Differences in Motivational Factors that Influence Participation in Research Studies

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Chapter 1:

Introduction

The United States ranks number one in the world when it comes to the amount of money that is spent on healthcare every year (Squires, 2011). However, the United States ranks last among developed nations for access to healthcare services and the quality of those services that are provided (Squires, 2011). As a consequence, there are many conditions, such as Type II Diabetes, high blood pressure, and infant mortality that are becoming more widespread. In response, researchers/physicians began discovering ways to address these issues. The Primary Care Research Center (PCRC) was developed to address some of these conditions and other primary care/public health issues that are prevalent in North Texas. The PCRC addresses these issues by implementing innovative research and collaborating with many of its partners, such as the University of North Texas Health Science Center (UNTHSC), Cook Children's Healthcare System, John Peter Smith Hospital System and many private primary care practices in the Dallas Fort Worth (DFW) area.

Dr. Kimberly Fulda, Assistant Professor in the Department of Family Medicine and the Associate Director of the Primary Care Research Center, served as the major professor for my practicum project. This study, entitled "Differences in Motivational Factors that Influence Participation in Research Studies" was conducted by surveying subjects from the community, various clinics and UNTHSC employees.

The aim of this study was to discover what factors motivate people to participate in research and enroll their children as subjects in research studies. More importantly, the

secondary aim of the study was to discover if these motivational factors differ by the parent's level of education, occupation, gender and race/ethnicity.

By determining what motivates people to participate in research and what motivates them to enroll their children in research studies, recruitment can become more effective. Additionally, increasing the number of people in research studies can also help close the health disparity gap by allowing the group of people in the greatest need to receive healthcare services.

I served as the student investigator on the study and was responsible for the following activities: developing the study, creating the research proposal and protocol, creating all study documents, obtaining IRB approval for the protocol and study documents, recruiting subjects, and conducting data entry and analysis.

Chapter 2:

Background and Literature Review

Whether it is a clinical trial to test the efficacy of a new drug, treatments for cancer or studies to examine risk factors for diseases, clinical research is an important resource for the medical profession. It allows treatments and other items to be tested in a small group so conclusions can be drawn about what would work in larger populations. In addition to treatments and drugs, research methods can be studied as well. As more is learned from these research studies, better research techniques can be utilized for subjects and more efficient treatments can be developed for a wide variety of diseases and conditions.

The major issue with clinical research, however, is low recruitment and retention rates, especially in pediatric studies (Rothmier, Lasley & Shapiro, 2003). There are many barriers present that hinder recruitment of potential research subjects. It is important for these barriers to be identified so that they may be overcome when researchers are recruiting subjects. One of the barriers is the lack of trust people have for physicians and researchers (Mills et al., 2006). Many people feel as though researchers "hide" information from research subjects or keep them from receiving treatments that may improve their conditions. This is a prevalent belief in minority populations, especially African Americans (Mills et al., 2006). Past experiences like the Tuskegee Syphilis Experiment have only enhanced the distrust some people have for researchers and physicians (Wendler, 2005). Some studies require extensive travel, (Mills et al., 2006) which might also limit participation in a study or keep certain groups (low income or minorities) from participating in research studies. Other barriers might include the following: complex study designs, risks associated with some studies, potential side effects of study drugs and negative attitudes toward research (Mills et al., 2006). Researchers must find ways to overcome these barriers in order to increase recruitment in clinical research studies.

In addition to barriers that must be addressed, it is important for researchers to evaluate what factors motivate people to participate in research. There is literature that discusses what motivates adults to participate in research, which include the following reasons: helping future patients and being contributors to scientific knowledge, getting medical treatment they could not otherwise afford or obtain, and finding out more about their health (Rothmier, Lasley & Shapiro, 2003).

Less is known regarding the reasons why a parent would agree to allow their child to enroll as a subject in a clinical research study. For many years, investigators were not permitted to use children as research subjects due to ethical issues and concerns regarding this vulnerable group (Wolthers, 2006). In order to address some of the disorders that are on the rise in children (diabetes, obesity, etc) and diseases that predominantly affect children, it is important to enroll minors in research studies. In order for that to be possible, researchers must understand what motivates parents to enroll their children in research. Many of the motivations identified in adults may also apply in pediatric studies. Parents may want to help other children or learn more about their child's condition if they suffer from some type of chronic disease (Harris et al., 2012). Participating in studies may also provide their child with a medical treatment they would not be able to obtain or afford (Fisher, McKevitt & Boaz, 2011). As more is discovered about what motivates parents to enroll their children in research, recruitment strategies can be tailored to address these motivations.

In addition to researchers identifying barriers and motivational factors that prevent or influence participation in research, they must also be able to know the role that education, gender, race/ethnicity and occupation play in a person's decision to participate in research or allow their children to participate in research. Although these variables have been studied independently, no studies were identified that examined all of these variables at one time or that demonstrated how a subject's motivation to participate may vary by some combination of these factors.

Specific Aims

Clinical research is used to learn about new disorders as well as for the implementation of new drugs, devices and treatments. However, the information that is learned is limited when the number of people enrolled in the study is low. There is literature addressing reasons why adults consent to participate in research (Almeida et. Al, 2007). Studies discuss how research participation differs between gender, race/ethnicity and education level individually (Mills et. Al, 2006). However, there is not information on the role gender, race/ethnicity and education play in what motivates people to participate in research. Nor is there information on how occupation relates to these motivational factors. Additionally, there is not an extensive amount of information on what motivates parents to enroll their children as subjects in clinical research studies.

This study was set up to answer the following specific aims:

Specific Aim#1: To determine what motivational factors influence a person's decision to participate in research studies.

Hypothesis 1.1: Factors that motivate people to participate in research will differ by education level.

Hypothesis 1.2: Factors that motivate people to participate in research will differ between individuals with healthcare-related occupations and individuals with non-healthcare-related occupations.

Hypothesis 1.3: Factors that motivate people to participate in research will differ by gender.

Hypothesis 1.4: Factors that motivate people to participate in research will differ by race/ethnicity.

Specific Aim #2: **To determine what motivational factors influence a person's decision to enroll their children in research studies.**

Hypothesis 2.1: Factors that motivate people to enroll their children in research studies will differ by the parent's education level.

Hypothesis 2.2: Factors that motivate people to enroll their children in research studies will differ between individuals with healthcare-related occupations and individuals with non-healthcare-related occupations.

Hypothesis 2.3: Factors that motivate people to enroll their children in research studies will differ by gender.

Hypothesis 2.4: Factors that motivate people to enroll their children in research will differ by race/ethnicity.

Specific Aim #3: To determine if there are differences between what motivates a person to participate in research from what motivates them to allow their child to participate in research.

Hypothesis 3.1: The factors that motivate people to participate in research will be different from the factors that motivate people to enroll their children in research.

Significance

The low recruitment and retention rates that are prevalent among many clinical research studies can eventually cause problems for researchers. Based on sample size analysis that is done before a study is conducted, researchers know approximately how many people they need to participate in a study in order to effectively analyze the data. However, if they cannot enroll enough people, bias will be introduced into the study and the validity of their results will be diminished.

By addressing the above mentioned specific aims, researchers will hopefully be able to determine what motivates people to participate in research and what prevents people from participating in research. Knowing and understanding this information will allow researchers to create documents and approach participants in a way that will make them more likely to participate. More importantly, it will allow researchers to understand why people allow their children to participate in research and why they do not allow their children to participate in research. This is extremely important for researchers to understand since pediatric trials are more likely to have low enrollment (Rothmier, Lasley & Shapiro, 2003). In addition, by understanding how these motivations and barriers differ by the participant's education, gender, race/ethnicity and occupation, researchers will gain even more insight into the population they

are targeting for their research project, thus helping to ensure that the research will most benefit those at the greatest risk.

Materials and Methods

In order to conduct this study, a questionnaire was developed by compiling questions from previous questionnaires presented in the literature on clinical trial participant recruitment (Mills et al., 2006) (Cico, Vogeley & Doyle, 2011) (Cassileth et al., 1982). The questionnaire was self-report and consisted of two sections which needed to be filled out by the adult participant. The first section had questions related to the adult participant, and the second section had questions regarding their child (if applicable). The first section contained seven questions which asked about the adult participant's age, gender, race/ethnicity, education level, occupation, previous research participation, and willingness to participate in future research. The second section contained six questions regarding the age of the adult participant's child, their gender, race/ethnicity, grade level, previous research participation, and willingness to allow their children to participate in future research. Both sections contained a table related to motivational factors and a list of potential barriers that might prevent a person from participating in research. The questionnaire is listed as Appendix A.

Each participant was recruited in-person from the UNTHSC campus, clinics and community locations. Since the questionnaires did not ask any personally identifying information, the Institutional Review Board (IRB) approved the study with a waiver of documentation of informed consent (2012-205). Therefore, the questionnaires contained a cover letter which explained the purpose of the study and possible confidentiality risk associated with

the study. After the questionnaires were completed, they were kept in a manila envelope until they were returned to the UNT Health Science Center. Once there, they were placed in a locked cabinet until they were entered into the database.

Based on information obtained using Power Analysis and Sample Size software (PASS) (2008), the sample size needed to be a minimum of 88 subjects in order to detect a medium to large effect size of difference in willingness to participate between demographic groups. This was based on an alpha of 0.05 and a power of 0.80. In an effort to accomplish this, 101 people were randomly selected from the UNT Health Science Center campus, clinics and community locations. The adults filling out the questionnaire were all 18 years of age or older. If they filled out the second section of the questionnaire, they responded for only one of their children under the age of 18.

Data Analysis

This study was a cross-sectional study comparing the variables listed in the hypotheses described above. The information obtained for each variable was acquired from the questionnaire (see Appendix A) given to each participant. All of the information obtained from the questionnaires was entered into a database created using Statistical Package for the Social Sciences (SPSS) software. After all of the information was entered into the primary database, a secondary database was created and the information was entered again. The two databases were then compared, and all discrepancies were examined and corrected. Descriptive statistics were then provided for each variable. In addition, SPSS software was used to manage and analyze the data collected from each questionnaire.

- **Specific Aim#1: To determine what motivational factors influence a person's decision to participate in research studies.**

To address specific aim #1, simple and multiple logistic regression analyses were used to examine the association between education, occupation, gender, and race/ethnicity with willingness to participate in clinical research. Additionally, odds ratios and 95% confidence intervals were calculated.

