1987 to July Week 4, 2009  
Accessed July 29th 2009*

1	exp privacy/ OR exp secrecy/ OR exp privileged communication/ OR exp anonymity/
2	exp preferences/ OR exp Health Knowledge/ OR exp attitudes/ OR exp computer attitudes/ or exp health attitudes/
3	exp medical records/ OR exp client records/ OR exp patient history/
4	1 AND 2 AND 3
5	limit 4 to (abstracts and yr="1995 - 2009")

*Table 13: SCOPUS  
Accessed July 26<sup>th</sup> 2009*

1	(confidential* OR priv*) AND
2	(attitude* OR health knowledge*) AND
3	(patient accept* OR patient prefer* OR patient attitude* OR patient view*) AND
4	(medical record* OR informatics OR medical informatics OR electronic medical record* OR emr* OR ehr* OR phr* OR electronic health record* OR personal health record* ) AND
5	(LIMIT-TO(PUBYEAR, 2009) OR LIMIT-TO(PUBYEAR, 2008) OR LIMIT-TO(PUBYEAR, 2007) OR LIMIT-TO(PUBYEAR, 2006) OR LIMIT-TO(PUBYEAR, 2005) OR LIMIT-TO(PUBYEAR, 2004) OR LIMIT-TO(PUBYEAR, 2003) OR LIMIT-TO(PUBYEAR, 2002) OR LIMIT-TO(PUBYEAR, 2001) OR LIMIT-TO(PUBYEAR, 2000) OR LIMIT-TO(PUBYEAR, 1999) OR LIMIT-TO(PUBYEAR, 1998) OR LIMIT-TO(PUBYEAR, 1997) OR LIMIT-TO(PUBYEAR, 1996) OR LIMIT-TO(PUBYEAR, 1995)) AND
6	(LIMIT-TO(LANGUAGE, "English")) AND
7	(LIMIT-TO(DOCTYPE, "ar"))

## APPENDIX B: STUDY QUESTIONS

### Demographics

Sex: Male  
Female

Age Group: 18-29  
30-49  
50-64  
65 - 74  
75 =<

Which of the following  
best describes you?

White, Not Hispanic  
Black, Not Hispanic  
Hispanic  
Asian/Pacific Islander  
Alaskan Native or Native  
American, Not Hispanic  
Other  
Please Specify: \_\_\_\_\_

Education

Less than high school  
High school  
College  
Graduate or Professional Degree

Marital Status

Single  
Married  
Divorced/Separated  
Widowed

Housing Type

Cottage  
Apartment  
Assisted Living Facility  
Nursing Home  
House  
Other  
Please Specify: \_\_\_\_\_

Relationship to the  
Resident

Self (I am the resident)  
Spouse  
Former Spouse  
Power of Attorney  
Parent of Resident

Sibling  
Adult Child  
Adult Grandchild  
Friend  
Other  
Please Specify: \_\_\_\_\_

How would you prefer to record your privacy preferences:

Mark only

one (1)

Fill out a paper form and give it to a nurse  
Fill out your preferences on computer  
Verbally instruct a nurse or care provider of your preference  
Verbally instruct a staff (such as secretary) of your preference  
Other  
Please Specify: \_\_\_\_\_

How often would you prefer a nurse to come to you and review your preferences?

Mark only

one (1)

Once a Month  
Once a Quarter  
Bi-annually  
Annually

If you were asked to write a short journal entry about your day to be used by researchers, how would you prefer to record it:

Mark all that  
apply

Write it down and give it to the researcher  
Type it into the computer  
Verbally dictate into a recording device  
Verbally tell a nurse, care provider, or staff member, who records it  
Verbally tell a researcher, who records it  
Verbally tell a family member, who, on your behalf, records it  
Other  
Please Specify: \_\_\_\_\_

Preferred Access Per Category of Data or Type of Data and Relationship to Resident

	Medication (Current or Previous)	Present illnesses	Past illnesses	Scheduled Appointments	Treatment or Service Plan (While At Hospital)	Discharge Plans (Once You Are Out of Hospital)	Events such as Falls and Hospitalization	Social and Mental Difficulties Such as Memory Problems or Depression	Smoking Habits	Alcohol Usage	Social Activity, such as Travel Habits	Contact Information - Phone #	Home and Other Contact Details
	Medical Information							Personal Profile		Sensitive Contact Info.			
Self													
Spouse													
Former Spouse													
Parent of Resident													
Sibling													
Adult Child													
Adult Grandchild													
Adolescent Grandchild													
Power of Attorney Holder													
Others: _____ _____													