Hypothesis 1.1: Factors that motivate people to participate in research will differ by education level.

Hypothesis 1.2: Factors that motivate people to participate in research will differ between individuals with healthcare-related occupations and individuals with non-healthcare-related occupations.

Hypothesis 1.3: Factors that motivate people to participate in research will differ by gender.

Hypothesis 1.4: Factors that motivate people to participate in research will differ by race/ethnicity.

For Specific Aim 1 hypotheses, only participants who said they were willing to participate in research were included. Chi-square analyses were run between motivational factors and education, occupation, gender, and race/ethnicity. Results were considered

statistically significant at alpha less than or equal to 0.05. For any two by two tables with cells that had an expected cell count of less than five, Fisher's Exact Test was used to determine statistical significance.

- **Specific Aim #2**: **To determine what motivational factors influence a person's decision to enroll their children in research studies.**

To address Specific Aim 2, simple and multiple logistic regression were used to examine the association between parents' education, occupation, gender, and race/ethnicity with willingness to allow a child participate in clinical research. Additionally, odds ratios and 95% confidence intervals were calculated**.**

<u>Hypothesis 2.1</u>: Factors that motivate people to enroll their children in research studies will differ by the parent's education level.

<u>Hypothesis 2.2</u>: Factors that motivate people to enroll their children in research studies will differ between individuals with healthcare related occupations and individuals with non-healthcare related occupations.

<u>Hypothesis 2.3</u>: Factors that motivate people to enroll their children in research studies will differ by gender.

<u>Hypothesis 2.4</u>: Factors that motivate people to enroll their children in research will differ by race/ethnicity.

For Specific Aim 2 hypotheses, only participants who said they were willing to allow their children to participate in research were included. Chi-square analyses were run between motivational factors and education, occupation, gender, and race/ethnicity. Results were considered statistically significant at alpha less than or equal to 0.05. For any two by two tables with cells that had an expected cell count of less than five, Fisher's Exact Test was used to determine statistical significance.

- **Specific Aim #3: To determine if there are differences between what motivates a person to participate in research from what motivates them to allow their child to participate in research.**

Hypothesis 3.1: The factors that motivate people to participate in research will be different from the factors that motivate people to enroll their children in research.

To address Specific Aim 3, a chi-square test was performed to analyze the differences between willingness to participate in research studies and willingness to allow a child to participate in clinical research. For any two by two tables with cells that had an expected cell count of less than five, Fisher's Exact Test was used to determine statistical significance.

Results

Sample Overview of Adult Participants

The primary purpose of this study was to determine what factors motivate a person to participate in research studies and what motivates people to enroll their children in research. In order to accomplish this purpose, a questionnaire was given to 101 participants and a series of demographic questions were asked about the adult participant. Descriptive statistics were used to determine the mean and standard deviation of the ages of the participants involved in this study. Due to inaccurate data, the age of the one of the participants was not included in the final analysis. The age ranges of the participants were 19-63 years of age. The average age of the participants was 39.38 (standard deviation of 11.590).

SPSS was then used to determine the gender (Table 1) and race/ethnicity (Table 2) of the participants involved in this study.

Table 1: Gender of the Adult Participants

Gender	Number of Participants	Percent
Male	30	29.7
Female	71	70.3

Table 2: Race/ethnicity of Adult Participants

Race/ethnicity	Frequency	Percent
Non-hispanic White	38	37.6
Non-hispanic Black	44	43.6
Non-hispanic Asian	4	4.0
Hispanic	9	8.9
Mixed Race	5	5.0
Other	1	1.0
Total	101	100.0

Table 3 shows the education level of the adult participants involved in the study.

Table 3: Education Level of Adult Participants

Education Level	Frequency	Percent
High school diploma/GED	6	5.9
Some college/Associate's degree	35	34.7
Undergraduate degree	28	27.7
Graduate/professional degree	32	31.7

In order to answer the specific aims of the study, it was important to know if the participants were employed at an academic institution and medical facility employment. If the participants were not employed at either of the above mentioned locations, they were asked to write in their occupation on the line denoted "other". If they responded "yes" to this question, they were asked to write in the name of the institution where they were employed. Two of the

participants in the sample did not respond to this question and were removed from the results. The responses from the medical facility and academic institution employment were later combined during Specific Aim 1 analysis (see Table 9).

The survey included questions about the participants' previous research experience. The results from this question were later used as a predictor in the multiple logistic regression analyses conducted for specific aims 1 & 2. Table 4 shows the results from the responses on previous research participation.

Table 4: Previous Research Participation of Adult

Response	Frequency	Percent
No	63	62.4
Yes	38	37.6
Total	101	100.0

The following question was regarding the participants' willingness to participate in research in the future. The results from this question were later used as the outcome variable during the analysis of the specific aims for this study. Table 5 shows the results from this question.

Table 5: Future Research Participation of Adult

Response	Frequency	Percent
No	21	20.8
Yes	80	79.2
Total	101	100.0

Although only 38 people said they have previously participated in research, 80 of the participants said they would participate in future research studies. For the 80 that responded "yes" to this question, they were then given a table of motivational factors that they were asked to rank from "not at all important" to "very important." Table 6 shows the responses to each of these questions. Each cell displays the number and percentage of participants that responded to each factor.

Table 6: Adult Motivational Factors

Factors	Not at all Important N (%)	Somewhat Important N (%)	Important N (%)	Very Important N (%)
Monetary Compensation	30 (37.5%)	28 (35.0%)	14 (17.5%)	8 (10.0%)
Contributing to scientific knowledge	2 (2.5%)	16 (20.0%)	28 (35.0%)	34 (42.5%)
Altruism (wanting to help others)	3 (3.8%)	11 (13.9%)	32 (40.5%)	33 (41.8%)
Learn more about own health condition(s)	5 (6.3%)	8 (10.1%)	36 (45.6%)	30 (38.0%)
Receive newest treatments or drugs	18 (22.8%)	21 (26.6%)	22 (27.8%)	18 (22.8%)
Receive free medical attention (office visits, lab work) or free medical treatments	19 (23.8%)	23 (28.7%)	23 (28.7%)	15 (18.8%)
Opportunity to make a difference	3 (3.8%)	8 (10.0%)	41 (51.2%)	28 (35.0%)
Opportunity to socialize with others (staff and participants)	34 (43.0%)	21 (26.6%)	14 (17.7%)	10 (12.7%)
Benefit to the entire family	9 (11.3%)	15 (18.8%)	25 (31.3%)	31 (38.8%)
Curiosity	12 (15.0%)	36 (45.0%)	21 (26.3%)	11 (13.8%)
Provides something to do	46 (57.5%)	22 (27.5%)	6 (7.5%)	6 (7.5%)

The last question of the first section included a list of barriers that have been found to prevent people from participating in research studies. Each participant, regardless if they indicated they would or would not participate in future research, was asked to select any barriers that would prevent them from participating in research. There were nine barriers listed on the

questionnaire. The last barrier listed on the questionnaire was "other." If the participants selected this response, they were asked to write in another barrier. Table 7 shows the barriers that were presented to each participant and displays the percentage of people that selected or did not select each barrier.

Table 7: Adult Barriers to Research Participation

Barriers	No N (%)	Yes N (%)
Study design seems too complicated	60 (59.4%)	41 (40.6%)
Potential side effects of intervention	28 (27.7%)	73 (72.3%)
Study has too many risks involved	12 (11.9%)	89 (88.1%)
Study does not have enough benefits	66 (65.3%)	35 (34.7%)
Transportation issues	86 (85.1%)	15 (14.9%)
Lack of family support	96 (95.0%)	5 (5.0%)
Fear/mistrust of physicians and/or researchers	71 (70.3%)	30 (29.7%)
Worry about negative effect on physician-patient relationship	97 (96.0%)	4 (4.0%)
Feeling of coercion to participate	70 (69.3%)	31 (30.7%)

Specific Aim#1: To determine what motivational factors influence a person's decision to participate in research studies.

In order to accomplish Specific Aim 1, the association between the factors that motivate people to participate in research and their education, occupation, gender and race/ethnicity was

examined. Due to the low number of participants with less than a college degree, the education levels were combined and recoded which allowed participants with less than a college degree to be compared to those with a college degree or more. For this analysis, participants with a college degree or more were set up as the reference group. Table 8 shows the education levels of the participants after being recoded.

Table 8: Education Level of Adult Participants Recoded

Education Level	Frequency
Less than a college degree	41
College degree or more	60
Total	101

For this analysis, participants working in healthcare-related occupations were the reference group. Since the question on academic institution employment also included responses from participants who worked in school districts and for other institutions that were not health care related, another variable was created. If participants indicated they worked for the UNT Health Science Center or other health related facilities, "yes" was placed in this column. Table 9 represents how many participants indicated they worked at healthcare facilities.

Table 9: Health care Facility Employment

Health care occupation	Frequency
No	72
Yes	29
Total	101

The gender (Table 1) and race/ethnicity (Table 2) of the participants were also examined. For this analysis, women were the reference group. Due to the low number of participants that identified themselves as non-Hispanic Asian, Hispanic, mixed race and other, the fields were combined with African American and re-labeled as "other". Non-Hispanic Caucasian participants became the reference group and were compared to the participants that were identified as "other". Table 10 shows the results of the race/ethnicity category that was recoded for analysis.

Table 10: Race/Ethnicity of Adult Participants Recoded

Race/ethnicity	Frequency
Non-Hispanic White	38
Other	63
Total	101

The outcome variable that was used in the regression analyses was willingness to participate in future research. In the final adjusted model, education level (recoded), health care occupation, race/ethnicity (recoded) and previous research participation were used in order to increase the ability to effectively analyze the variables or increase the power. Table 11 shows the

results from the simple and multiple logistic regression analyses that were performed for all of the variables.

Table 11: Simple and Multiple Logistic Regression for All Variables

		95 % CI (unadjusted)			95 % CI (adjusted)	
Variable	**OR (unadjusted)**	**Lower**	**Upper**	**OR (adjusted)**	**Lower**	**Upper**
Education Level recoded	**.255**	.092	.706	**.208**	.062	.695
Health care occupation	**.093**	.012	.729	.154	.018	1.346
Gender	.347	.225	1.689	.797	.223	2.842
Race/ethniticity	**2.769**	1.036	7.399	2.591	.810	8.287
Previous Research Participation				**.098**	.012	.826

The unadjusted model showed that education level was associated with willingness to participate. Based on the odds ratio and 95% CI, people with less than a college degree were 75% less likely to participate in clinical research studies than people with a college degree or more. When controlling for other factors such as race/ethnicity, occupation and past research participation, education level was still associated with willingness to participate in research. Based on the odds ratio and 95% CI, people with less than a college degree were 79% less likely to participate in research than those with a college degree or more.

The unadjusted model showed that health care related occupations were associated with willingness to participate in research. Based on the odds ratio and 95% CI, people who did not work in a health care related occupation were 90% less likely to participate in clinical research studies than people who did work in a health care related occupation. When controlling for other

factors such as race/ethnicity, education and past research participation, occupation was no longer associated with willingness to participate in research. This could have been due the other factors being confounding factors or the other factors could have reduced the power to analyze the data.

The unadjusted model and adjusted model showed that the gender was not associated with willingness to participate in research. Based on the odds ratio and 95% CI, there was no difference between a person's gender and their willingness to participate in research.

The unadjusted model showed race/ethnicity was associated with a person's willingness to participate in future research studies but the results differed than what was expected. The reference group was the group that identified themselves as "Non-Hispanic white". The current study showed that people who identified themselves as "other" were over two times more likely to participate in research than those who identify themselves as "Non-Hispanic white". In the adjusted model, race/ethnicity was no longer associated with willingness to participate in future research.

The adjusted model showed that previous research participation was associated with a person's willingness to participate in future research studies. Participants who have not participated in previous research were 90% less likely to participate in future research studies.

<u>Hypothesis 1.1</u>: Factors that motivate people to participate in research will differ by education level.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between education level of the participants and the factors that motivate them to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". The 80 participants that responded "yes" to participating in future research were used to determine the association between education level and willingness to participate in future research. Table 12 shows the results for each motivational factor.

Table 12: Results of Motivational Factors Related to Education of Adult

Factors	Response	Less than College degree N (%)	College degree or more N (%)	P –Value
Monetary compensation	Less important	19 (70.4%)	38 (73.1%)	.799
	More important	8 (29.6%)	14 (26.9%)	
Contributing to Scientific Knowledge	Less important	6 (22.2%)	11 (21.2%)	.913
	More important	21 (77.8%)	41 (78.8%)	
Altruism	Less important	4 (14.8%)	9 (17.6%)	1.000
	More important	23 (85.2%)	42 (82.4%)	
Learn about own health condition	Less important	1 (3.7%)	11 (21.6 %)	*.049
	More important	26 (96.3%)	40 (78.4%)	
Receive newest treatment/drugs	Less important	11 (42.3%)	27 (51.9%)	.423
	More important	15 (57.7%)	25 (48.1%)	
Receive free medical attention	Less important	11 (40.7%)	30 (57.7%)	.153
	More important	16 (59.3%)	22 (42.3%)	
Opportunity to make difference	Less important	2 (7.4%)	8 (15.4%)	.480
	More important	25 (92.6%)	44 (84.6%)	
Opportunity to socialize	Less important	13 (50.0%)	41 (78.8%)	*.009
	More important	13 (50.0%)	11 (21.2%)	
Benefit to entire family	Less important	3 (11.1%)	20 (38.5%)	*.011
	More important	24 (88.9%)	32 (61.5%)	
Curiosity	Less important	14 (51.9%)	33 (63.5%)	.319
	More important	13 (48.1%)	19 (36.5%)	
Provides something to do	Less important	20 (74.1%)	47 (90.4%)	.095
	More important	7 (25.9%)	5 (9.6%)	

There were three (learn about own health condition, opportunity to socialize, benefit to entire family) motivational factors that were associated with a participant's education level. 96.3% of the participants with less than a college degree indicated that learning about own health

condition was more important compared to 78.4% of those with a college degree or more. 78.8% of the participants with a college degree or more thought the opportunity to socialize with others was less important while 50% without a college degree thought it was less important. Additionally, 88.9% of the participants with less than a college degree thought research benefiting their entire family was more important while only 61.5% of those with a college degree or more thought it was more important.

Hypothesis 1.2: Factors that motivate people to participate in research will differ between individuals with healthcare-related occupations and individuals with non-healthcare-related occupations.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between occupation and the factors that motivate people to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 13 shows the chi-square results for each motivational factor.

Table 13: Results of Motivational Factors Related to Occupation of Adult

Factors	Response	Non-Health care Occupation N (%)	Health care Occupation N (%)	P -Value
Monetary compensation	Less important	38 (74.5%)	19 (67.9%)	.528
	More important	13 (25.5%)	9 (32.1%)	
Contributing to Scientific Knowledge	Less important	16 (31.4%)	1 (3.6%)	*.004
	More important	35 (68.6%)	27 (96.4%)	
Altruism	Less important	13 (26.0%)	0 (0%)	*.003
	More important	37 (74.0%)	28 (100.0%)	
Learn about own health condition	Less important	9 (18.0%)	3 (10.7%)	.521
	More important	41 (82.0%)	25 (89.3%)	
Receive newest treatment/drugs	Less important	22 (44.0%)	16 (57.1%)	.265
	More important	28 (56.0%)	12 (42.9%)	
Receive free medical attention	Less important	29 (56.9%)	12 (42.9%)	.233
	More important	22 (43.1%)	16 (57.1%)	
Opportunity to make difference	Less important	9 (17.6%)	1 (3.6%)	.088
	More important	42 (82.4%)	27 (96.4%)	
Opportunity to socialize	Less important	35 (70.0%)	19 (67.9)	.844
	More important	15 (30.0%)	9 (32.1%)	
Benefit to entire family	Less important	16 (31.4%)	7 (25.0%)	.551
	More important	35 (68.6%)	21 (75.0%)	
Curiosity	Less important	35 (68.6%)	12 (42.9%)	*.026
	More important	16 (31.4%)	16 (57.1%)	
Provides something to do	Less important	47 (92.2%)	20 (71.4%)	*.021
	More important	4 (7.8%)	8 (28.6%)	

There were four (contributing to scientific knowledge, altruism, curiosity, provides something to do) motivational factors that were statistically associated with a participant's occupation. According to the results, 96.4% of the participants in health care related occupations thought contributing to scientific knowledge was more important while 68.6% of the participants

in non-health care related occupations thought it was more important. There were also differences in altruism or wanting to help others. 100% of the participants in health care related occupations thought altruism was more important compared to 74% in those without health care related occupations. 57.1% of the participants in health care related occupations were motivated to participate in research out of curiosity compared to only 31.4% of those not in health care related occupations. In addition, 92.2% of the participants in non- health care related occupations thought "provides something to do" was not a motivational factor compared to 71.4% in those with healthcare related occupations.

Hypothesis 1.3: Factors that motivate people to participate in research will differ by gender.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between gender and the factors that motivate people to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 14 shows the results for each of the motivational factors.

Table 14: Results of Motivational Factors Related to Gender of Adult

Factors	Response	Male N (%)	Female N (%)	P -Value
Monetary compensation	Less important	**16 (76.2%)**	**41 (70.7%)**	**.630**
	More important	**5 (23.8%)**	**17 (29.3%)**	
Contributing to Scientific Knowledge	Less important	**5 (23.8%)**	**12 (20.7%)**	**.764**
	More important	**16 (76.2%)**	**46 (79.3%)**	
Altruism	Less important	**5 (23.8%)**	**8 (14.0%)**	**.320**
	More important	**16 (76.2%)**	**49 (86.0%)**	
Learn about own health condition	Less important	**8 (38.1%)**	**4 (7.0%)**	***.002**
	More important	**13 (61.9%)**	**53 (93.0%)**	
Receive newest treatment/drugs	Less important	**14 (66.7%)**	**24 (42.1%)**	**.054**
	More important	**7 (33.3%)**	**33 (57.9%)**	
Receive free medical attention	Less important	**11 (52.4%)**	**30 (51.7%)**	**.959**
	More important	**10 (47.6%)**	**28 (48.3%)**	
Opportunity to make difference	Less important	**4 (19.0%)**	**6 (10.3%)**	**.443**
	More important	**17 (81.0%)**	**52 (89.7%)**	
Opportunity to socialize	Less important	**14 (70.0%)**	**40 (69.0%)**	**.931**
	More important	**6 (30.0%)**	**18 (31.0%)**	
Benefit to entire family	Less important	**9 (42.9%)**	**14 (24.1%)**	**.106**
	More important	**12 (57.1%)**	**44 (75.9%)**	
Curiosity	Less important	**14 (66.7%)**	**33 (56.9%)**	**.435**
	More important	**7 (33.3%)**	**25 (43.1%)**	
Provides something to do	Less important	**20 (95.2%)**	**47 (81.0%)**	**.166**
	More important	**1 (4.8%)**	**11 (19.0%)**	

There was one factor (learning about own condition) that was statistically associated with a participant's gender, and one factor (receive newest treatment/drug) that approached significance. 93% of the participants who are women thought learning about their own health

condition was a more important factor in participating in research while 61.9 % of men thought it was more important.

<u>Hypothesis 1.4</u>: Factors that motivate people to participate in research will differ by race/ethnicity.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between race/ethnicity of the participants and the factors that motivate them to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 15 shows the results for each motivational factor.