## APPENDIX C: DATA COLLECTION SCRIPT

Hello, *<state name>*. You agreed to meet with me to participate in an interview. This will take no longer than 1 hour. Upon the 1 hour mark, we will conclude the question being discussed and end the interview. To help me transcribe your answers for use in my thesis, I will record our conversation using a recording device. Before we start, I have a few things to discuss with you. This study asks about the level of access and not who can act on the information granted to them. The 1 hour starts now.

*<Review the consent form>*

Remember, you can choose to not be part of the study at any time, including once we are done. If you chose to do so, there is no penalty in any way to you and your answers will be removed from my records. Would you like to participate?

*<Sign documents>*

This study is split into 3 sections: Demographics, the who you are; How to record your preferences of who can see what; and the last section is about the level of access you prefer to give specific categories of relatives.

---

You are a *<Male or Female>*.

How old are you? *<Record age group>*

Which of the following best describes you?

- White, not Hispanic
- Black, not Hispanic
- Hispanic
- Asian/pacific islander
- Alaskan native or native American, not Hispanic
- Other, please specify

What is your highest degree?

- Less than high school,
- high school,
- college,
- graduate or professional degree. *<if asked, a professional degree is one that prepares the student for a specific profession. Such professions require license or other regulation to enter.>*

What is your marital status: single, married, divorced or separated, widowed.

What kind of home do you live in?

- Cottage
- Apartment
- Assisted living facility
- Nursing home
- House
- Other, please specify

*<If interviewee is a resident, record 'self' for the relationship to resident question and continue to the next section.>*

*<else>*

What is your relationship to the resident *<name>*? The choices are: spouse, former spouse, power of attorney holder, parent of resident, sibling, adult child, adult grandchild, friend, other (please specify).

*</else>*

That concluded the demographic section. Any questions? Would you like to continue?

---

These questions ask how and how often you would like to record your preference for who accesses what kind of information.

How would you like to record your privacy preference? Please choose only one of the following:

- Fill out a paper form and give it to the nurse
- Fill out your preferences on computer
- Verbally instruct a nurse or care provider of your preference. <if asked, a care provider is a doctor or similar>
- Verbally instruct a staff (such as the secretary) of your preference

How often would you prefer a nurse to come to you and review your preferences? You would be able to review your preference at any time. This question is asking about a nurse or staff member coming to you to review your preferences. Please choose only one of the following:

- Once a month
- Once a Quarter (about every 3 months)
- Bi-annually (twice a year)
- Annually

If you were asked to write a short journal entry about your day to be used by researchers, how would you prefer to record it? Choose all that apply:

- Write it down and give it to the researcher or nurse
- Type it into a computer
- Verbally dictate into a record device (such as the one I have here)
- Verbally tell a nurse, care provider, or staff member, who records it
- Verbally tell a researcher, who records it
- Verbally tell a family member, who, on your behalf, records it
- Other, please specify

This concludes this section. Do you have any questions? Would you like to continue?

---

*<if resident, hand individual 2 sheets, one with types of family and other with types of information>*

Some of these questions may be uncomfortable and you may withdraw from the study at any time or choose to not answer that specific question. The types of information do not ask you if you have it. It asks about the general category, which may or may not pertain to you.

I just gave you two pieces of papers *<if on phone, just explain>*. There are 9 types of family. If a type does not pertain to you but you would like to answer anyway, feel free. The types are: yourself, spouse, former spouse, parent of resident, sibling, adult child, adult grandchild, adolescent grandchild (under the age of 18), and power of attorney holder (the person you choose to make decisions on your behalf if you are unable to do so). If you have a type that I did not state, you can add one to the list. The types of information are divided into 3 categories. Your medical information. Your personal profile, which focuses on habits. And your sensitive contact information. Questions? Would you like to review the individual types of information within one or all of the categories? *</if>*

This was a lot up front. The following questions are structured to make it easier to understand. Do you have questions?

---

*<Loop through each category of information starting with Medical Information>*

---

Would you like your *<family member type>* to have full access to your medical information?

*<if no>* Would you like your *<family member type>* to have no access to your medical information?