Table 15: Results of Motivational Factors Related to Race/Ethnicity of Adult

Factors	Response	Caucasian N (%)	Other N (%)	P -Value
Monetary compensation	Less important	18 (72.0%)	39 (72.2%)	.984
	More important	7 (28.0%)	15 (27.8%)	
Contributing to Scientific Knowledge	Less important	6 (24.0%)	11 (20.4%)	.715
	More important	19 (76.0%)	43 (79.6%)	
Altruism	Less important	5 (20.0%)	8 (15.1%)	.746
	More important	20 (80.0%)	45 (84.9%)	
Learn about own health condition	Less important	5 (20.0%)	7 (13.2%)	.507
	More important	20 (80.0%)	46 (86.8%)	
Receive newest treatment/drugs	Less important	14 (58.3%)	24 (44.4%)	.257
	More important	10 (41.7%)	30 (55.6%)	
Receive free medical attention	Less important	14 (56.0%)	27 (50.0%)	.620
	More important	11 (44.0%)	27 (50.0%)	
Opportunity to make difference	Less important	5 (20.0%)	5 (9.3%)	.274
	More important	20 (80.0%)	49 (90.7%)	
Opportunity to socialize	Less important	21 (84.0%)	33 (62.3%)	.052
	More important	4 (16.0%)	20 (37.7%)	
Benefit to entire family	Less important	11 (44.0%)	12 (22.2%)	*.048
	More important	14 (56.0%)	42 (77.8%)	
Curiosity	Less important	16 (64.0%)	31 (57.4%)	.579
	More important	9 (36.0%)	23 (42.6%)	
Provides something to do	Less important	24 (96.0%)	43 (79.6%)	.091
	More important	1 (4.0%)	11 (20.4%)	

There was one factor (benefit to the entire family) which was statistically significant and one factor (opportunity to socialize) that approached significance. For the factor that was

statistically significant, which was research benefiting the entire family, 56% of participants who identified as non-Hispanic Caucasian (white) thought this was more important compared to 77.8% of those participants who identified themselves as "other."

Sample Overview of Responses for Child

In order to analyze Specific Aim 2 of this study, which was related to the participants' willingness to allow their children to participate in research, the frequencies of the children's gender, races/ethnicities, and grade levels were taken. This section was only supposed to be answered if the adult participant had a child under the age of 18. In addition, the participants were asked to only complete the questionnaire on one of their children, if they had multiple children in the age range. Out of the 101 people that participated in this study, 54 of them completed section 2. Out of the 54 adult participants with children, 27 of them were males and 27 of them were females. Table 16 shows the race/ethnicity of the participants' children.

Table 16: Race/Ethnicity of the Participants' Children

Race/ethnicity	Frequency	Percent
Non-Hispanic White	13	24.1
Non-Hispanic Black	27	50.0
Non-Hispanic Asian	2	3.7
Hispanic	6	11.1
Mixed Race	6	11.1

It was also important to understand the grade levels of the participants' children. Their ages and levels of understanding may have had an impact on the parents' willingness to allow

them to participate in future research. Table 17 shows the grade levels of the participants' children.

Table 17: Grade levels of the Participants' Children

Grade Levels	Frequency	Percent
Pre-kinder-1st	30	29.7
2nd-5th	13	12.9
6th-8th	4	4.0
9th-12th	7	7.0

In addition to understanding the demographics of the children involved in the study, it is also important to understand the children's previous research experience, if any, and the parents' willingness to allow their child to participate in the future. Table 18 shows the results from the question regarding previous research participation of the participants' child. Table 19 shows the results from the questions regarding future research participation of the child.

Table 18: Previous Research Participation of Child

Response	Frequency	Percent
No	47	87.0
Yes	7	13.0

Table 19: Future Research Participation of Child

Response	Frequency	Percent
No	25	46.3
Yes	29	53.7

Although 54 participants completed section 2, only 29 of them with children indicated they would let their children participate in future research. Of those that responded "yes" to allowing their children to participate in future research, they were asked to rank the importance of certain motivational factors.

The last question of the second section included a list of barriers that have been found to prevent people from allowing their children to participate in research studies. Each participant, regardless if they indicated they would or would not participate in future research, was asked to select any barriers that would prevent them from allowing their children to participate in research. There were nine barriers listed on the questionnaire. The last barrier listed on the questionnaire was "other." If the participants selected this response, they were asked to write in another barrier. Table 20 shows the barriers that were presented to each participant and displays the percentage of people that selected or did not select each barrier.

Table 20: Child Barriers to Research Participation

Barriers	No N (%)	Yes N (%)
Study design seems too complicated	36 (67.9%)	17 (32.1%)
Potential side effects of intervention	8 (15.1%)	45 (84.9%)
Study has too many risks involved	6 (11.3%)	47 (88.7%)
Study does not have enough benefits	35 (66.0%)	18 (34.0%)
Transportation issues	46 (86.8%)	7 (13.2%)
Lack of family support	47 (88.7%)	6 (11.3%)
Fear/mistrust of physicians and/or researchers	34 (64.2%)	19 (35.8%)
Worry about negative effect on physician-patient relationship	45 (84.9%)	8 (15.1%)
Feeling of coercion to participate	34 (64.2%)	19 (35.8%)

Specific Aim #2: **To determine what motivational factors influence a person's decision to enroll their children in research studies.**

Specific Aim 2 examined the association between parent education, occupation, race/ethnicity, and gender of the adult with willingness to allow their children to participate in clinical research in the future. In order to assess this association, analyses that were conducted in Specific Aim 1 were also used in this aim. However, the outcome variable was changed. The outcome variable was willingness to allow children to participate in future research. Table 19 shows that there were 29 people that indicated they would allow their children to participate in research in the future. This variable was compared to the education of the parents (which is shown in Table 8).

In order to examine if the factors that motivate people to enroll their children in research differ by the parent's occupation, the information from Table 9 was used to conduct the analyses. Participants' willingness to allow their child to participate in future research was also used as the outcome variable in this analysis.

Analyses were also conducted to determine if the factors that motivate people to enroll their children in research differed by the parent's gender. As stated earlier, there were 30 male participants and 71 female participants involved in this study. The same analysis was conducted on this variable.

Additionally, the role race/ethnicity plays in the factors that motivate people to participate in research studies was examined. The race/ethnicity of the participants after combining all of the participants that indicated they were African American, Hispanic, Non-Hispanic Asian, mixed race or other into one broad category. The same analysis was conducted using the same outcome variable (willingness to allow their children to participate in future research). Table 21 shows the results of the simple and multiple logistic regression analyses that were conducted on each variable.

Table 21: Simple and Multiple Logistic Regression for Each Variable (Child)

		95 % CI (unadjusted)			95 % CI (adjusted)	
Variable	**OR (unadjusted)**	**Lower**	**Upper**	**OR (adjusted)**	**Lower**	**Upper**
Education Level	.414	.138	1.242	.349	.096	1.265
Health care occupation	.312	.084	1.151	.290	.064	1.316
Gender	.676	.205	2.235	.594	.136	2.602
Race/ethnicity	.992	.284	3.469	.868	.202	3.733
Adult previous research participation				**.187**	.051	.687

The unadjusted model and adjusted model showed that education was not associated with willingness to allow their child to participate in research. Based on the odds ratio and 95% CI, there was no association between a person's education and their willingness to allow their child to participate in research.

The unadjusted model and adjusted model showed that occupation was not associated with willingness to allow their child to participate in research. Based on the odds ratio and 95% CI, there was no association between a person's occupation and their willingness to allow their child to participate in research.

The unadjusted model and adjusted model showed that gender was not associated with willingness to allow their child to participate in research. Based on the odds ratio and 95% CI, there was no association between a person's gender and their willingness to allow their child to participate in research.

The unadjusted model and adjusted model showed that race/ethnicity was not associated with willingness to allow their child to participate in research. Based on the odds ratio and 95% CI, there was no association between a person's race/ethnicity and their willingness to allow their child to participate in research.

The adjusted model showed that there was an association between the previous research participation of the adult participant and their willingness to allow their child to participate in future research studies. The adult participants who had not previously participated in research were less likely to allow their children to participate in research in the future.

<u>Hypothesis 2.1</u>: Factors that motivate people to enroll their children in research studies will differ by the parent's education level.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there was an association between education of the parent and the factors that motivate them to allow their child to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 22 shows the results for each motivational factor.

Table 22: Results of Motivational Factors Related to Education of Parent

Factors	Response	Less than College degree N (%)	College degree or more N (%)	P –Value
Monetary compensation	Less important	8 (80.0%)	12 (63.2%)	*.027
	More important	2 (20.0%)	7 (36.8%)	
Contributing to Scientific Knowledge	Less important	0 (0.0%)	5 (26.3%)	.134
	More important	10 (100.0%)	14 (73.7%)	
Altruism	Less important	0 (0.0%)	8 (42.1%)	*.027
	More important	10 (100.0%)	11 (57.9%)	
Learn about child health condition	Less important	0 (0.0%)	0 (0.0%)	No difference
	More important	10 (100.0%)	19 (100.0%)	
Receive newest treatment/drugs	Less important	4 (40.0%)	8 (42.1%)	1.000
	More important	6 (60.0%)	11 (57.9%)	
Receive free medical attention	Less important	5 (50.0%)	13 (68.4%)	.432
	More important	5 (50.0%)	6 (31.6%)	
Opportunity to make difference	Less important	0 (0.0%)	6 (33.3%)	.062
	More important	10 (100.0%)	12 (66.7%)	
Opportunity to socialize	Less important	4 (40.0%)	15 (78.9%)	.051
	More important	6 (60.0%)	4 (21.1%)	
Benefit to entire family	Less important	1 (10.0%)	6 (31.6%)	.367
	More important	9 (90.0%)	13 (68.4%)	
Curiosity	Less important	6 (60.0%)	16 (84.2%)	.193
	More important	4 (40.0%)	3 (15.8%)	
Provides something to do	Less important	7 (70.0%)	16 (84.2%)	.633
	More important	3 (30.0%)	3 (15.8%)	

There were two factors (monetary compensation and altruism) that were statistically associated with education level of the parent and their willingness to allow their child to participate in research. 80% of parents with less than a college degree thought monetary

compensation was less important compared to only 63.2% of parents with a college education or more. Also, 100% of parents with less than a college degree thought altruism or wanting to help others was more important compared to 57.9% of parents with a college degree or more. One factor (opportunity to socialize with others) approached significance. All parents, regardless of their education level thought learning about their child's health condition was more important.

<u>Hypothesis 2.2</u>: Factors that motivate people to enroll their children in research studies will differ between individuals with healthcare related occupations and individuals with non-healthcare related occupations.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between occupation of the parent and the factors that motivate them to allow their child to participate in research Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 23 shows the results for each motivational factor.

Table 23: Results of Motivational Factors Related to Occupation of Parent

Factors	Response	Non-Health care related occupation N (%)	Health care occupation N (%)	P –Value
Monetary compensation	Less important	13 (72.2%)	7 (63.6%)	.694
	More important	5 (27.8%)	4 (36.4%)	
Contributing to Scientific Knowledge	Less important	5 (27.8%)	0 (0.0%)	.126
	More important	13 (72.2%)	11 (100.0%)	
Altruism	Less important	6 (33.3%)	2 (18.2%)	.671
	More important	12 (66.7%)	9 (81.8%)	
Learn about child health condition	Less important	0 (0.0%)	0 (0.0%)	No difference
	More important	18 (100.0%)	11 (100.0%)	
Receive newest treatment/drugs	Less important	7 (38.9%)	5 (45.5%)	1.000
	More important	11 (61.1%)	6 (54.5%)	
Receive free medical attention	Less important	12 (66.7%)	6 (54.5%)	.696
	More important	6 (33.3%)	5 (45.5%)	
Opportunity to make difference	Less important	5 (29.4%)	1 (9.1%)	.355
	More important	12 (70.6%)	10 (90.9%)	
Opportunity to socialize	Less important	11 (61.1%)	8 (72.7%)	.694
	More important	7 (38.9%)	3 (27.3%)	
Benefit to entire family	Less important	4 (22.2%)	3 (27.3%)	1.000
	More important	14 (77.8%)	8 (72.7%)	
Curiosity	:Less important	17 (94.4%)	5 (45.5%)	*.006
	More important	1 (5.6%)	6 (54.5%)	
Provides something to do	Less important	16 (88.9%)	7 (63.6%)	.164
	More important	2 (11.1%)	4 (36.4%)	

One factor (curiosity) was statistically significant. 94.4% of people who did not have a health care related occupation thought curiosity was less important compared to 45.5% of those who did work in a health care related occupation. All parents, regardless of their occupation, thought learning about their child's health condition was more important.

<u>Hypothesis 2.3</u>: Factors that motivate people to enroll their children in research studies will differ by gender.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between gender of the parent and the factors that motivate them to allow their child to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 24 shows the results for each motivational factor.

Table 24: Results of Motivational Factors Related to Gender of Parent

Factors	Response	Male N (%)	Female N (%)	P –Value
Monetary compensation	Less important	5 (71.4%)	15 (68.2%)	1.000
	More important	2 (28.6%)	7 (31.8%)	
Contributing to Scientific Knowledge	Less important	1 (14.3%)	4 (18.2%)	1.000
	More important	6 (85.7%)	18 (81.8%)	
Altruism	Less important	2 (28.6%)	6 (27.3%)	1.000
	More important	5 (71.4%)	16 (72.7%)	
Learn about child health condition	Less important	0 (0.0%)	0 (0.0%)	No difference
	More important	7 (100.0%)	22 (100.0%)	
Receive newest treatment/drugs	Less important	4 (57.1%)	8 (36.4%)	.403
	More important	3 (42.9%)	14 (63.6%)	
Receive free medical attention	Less important	5 (71.4%)	13 (59.1%)	.677
	More important	2 (28.6%)	9 (40.9%)	
Opportunity to make difference	Less important	2 (28.6%)	4 (19.0%)	.622
	More important	5 (71.4%)	17 (81.0%)	
Opportunity to socialize	Less important	4 (57.1%)	15 (68.2%)	.665
	More important	3 (42.9%)	7 (31.8%)	
Benefit to entire family	Less important	1 (14.3%)	6 (27.3%)	.646
	More important	6 (85.7%)	16 (72.7%)	
Curiosity	Less important	5 (71.4%)	17 (77.3%)	1.000
	More important	2 (28.6%)	5 (22.7%)	
Provides something to do	Less important	6 (85.7%)	17 (77.3%)	1.000
	More important	1 (14.3%)	5 (22.7%)	

None of the factors were statistically significant. However, all parents, regardless of their gender, thought learning about their child's health condition was more important.

<u>Hypothesis 2.4</u>: Factors that motivate people to enroll their children in research will differ by race/ethnicity.

Chi-square and/or Fisher's Exact tests were performed on each motivational factor to determine if there is an association between race/ethnicity of the parent and the factors that motivate them to allow their child to participate in research. Each motivational factor was recoded to combine "not at all important" with "somewhat important" and "important" with "very important." The "not at all important/somewhat important" group will be referred to as "less important" and the "important/very important" group will be referred to as "more important". Table 25 shows the results for each motivational factor.

Table 25: Results of Motivational Factors Related to Race/Ethnicity of Parent

Factors	Response	Caucasian N (%)	Other N (%)	P -Value
Monetary compensation	Less important	7 (100.0%)	13 (59.1%)	.066
	More important	0(0.0%)	9 (40.9%)	
Contributing to Scientific Knowledge	Less important	2 (28.6%)	3 (13.6%)	.569
	More important	5 (71.4%)	19 (86.4%)	
Altruism	Less important	3 (42.9%)	5 (22.7%)	.357
	More important	4 (57.1%)	17 (77.3%)	
Learn about child health condition	Less important	0 (0.0%)	0 (0.0%)	No difference
	More important	7 (100.0%)	22 (100.0%)	
Receive newest treatment/drugs	Less important	3 (42.9%)	9 (40.9%)	1.000
	More important	4 (57.1%)	13 (59.1%)	
Receive free medical attention	Less important	4 (57.1%)	14 (63.6%)	1.000
	More important	3 (42.9%)	8 (36.4%)	
Opportunity to make difference	Less important	3 (42.9%)	3 (14.3%)	.144
	More important	4 (57.1%)	18 (85.7%)	
Opportunity to socialize	Less important	6 (85.7%)	13 (59.1%)	.367
	More important	1 (14.3%)	9 (40.9%)	
Benefit to entire family	Less important	2 (28.6%)	5 (22.7%)	1.000
	More important	5 (71.4%)	17 (77.3%)	
Curiosity	Less important	5 (71.4%)	17 (77.3%)	1.000
	More important	2 (28.6%)	5 (22.7%)	
Provides something to do	Less important	7 (100.0%)	16 (72.7%)	.289
	More important	0 (0.0%)	6 (27.3%)	

None of the factors was statistically significant. However, all parents, regardless of their race/ethnicity thought learning about their child's health condition was more important.

Specific Aim #3: To determine if there are differences between what motivates a person to participate in research from what motivates them to allow their child to participate in research.

Hypothesis 3.1: The factors that motivate people to participate in research will be different from the factors that motivate people to enroll their children in research.

The purpose of this aim was to determine if there was a difference between what motivates a person to participate in research and what motivates them to allow their children to participate in research. The following information shows the results of the chi-square analyses that were conducted.

Monetary Compensation-Table 26

		Less important N (%)	More important N (%)	P-value
Monetary compensation-Adult	Less important	17 (94.4%)	1 (5.6%)	.000
	More important	3 (27.3%)	8 (72.7%)	

Of the 18 participants that responded monetary compensation was less important for themselves, 17 (94.4%) responded it was less important for their child, and 1 (5.6%) responded that it was more important for their child. Of the 11 participants that responded monetary

compensation was more important for themselves, 8 (72.7%) responded it was more important for their child, and 3 (27.3%) responded it was less important.

Contributing to Scientific Knowledge-Table 27

		Less important N (%)	More important N (%)	P-value
Contributing to scientific knowledge-Adult	Less important	3 (60.0%)	2 (40.0%)	.024
	More important	2 (8.3%)	22 (91.7%)	

Of the 5 participants that responded contributing to scientific knowledge was less important for themselves, 3 (60.0%) responded it was less important for their child, and 2 (40.0%) responded that it was more important for their child. Of the 24 participants that responded contributing to scientific knowledge was more important for themselves, 22 (91.7%) responded it was more important for their child, and 2 (8.3%) responded it was less important.

Altruism-Table 28

		Less important N (%)	More important N (%)	P-value
Altruism-Adult	Less important	5 (100.0%)	0 (0.0%)	.001
	More important	3 (13.0%)	20 (87.0%)	

Of the 5 participants that responded altruism was less important for themselves, 5 (100.0%) responded it was less important for their child. Of the 23 participants that responded altruism was more important for themselves, 20 (87.0%) responded it was more important for their child, and 3 (13.0%) responded it was less important.

Learning about own health condition-Table 29

		Less important N (%)	More important N (%)	P-value
Learning about own health condition-Adult	Less important	0 (0.0%)	5 (100.0%)	
	More important	0 (0.0%)	23 (100.0%)	

Of the 5 participants that responded learning about own health condition was less important for themselves, 5 (100.0%) responded it was less important for their child. Of the 23 participants that responded learning about own health condition was more important for

themselves, 23 (100.0%) responded it was more important for their child. There was no association between these groups.

Receive newest treatments/drugs-Table 30

		Less important N (%)	More important N (%)	P-value
Receive newest treatments/drugs-Adult	Less important	10 (76.9%)	3 (23.1%)	X^2=11.499, df=1 P-value=.001
	More important	2 (13.3%)	13 (86.7%)	

Of the 13 participants that responded receiving the newest treatments/drugs was less important for themselves, 10 (76.9%) responded it was less important for their child, and 3 (23.1%) responded it was more important for their child. Of the 15 participants that responded receiving the newest treatments/drugs was more important for themselves, 13 (86.7%) responded it was more important for their child, and 2 (13.3%) responded it was less important for their child.

Receive free medical attention-Table 31

		Less important N (%)	More important N (%)	P-value
Receive free medical attention-Adult	Less important	15 (88.2%)	2 (11.8%)	.001
	More important	3 (25.0%)	9 (75.0%)	

Of the 17 participants that responded receiving free medical attention as less important for themselves, 15 (88.2%) responded that it was less important for their child, and 2 (11.8%) responded that it was more important for their child. Of the 12 participants that responded receiving free medical attention as more important for themselves, 9 (75.0%) responded that it was more important for their child, and 3 (25.0%) responded that it was less important for their child.

Opportunity to make a difference-Table 32

		Less important N (%)	More important N (%)	P-value
Opportunity to make a difference-Adult	Less important	4 (100.0%)	0 (0.0%)	.001
	More important	2 (8.3%)	22 (91.7%)	

Of the 4 participants that responded opportunity to make a difference was less important for themselves, 4 (100.0%) responded that it was less important for their child. Of the 24 participants that responded opportunity to make a difference was more important for themselves, 22 (91.7%) responded that it was more important for their child, and 2 (8.3%) responded that it was less important for their child.