*<if no>* The options are: full access, case-by-case access, or no access.

- Access to your medical information?
  - Present Illnesses?
  - Past Illnesses?
  - Scheduled Appointments?
  - Treatment or Service Plans (while you are at the hospital)?
  - Discharge Plans (Once you are out of the hospital)?
  - Events such as falls or hospitalization?
  - Social and mental problems, such as memory Problems or Depression?  
Remember this is the category, not asking you if you have these conditions.
- 

Would you like your *<family member type>* to have full access to your Personal profile?

*<if no>* would you like your *<family member type>* to have no access to your personal profile?

*<if no>* The options are: full access, case-by-case access, or no access.

- Smoking habits?
  - Alcohol usage?
  - Activity, such as travel habits?
-

Would you like your *<family member type>* to have full access to your sensitive contact information?

*<if no>* Would you like your *<family member type>* to have access to your sensitive contact information?

*<if no>* the options are: full access, access only after you give the ok, no access at all.

- Phone Number
  - Home and other contact information (such as address)
- 
- 

Thank you for taking the time to do this interview. Do you have any questions? Would you like to withdraw your participate from the study?

*<if resident, then>* I would like to interview one of your relatives with the same survey we just finished. This is completely volunteer and you do not have to allow me to do so. *<if yes>* Thank you, who would you like for me to contact? Their phone number? *</if>* *<if no>* Thank you for considering the option. This has no ill effects on your participation*</if>* *</if>*

*<if resident>*Thank you and this copy of the consent form is for you to keep. My copy will be kept secure in my advisors locked cabinet. *</if>*

*<if relative>* Thank you for your participation. A copy of your verbal agreement was record in a form of a waiver of documentation consent form and will be kept secure in my advisor's locked cabinet.*</if>*

## APPENDIX D: AGGREGATED RESULTS OF ACCESS MATRIX

**TABLE 10: Results Matrix**

	Medication (Current or Previous)	Present illnesses	Past illnesses
<b>Medical Information</b>			
Self	12 Full Access-Category Level	12 Full Access-Category Level	12 Full Access-Category Level
Spouse	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss
Former Spouse	1 Choose Not to Discuss	1 Choose Not to Discuss	1 Choose Not to Discuss
Parent of Resident	2 Full Access-Category Level	2 Full Access-Category Level	2 Full Access-Category Level
Sibling	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss
Adult Child	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable
Adult Grandchild	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss
Adolescent Grandchild	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss
Power of Attorney Holder	12 Full Access-Category Level	12 Full Access-Category Level	12 Full Access-Category Level
Others: <u>Niece &amp; Nephews, Step Children</u>	3 Full Access-Category Level	3 Full Access-Category Level	3 Full Access-Category Level

**TABLE 10: Results Matrix(Continued)**

	Scheduled Appointments	Treatment or Service Plan	Discharge Plans
<b>Medical Information</b>			
Self	12 Full Access-Category Level	12 Full Access-Category Level	12 Full Access-Category Level
Spouse	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss
Former Spouse	1 Choose Not to Discuss	1 Choose Not to Discuss	1 Choose Not to Discuss
Parent of Resident	2 Full Access-Category Level	2 Full Access-Category Level	2 Full Access-Category Level
Sibling	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss
Adult Child	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable
Adult Grandchild	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss
Adolescent Grandchild	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss
Power of Attorney Holder	12 Full Access-Category Level	12 Full Access-Category Level	12 Full Access-Category Level
Others: <u>Niece &amp; Nephews, Step</u>	3 Full Access-Category Level	3 Full Access-Category Level	3 Full Access-Category Level

<u>Children</u>			
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**TABLE 10: Results Matrix (Continued)**

	Events such as Falls and Hospitalization	Social and Mental Difficulties Such as Memory Problems or Depression
<b>Medical Information</b>		
Self	12 Full Access-Category Level	12 Full Access-Category Level
Spouse	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss
Former Spouse	1 Choose Not to Discuss	1 Choose Not to Discuss
Parent of Resident	2 Full Access-Category Level	2 Full Access-Category Level
Sibling	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss	3 Full Access-Category Level 2 Case-by-case Access-Individual Level 3 NO Access-Category Level 3 Not Applicable 1 Choose Not to Discuss
Adult Child	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable	9 Full Access-Category Level 1 NO Access-Category Level 2 Not Applicable
Adult Grandchild	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss	5 Full Access-Category Level 1 Case-by-case Access-Individual Level 5 Not Applicable 1 Choose Not to Discuss
Adolescent Grandchild	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	2 Full Access-Category Level 1 Full Access - Individual Level 1 Case-by-case Access - Individual Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss
Power of Attorney Holder	12 Full Access-Category Level	12 Full Access-Category Level
Others: <u>Niece &amp; Nephews, Step Children</u>	3 Full Access-Category Level	3 Full Access-Category Level