Opportunity to Socialize-Table 33

		Less important N (%)	More important N (%)	P-value
Opportunity to Socialize-Adult	Less important	16 (88.9%)	2 (11.1%)	.001
	More important	3 (27.3%)	8 (72.7%)	

Of the 18 participants that responded opportunity to socialize was less important for themselves, 16 (88.9%) responded that it was less important for their child, and 2 (11.1%) responded that it was more important for their child. Of the 11 participants that responded opportunity to socialize was more important for themselves, 8 (72.7%) responded that it was more important for their child, and 3 (27.3%) responded that it was less important for their child.

Benefit to entire family-Table 34

		Less important N (%)	More important N (%)	P-value
Benefit to entire family-Adult	Less important	3 (50.0%)	3 (50.0%)	.131
	More important	4 (17.4%)	19 (82.6%)	

Of the 6 participants that responded benefit to the entire family was less important for themselves, 3 (50.0%) responded that it was less important for their child, and 3 (50.0%) responded that it was more important for their child. Of the 23 participants that responded benefit the entire family was more important for themselves, 19 (82.6%) responded that it was more important for their child, and 4 (82.6%) responded that it was not/somewhat important for their child.

Curiosity-Table 35

		Less important N (%)	More important N (%)	P-value
Curiosity-Adult	Less important	18 (100.0%)	0 (0.0%)	.000
	More important	4 (36.4%)	7 (63.6%)	

Of the 18 participants that responded curiosity was less important for themselves, 18 (100.0%) responded that it was less important for their child. Of the 11 participants that responded curiosity was more important for themselves, 7 (63.6%) responded that more important for their child, and 4 (36.4%) responded that it was less important for their child.

Provides something to do-Table 36

		Less important N (%)	More important N (%)	P-value
Provides something to do-Adult	Less important	21 (91.3%)	2 (8.7%)	.008
	More important	2 (33.3%)	4 (66.7%)	

Of the 23 participants that responded provides something to do was less important for themselves, 21 (91.3%) responded that it was less important for their child, and 2 (8.7%) responded that it was more important for their child. Of the 6 participants that responded provides something to do was more important for themselves, 4 (66.7%) responded that it was more important for their child, and 2 (33.3%) responded that it was less important for their child.

Discussion

Previous studies on research participation identified several motivational factors and barriers. These factors were used in the questionnaire designed for this study, and the data collected from each questionnaire were analyzed to determine if the factors that motivate people

to participate in research or allow their child to participate in research differ by education, occupation, gender, and race/ethnicity.

Some of the information identified during this study supports previously published results. However, there were also differences that were discovered, with varying reasons for the differences between this study and previous studies.

Several of the literature sources used for the background of this study cited contributing to scientific knowledge as a factor that motivates people to participate in research (Cassileth et al., 1982) (Hunsaker et al, 2012) (Paradis, Phelan & Brinich, 2010) (Fisher, McKevitt & Boaz, 2011). The current study examined the relationship between occupation and contributing to scientific knowledge and found that there was a significant association between occupation and this factor (96.4% of those in health care related occupations). The information listed in the literature did not analyze the role occupation plays in this motivational factor.

Another factor that was discovered to play a role in research participation was altruism or wanting to help others. Paradis and colleagues (2010) reported that 72% of participants cited altruism as a factor that motivated them to participate in research, and that only 24% of those participants with less than a high school education participated for reasons of self interest. The results from the current study discovered that 100% of the participants cited altruism as a factor that motivates them to participate in research. One result that was different from the literature was about those with less than a college degree being more interested in research that benefits self rather than society. The results from this study showed that 100% of the participants with

less than a college degree listed altruism as a factor that motivates them to enroll their children in research studies compared to 57.9% with a college degree or more.

Additionally, the literature presents conflicting information on the role monetary compensation plays in people participating in research. A study about phase I study participation (Almeida et al., 2007) discovered that most of their participants ranked monetary compensation as extremely important. The results from the current study were different than the literature. The current study did not find monetary compensation to be an important factor in participating in research. 70.4% of the participants with less than a college degree found monetary compensation to be "not" or "somewhat important" compared to 73% of those with a college degree or more. 74.5% of the participants in non-healthcare-related occupations indicated that monetary compensation was "not" or "somewhat important" compared to 67.9% of those in healthcare-related occupations. Men and women almost equally thought monetary compensation was "not" or "somewhat important". Additionally, race/ethnicity did not play a role in the importance of monetary compensation. Whites and those identifying as other equally thought monetary compensation was "not" or "somewhat important".

Previous studies found that many of their participants were motivated to participate in research because it would allow them to get free medical attention or receive the newest/best treatments and drugs available (Almeida et al., 2007) (Fisher, McKevitt & Boaz, 2010). Participants in the current study were presented with both of these options in the motivational factor section. Responses indicated that there was no significant association with education, occupation, and race/ethnicity with receiving newest/best medical treatments and receiving free medical attention. The high education levels of the participants involved in this study may have

played a role in these results. By having a higher level of education, there is a greater probability they will have jobs that pay well and provide medical benefits which would allow them to receive the medical care they need.

Another factor examined in the literature (Almeida et al, 2007) was curiosity. Almeida and colleagues (2007) discovered that curiosity was a less powerful motivator among their participants. However, in the current study, 57% of participants in health care related occupations were more likely to participate in research out of curiosity. However, curiosity was not discovered as a factor that motivates people to enroll their children in research studies. Of the participants who worked in non-health care related occupations, 94.4% cited that curiosity was not a factor in allowing their children participate in research.

One of the other factors examined was learning about own health. Harris (2012) found a strong correlation between participants' strong desire to learn about their child's health or their own health and their willingness to participate in research studies. This study found that greater educational achievement and female sex were strongly associated with learning about own health and motivation to participate in research.

In addition to the motivational factors that were identified, there were also barriers to participating in research. Almeida and colleagues (2007) discovered that 76% of the participants worried about studies being too risky. Major barriers that identified in this study were the study appearing to be too risky and not having enough benefits.

Results of this study were closely related to the results discovered in the literature. However, there were some differences. There were not any studies that examined the relationship between education, gender, race/ethnicity and occupation of the parent and the willingness to allow a child to participate in research. In addition, there was not much information on how health care related occupations are associated with a person's willingness to participate. Results from this study were able to provide information in some of these areas that have not previously been examined yet.

However, another study in the literature (Rothmier, Lasley & Shapiro, 2003) discovered that monetary compensation did not statistically influence a parent's decision to enroll their children in research. They also believed there was a correlation between income level of the parent and importance of financial rewards. 80% of these participants with less than a college degree indicated that monetary compensation was not an important factor in motivating them to allow their children participate in research compared to 63.2% of those with a college degree or more. The level of education was asked on the questionnaire. However, income was not asked. This 80% that indicated monetary compensation was not an important factor in them allowing their child to participate in research may have had a higher level of income even though their education level was lower.

There were some limitations that were encountered during the course of this study. Because this is a cross-sectional study, the main limitation is that no temporal associations can be made between the variables being compared. Also, equal numbers of males and females or different ethnicities were not surveyed which limited the power or ability to answer all research

questions proposed. In addition, there was not a validated instrument available for use. Careful considerations had to be made regarding these limitations.

Conclusion

The purpose of this study was to determine what factors motivate a person to participate in research and allow their children to participate in research. In addition, these motivational factors were analyzed to determine if they differ by education, occupation, race/ethnicity and gender. In order to accomplish this goal, a cross-sectional study was developed. The study included one questionnaire which asked a series of questions about the adult participant and a series of questions regarding the adult participant's child (if applicable).

Data were collected from 101 participants, and different analyses were conducted in order to answer the specific aims and hypotheses related to the study. Descriptive statistics, simple and multiple logistic regressions were conducted on each variable. In addition, odds ratio and 95% CI were calculated and used to analyze the statistical significance of each variable. Chi-square and Fisher's Exact analyses were also conducted to determine if these motivational factors differed by the variables listed in the hypotheses.

There were motivational factors that were found to be statistically significant based on education, occupation, race/ethnicity and gender. For the adult participant, education was associated with learning about own health, benefit to entire family and opportunity to socialize. Occupation was also associated with contributing to scientific knowledge, altruism and curiosity and provides something to do. Gender and race/ethnicity were also associated with learning about own health and benefit entire family respectively. Additionally, the factors that motivate

people to enroll their children in research studies were discovered. Parent's education was associated with monetary compensation and altruism while occupation of the parent was associated with curiosity.

Many people in the United States due to their low socioeconomic statuses are unable to receive adequate health care. For this group of people, research may be a good alternative for them. They can participate in research studies and learn more about their health or the health of their children by receiving tests or medical care they would not normally be able to afford.

By researchers using the information collected in this study, they can figure out ways to address the issue of low recruitment in research studies. Future studies can be developed that tests out different research strategies in these groups of people based on what motivates them and prevents them from participating in research to determine what strategies increase participation in these groups.

By eliminating the low recruitment issues in clinical research, researchers are likely to have more power to analyze information and reach conclusions without biases. In addition, increased research participation can help reduce some of the health disparities that are prevalent in certain communities by offering healthcare services to those at the greatest risk.

Chapter 3:

Internship Site and Experience

My internship experience was conducted with Dr. Kimberly Fulda in the Department of Family Medicine and the Primary Care Research Center (PCRC). The PCRC was developed to address some of the conditions and other primary care/public health issues that are prevalent in North Texas, such as Type II Diabetes, childhood obesity and infant mortality. The PCRC addresses this by implementing innovative research and collaborating with many of its partners, such as the University of North Texas Health Science Center (UNTHSC), Cook Children's Healthcare System, John Peter Smith Hospital System and many private primary care practices in the DFW area.

While working for Dr. Fulda, I was responsible for daily activities associated with various studies that were being developed or implemented throughout the duration of my internship. One of the studies that I was responsible for working on was entitled "Bringing it Home: Improving COPD Diagnosis in Family Medicine." The primary aim of this study is to assess provider's current knowledge, performance and attitudes associated with the use of spirometry in patients that are at risk for chronic obstructive pulmonary disease or COPD. The secondary aim of this study is to offer individualized information on the use and interpretation of spirometry to each of the participants in the form of CME credit.

In the beginning, I was responsible for creating a checklist and making copies for the COPD folders. Once the copies were completed, I organized the surveys and put them in folders for each participant. Once the folders were complete, we began recruiting providers for the study. This required me and other members of the research team to go out to various clinics and ask providers to enroll in the study. If they agreed to participate, they were asked

to sign the consent document and complete the pre-survey, which was used to assess the provider's current knowledge and uses of spirometry.

After all of the participants were enrolled, I looked at the surveys and assessed where the providers needed the most information and submitted that list to the research coordinator and Dr. Fulda who is the P.I. on the study. The Professional and Continuing Education (PACE) Office is currently trying to create the individual CME information for each provider. Once the CME part of the study has been completed, the participants will be asked to do a post-survey, which will be used to see if their understanding and use of spirometry has improved.

The other study that I primarily worked on during my internship was a study entitled "Factors Associated with Being at Risk for Type 2 Diabetes among Mexican American and Mexican Children." The primary aim of this study is to assess and compare the prevalence of factors (psychosocial, family and environmental) among Mexican-American and Mexican children who are 10-14 years of age that reside in Tarrant and Toluca counties. The secondary aim of this study is to determine if these factors are associated with being high risk for type 2 diabetes among children who are 10-14 years of age.

One of the duties I was responsible for was creating the checklist and putting together the folders for the study. I also assisted the research coordinator in duties associated with the IRB submissions (adding key personnel and updating study documents) and creating databases for various aspects related to the study. In addition, I participated in many recruitment activities including: screening at UNTHSC affiliated clinics, calling local establishments such as grocery stores and churches to find recruitment opportunities and assisting the research coordinator in gathering materials for larger recruitment events.

I also played a large role in data collection for this study. Once participants were recruited and scheduled, I helped process them. I consented some of the participants if they

spoke English. However, if they were Spanish speaking, I assisted other research team members. These duties included: making copies of the consent documents for the participant's records, getting the children's measurements (height, weight, BMI, waist and hip circumference), checking their blood sugar levels and blood pressure, ensuring all documents were filled out entirely and accurately, requesting physicians to check for Acanthosis Nigricans, giving compensation to the participants and taking them to the lab for the blood draw. Additionally, if participants agreed to store extra blood for future research studies, we would have to process blood samples, label them and store them in the research freezer.

Once the participant was processed, I completed the forms the next day by assessing if they were high or low risk and checking their lab results to see if they were normal or abnormal. Once this had been determined, the lab results had to be signed by a physician and mailed to the participant. In addition to the above mentioned duties, I also learned about reconciling billing issues with the lab company, maintaining budgets, conducting chart audits, writing notes to file and protocol deviation memos to the IRB.

I was also able to attend an IRB full board review meeting in October of 2012. I was also able to assist Dr. Fulda with her breastfeeding study that will begin in March by conducting a literature review, locating assessments and surveys that will be used during the study and helping with the writing of the protocol that was submitted to the IRB.

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Appendix A: Questionnaire

December 1, 2012

Dear potential study participant,

I am a graduate student at the University of North Texas Health Science Center which is located in Fort Worth. I am excited to ask you to be part of a study that will look at what factors motivate people to participate in research and what factors motivate people to enroll their children in research studies. More importantly, I am looking to see if these factors differ by education level, occupation, gender and race/ethnicity. By determining what motivates people to participate in research and enroll their children in research studies, researchers can use this information to enroll more participants which will benefit the medical field as a whole. The study is titled "Differences in Motivational Factors that Influence Participation in Research Studies," and is being conducted under the guidance of Dr. Kimberly Fulda who is the principal investigator.

If you agree to participate, please complete the attached survey. The survey consists of two sections. One section includes questions related to you, and one section includes questions related to your child (if applicable). Your child must be under the age of 18 for you to answer the child specific questions. It will take approximately 15 minutes to complete. No personal identifying information will be collected or stored on you or your child.

Your participation in this research study is voluntary. You can choose not to be in the study or leave it at any time without penalty or loss of benefits that you are otherwise entitled. If you are a patient at a UNT Health clinic, your participation (or non-participation) will not affect the care you receive. If you are an employee or student at UNTHSC, your employment or student status will not be affected by your participation or non-participation. There is a chance your confidentiality will be breached during this research study. However, the investigators will not collect your name or any other identifiers and all survey responses will be kept in a locked storage cabinet.

If a study-related problem occurs, or if you have any questions about the study, you may contact Dr. Kimberly Fulda (principal investigator) at (817) 735-0225 or Dr. Brian A. Gladue, Chairman of the Institutional Review Board, University of North Texas Health Science Center at Fort Worth at (817) 735-0409.

We would greatly appreciate your participation in this study and thank you for your consideration, time and effort.

Sincerely,

Michelle Lee

Michelle Lee
Student Research Assistant
UNT Health Science Center

Motivational factors that Influence Participation in Clinical Research

Section 1: The questions in this section are about you and how you feel about participating in research. Please select the appropriate answer or fill in your response.

---

1. What is your age? _____

2. What is your gender?
   a. Male
   b. Female

3. What race/ethnicity do you consider yourself to be?
   a. Non-Hispanic White/Caucasian
   b. Non-Hispanic Black/African American
   c. Non-Hispanic Asian
   d. Hispanic
   e. Mixed race
   f. Other_____

4. What is your highest education level?
   a. Junior high/some high school attended
   b. High school diploma/GED
   c. Some college/Associate's degree
   d. Undergraduate college degree
   e. Graduate/professional degree

5. What is your occupation?
   a. Employee at an academic institution ____Yes ____No
      If **YES**, which institution? _____
   b. Employee at a medical facility ____Yes ____No
      If **YES,** what is your job title (Physician, Nurse, Office personnel, etc)?
      _____
   c. Other_____

6. Have you ever participated in a research study?

   a. Yes

   b. No

7. Would you participate in a research study in the future?

   a. Yes

   b. No

   If NO, please skip to question #9

8. If you would participate in research in the future, how important are each of the following factors? Please select the category that best represents how you feel regarding each factor.

Factors	Not at all Important	Somewhat Important	Important	Very Important
Monetary Compensation				
Contributing to scientific knowledge				
Altruism (wanting to help others)				
Learn more about own health condition(s)				
Receive newest treatments or drugs				
Receive free medical attention (office visits, lab work) or free medical treatments				
Opportunity to make a difference				
Opportunity to socialize with others (staff and participants)				
Benefit to the entire family				
Curiosity				
Provides something to do				

9. The following factors have been identified as barriers that keep people from participating in research. From the following list, please select which barriers would prevent you from participating in research. **Select all that apply.**

____If wording of study design or protocol seems too complicated

____Potential side effects of the intervention

____If the study has too many risks involved

____If the study does not have enough benefits

____Issues with transportation getting to the research site

____Lack of family support

____Fear or mistrust of physicians and/or researchers

____Worry that participation may negatively affect the doctor-patient relationship

____Feeling of coercion to participate

____Other_____

Section #2: Please complete if you have a child. The following sets of questions pertain to your child. If you have more than one child (under the age of 18), please answer questions for only one child.

10. What is your child's age? _____

11. What is your child's gender?
    a. Male
    b. Female

12. What race/ethnicity do you consider your child to be?
    a. Non-Hispanic White/Caucasian
    b. Non-Hispanic Black/African American
    c. Non-Hispanic Asian
    d. Hispanic
    e. Mixed race
    f. Other_____

13. If your child attends school, what grade is he/she in? _____

14. Has your child ever participated in a research study?

    a. Yes

    b. No

15. Would you allow your child to participate in a research study in the future?

    a. Yes

    b. No

    If NO, please skip to question #17

16. If you would allow your child to participate in research in the future, how important are each of the following factors? Please select the category that best represents how you feel regarding each factor.

Factors	Not at all Important	Somewhat Important	Important	Very Important
Monetary Compensation				
Contributing to scientific knowledge				
Altruism (wanting to help others)				
Learn more about child's health condition(s)				
Receive newest treatments or drugs				
Receive free medical attention (office visits, lab work) or free medical treatments				
Opportunity to make a difference				
Opportunity to socialize with others (staff and participants)				
Benefit to the entire family				
Curiosity				
Provides something to do				

17. The following factors have been identified as barriers that keep people from participating in research. From the following list, please select which barriers would prevent you from allowing your child to participate in research. **Select all that apply**.

____If wording of study design or protocol seems too complicated

____Potential side effects of the intervention

____If the study has too many risks involved

____If the study does not have enough benefits

____Issues with transportation getting to the research site

____Lack of family support

____Fear or mistrust of physicians and/or researchers

____Worry that participation may negatively affect the doctor-patient relationship

____Feeling of coercion to participate

____Other_____

Week 1: August 20-24

August 20, 2012

I began my internship with a training session at the PCC for the Diabetes study. Dr. Schranz taught us how to get blood glucose readings using a glucometer, how to properly take waist and hip circumference measurements, use the Tanita to calculate a patient's BMI, take blood pressure and height measurements. We also received training from one of the laboratory managers on how to process our blood samples. In the afternoon, I read the protocol for the COPD and Diabetes studies and became familiar with the materials associated with both studies.

August 21, 2012

In the morning, I put together folders for the COPD study, which included: a checklist, consent form and surveys. I later had a meeting with Dr. Fulda and Randi regarding the Diabetes folders. I then went to the Family Medicine Office to make copies and start putting the materials in each folder.

August 22, 2012

In the morning, I worked on making changes to the checklist that will be placed in the Diabetes folders. Once the changes were complete, Randi and I had them approved by Dr. Fulda. I then completed a spreadsheet that will be used to log glucometer calibration readings in the lab. In the afternoon, I worked with Randi on completing conflict of interest forms and change of key personnel forms for a student being added to research projects. I then continued making copies for the Diabetes folders.

August 23, 2012

I was out on this day due my scheduled MCAT exam.

August 24, 2012

When I first arrived at my internship site, I sent a reminder email to the research group regarding our training session on Monday, August 27th. I then finished putting together the folders for the Diabetes study. I also met with Dr. Fulda and we discussed changes made to the surveys in the Diabetes folders and how to get send those changes to the IRB for approval. We then walked the updated paperwork to the IRB. After we returned, Dr. Fulda and I discussed possible ideas for my research project and the CDSS Survey Study. In the afternoon, I made changes to a label template that will be used in the Diabetes study. In addition, I worked on the expedited review application, cover letter and protocol for the CDSS Survey Study.