TABLE 10: Results Matrix(Continued)

	Smoking Habits	Alcohol Usage	Social Activity, such as Travel Habits
<b>Personal Profile</b>			
Self	11 Full Access- Category Level 1 NO Access - Category Level	11 Full Access- Category Level 1 NO Access - Category Level	11 Full Access- Category Level 1 NO Access - Category Level
Spouse	8 Full Access- Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access- Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access- Category Level 2 Not Applicable 3 Choose Not to Discuss
Former Spouse	1 Choose Not to Discuss	1 Choose Not to Discuss	1 Choose Not to Discuss
Parent of Resident	2 Full Access- Category Level	2 Full Access- Category Level	2 Full Access- Category Level
Sibling	7 Full Access- Category Level 1 Case-by-case Access- Individual Level 3 Not Applicable 1 Choose Not to Discuss	7 Full Access- Category Level 1 Case-by-case Access- Individual Level 3 Not Applicable 1 Choose Not to Discuss	7 Full Access- Category Level 1 Case-by-case Access- Individual Level 3 Not Applicable 1 Choose Not to Discuss
Adult Child	10 Full Access- Category Level 2 Not Applicable	10 Full Access- Category Level 2 Not Applicable	10 Full Access- Category Level 2 Not Applicable
Adult Grandchild	6 Full Access- Category Level 5 Not Applicable 1 Choose Not to Discuss	6 Full Access- Category Level 5 Not Applicable 1 Choose Not to Discuss	6 Full Access- Category Level 5 Not Applicable 1 Choose Not to Discuss
Adolescent Grandchild	4 Full Access- Category Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	4 Full Access- Category Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss	4 Full Access- Category Level 2 NO Access - Category Level 5 Not Applicable 1 Choose Not to Discuss
Power of Attorney Holder	11 Full Access- Category Level 1 NO Access - Category Level	11 Full Access- Category Level 1 NO Access - Category Level	11 Full Access- Category Level 1 NO Access - Category Level
Others: <u>Niece &amp; Nephews, Step Children</u>	3 Full Access- Category Level	3 Full Access- Category Level	3 Full Access- Category Level

**TABLE 10: Results Matrix (Continued)**

	Contact Information - Phone #	Home and Other Contact Details
<b>Sensitive Contact Information</b>		
Self	11 Full Access-Category Level 1 NO Access - Category Level	11 Full Access-Category Level 1 NO Access - Category Level
Spouse	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss	8 Full Access-Category Level 2 Not Applicable 3 Choose Not to Discuss
Former Spouse	1 Choose Not to Discuss	1 Choose Not to Discuss
Parent of Resident	2 Full Access-Category Level	2 Full Access-Category Level
Sibling	7 Full Access-Category Level 1 Case-by-case Access-Individual Level 3 Not Applicable 1 Choose Not to Discuss	7 Full Access-Category Level 1 Case-by-case Access-Individual Level 3 Not Applicable 1 Choose Not to Discuss
Adult Child	10 Full Access-Category Level 2 Not Applicable	10 Full Access-Category Level 2 Not Applicable
Adult Grandchild	6 Full Access-Category Level 5 Not Applicable 1 Choose Not to Discuss	6 Full Access-Category Level 5 Not Applicable 1 Choose Not to Discuss
Adolescent Grandchild	6 Full Access-Category Level 5 Not Applicable 1 Choose Not to Discuss	6 Full Access-Category Level 5 Not Applicable 1 Choose Not to Discuss
Power of Attorney Holder	11 Full Access-Category Level 1 NO Access - Category Level	11 Full Access-Category Level 1 NO Access - Category Level
Others: <u>Niece &amp; Nephews, Step Children</u>	3 Full Access-Category Level	3 Full Access-Category Level