Week 2: August 27-31

August 27, 2012

We started this week with a training session and a practice run through using a "fake patient." During this training, we discussed proper order for conducting the study and how to appropriately give informed consent/assent to the participants. After the training, I attended my first committee meeting to discuss my practicum research project. Following this meeting, I went to the library to get help with conducting an extensive literature review. I then read through abstracts from various articles to help with deciding on a topic.

August 28, 2012

When I first arrived, I made changes to the change in key personnel form for the new student being added to the research project. After that, Randi and I walked the updated forms to the IRB for approval. While there, I was able to meet Dr. Gladue and other key personnel in their office. I then worked on my research project which consisted of printing and reading more journal articles. In the afternoon, a few people from the research team met and practiced the informed consent process.

August 29, 2012

I first met with Randi on the items that need to be completed for the day. She informed me that there was not anything urgent at that time and that I should continue working on my research project. I then began typing my daily journal so that it will be ready for Dr. Fulda's review. I also typed a bulleted outline regarding the informed consent process which will be used as a reference tool when we begin consenting participants. After that, I continued reading articles for my research project.

I left the internship site at 11:30 due to having a sick child at home. However, once at home, I continued to read articles related to my practicum project.

August 30, 2012

At 8:30, the research team attended a training session with Dr. Franks on how to accurately score the CDI assessment which will be used in the Diabetes study. After the training session, I continued to work on research for my practicum project. Once I had finished reading several articles, I met with Dr. Fulda to discuss my topic. I then researched pictures of Acanthosis Nigricans and sent the link to Dr. Fulda. I then spent the last couple of hours working on the Clinical Demographic Survey Study protocol.

August 31, 2012

In the morning, I went with Dr. Fulda and Randi to label boxes at the Patient Care Center. If patients agree to store their blood for future research projects, the extra blood will be stored in those boxes. I then created a table that will be used to house information regarding the aliquot tubes that are being stored at the PCC. I then made copies of the tables, labeled them and created

a binder where they will be stored in Dr. Fulda's office. I then updated the aliquot label template and printed enough labels for the first few patients we will see. In the afternoon, I continued working on the Clinical Demographic Survey Study protocol. I then made an appointment with Dr. Fulda next week to review the work I have completed thus far on this project. The rest of the day was spent conducting more research for my practicum project.

Week 3: September 3-7

September 3, 2012

Internship site closed due to the Holiday

September 4, 2012

In the morning, I worked on my practicum proposal so it will be ready for review by Dr. Fulda in the next couple of weeks. In the afternoon, I attended Dr. Fulda's PEDs meeting at the Patient Care Center. While there, I was able to meet other people that will be working on the Diabetes study with us. I also learned about the other pediatric study that is being conducted and listened as the two teams discussed ways to eliminate duplicate recruitment and scheduling conflicts. I then made changes to the CDSS Survey as suggested by Dr. Cardarelli and Dr. Fulda. I then continued to work on my research proposal.

September 5, 2012

Randi gave me a few tasks to complete for the Diabetes study in the morning. I created a cheat sheet on genetic conditions that can be used to answer questions during recruitment phone calls. I also created a cheat sheet for abnormal lab values for the different tests that will be run during the study. This will allow us to quickly refer to these values and know if they are out of the normal range. I also made a sheet with a list of physician's names so our research team will know which physicians are available at each site. After lunch, I worked on my research proposal and met with Dr. Fulda regarding the changes made to the CDSS survey. I then made the changes to the CDSS survey based on the changes we discussed.

September 6, 2012

In the morning, I finished making changes to the CDSS survey and emailed the updated version to Dr. Fulda. I then made corrections to the physician lists I created. After that, I made copies of the abnormal lab values cheat sheets and laminated them. After lunch, I went to the PCC with Randi to consent more physicians for the COPD study. We were able to get informed consent and surveys on 3 participants. Once the surveys were complete, Randi and I made sure the surveys were complete and wrote the UINs on each document. I then cut out the remaining abnormal lab value cheat sheets. I then started working on a timeline for my practicum project per Dr. Fulda's request. At 4:30, I went back to the PCC with Randi to pick up a folder from one of our participants that needed more time.

September 7, 2012

I met with Randi in the morning to discuss what needed to be completed for the day. I then made changes to the DM MX checklist, made copies of the updated form and added them to the folders. I also made copies of the CDI inventory results form and added it to the folders as well. After lunch, I met with Dr. Fulda to discuss my practicum report timeline and to finalize my research question. Dr. Fulda gave me a few tasks to complete over the weekend and we scheduled another meeting for Monday, September 10th. I then met with Randi again and we completed other tasks related to the DM MX study so we would be ready for our first participants. I then continued making changes to the CDSS survey and emailed it to Dr. Fulda for review.

Week 4: September 10-14

September 10, 2012

In the morning, I printed articles that contained survey questions related to my research topic. I also completed typing my daily log for last week and began typing my log for this week. I then typed out my specific aims and hypothesis questions so they would be ready for my meeting with Dr. Fulda in the afternoon. In addition, I read all of the articles I printed out and began typing an outline for my research proposal and term paper that are due at the end of the month. After lunch, I met with Dr. Fulda to discuss my progress on my specific aims and hypothesis. After our discussion, I made changes to my specific aims and hypothesis and emailed them to her. I also worked on creating an aliquot tube spreadsheet in Excel that will allow us to keep track of the tubes we are storing in the DM MX study. I then completed the outline for my research proposal so I could begin working on it.

September 11, 2012

In the morning, I met with Randi so I could practice the informed consent before our first participants start coming in for appointments. At 9:00, I attended training for the new conflict of interest policy. I then began typing out my research proposal. I also met with Dr. Fulda regarding my specific aims and hypotheses. We made some changes to them. After lunch, I typed out the revised aims and hypotheses and emailed them to Dr. Fulda for review. After that, I continued working on my research proposal for the rest of the afternoon.

September 12, 2012

In the morning, Randi and I finalized everything for the DM MX study so we would be ready for the first participant. I spent the rest of the morning working on my research proposal. In the afternoon, Dr. Fulda emailed a few changes to my hypotheses and specific aims. I made those changes and continued working on my proposal.

September 13, 2012

I was out of the office on this day due to being sick.

September 14, 2012

In the morning, I checked in with Randi to see how everything went with the first participant. I helped her fill out the rest of the chart form and high/low risk assessment form. I also found some online conversion tools that can be used on the study. I then worked on my proposal until lunch. After lunch, Randi and I went to the PCC with Dr. Fulda to discuss patient schedules so we will be ready for recruiting subjects next week. Randi and I also discussed some study issues with Dr. Fulda and Dr. Franks. I then spent the rest of the afternoon working on my proposal.

Week 5: September 17-21

September 17, 2012

In the morning, I checked my calendar and email. At 9:00, I went to Randi's office to discuss recruitment at the Seminary clinic. After that, I went with another member of the research team to Seminary to look at their patient schedule for the day. Once there, we figured out that we would have some children that meet our subject profile later in the afternoon. We then went back to campus. After that, I worked on my proposal until lunch. After lunch, we went back to Seminary. While there, we spoke to one of the physicians about the proper location and way to recruit their patients. We spoke to 3 parents and were able to get one to agree to our study. We then went back to campus where I worked on my proposal until it was time to leave.

September 18, 2012

Randi and I attended a physician meeting at the PCC in hopes of recruiting Physicians and PA's to our COPD study. While there, we were able to set up a time to go to the PCC and pick up a study from one of the Physicians as well as consent a PA to be in our study. After that, we went back to the office to work on more study related items. I took some paperwork to the IRB for Randi and worked on my proposal as well. In the afternoon, I worked with Randi on putting together study and recruitment binders so we will have complete access to the documents we need. I also continued working on my proposal until it was time to leave.

September 19, 2012

Randi and I had a subject scheduled for 11:00. I began working on my proposal and then met with Randi at 10:00 to start getting research materials ready. I was then informed that our subject rescheduled their appointment to a later date. I then continued working on reading articles that will be used for my proposal. I then went with Randi to the PCC to pick up a survey from a physician for our COPD study. After lunch, I met with Dr. Fulda regarding the research methods for my proposal. I then worked on my proposal for the rest of the afternoon.

September 20, 2012

In the morning, Randi and I went to the Eagle Ranch clinic to pick up a COPD survey from one of the PA's. While there, we checked their schedule for potential participants in the Diabetes study and put up flyers with study information in each of the exam rooms. After leaving Eagle

Ranch, I worked on my proposal until 2:00. I then gathered my materials and met Randi at the PCC to begin processing a participant. While waiting, we set up all of the materials we needed to process these participants. The participants did not show up so I went back to the office and continued working on my proposal.

September 21, 2012

In the morning, I went to the Family Medicine clinic to screen participants for the Diabetes study. They did not have anyone in the age ranges we are looking for. I then went to the Pediatric clinic to screen their patients. There were two that met the criteria we were looking for. I waited for the first patient but that patient did not show up for their appointment. I then went back to the PCC and worked on my proposal until the next appointment. After lunch, I continued working on my proposal until 2:00. I went with Randi to the PCC to begin getting our materials ready to process another participant. We processed the second participant for the rest of the day.

Week 6: September 24-28

September 24. 2012

At 9:00, I went with a member of our research team to Seminary to screen and recruit patients for the Diabetes study. I also spoke to one of the physicians about participating in the COPD study as well. Once that patient was screened, we returned to campus. I worked on my proposal until lunch. After lunch, we went back to Seminary to screen more patients for the Diabetes study. I then worked on my proposal until it was time to leave for the day.

September 25. 2012

I worked on my proposal from 8:00 until lunch. After lunch, I went with another member of our research team to Seminary. While there, I checked with the Physician to see if he finished the COPD study. We also screened patients for the Diabetes study. In addition, we put up flyers for the Diabetes study in the exam and waiting areas. After returning to campus, I continued working on my proposal.

September 26, 2012

We had a participant scheduled for the Diabetes study so we arrived early to set up all of our materials. We then waited for the participant but they had to reschedule. I then worked on my proposal until lunch. After lunch, I went with another member of our research team to Seminary to screen and recruit participants. While there, we put up flyers in the exam rooms and spoke to about 3 potential study participants. We then went back to campus around 3:00. I then worked on my survey until it was time to leave for the day.

September 27, 2012

In the morning, I finished my survey and emailed the draft to Dr. Fulda. I then worked on my term paper for Dr. Gwirtz until lunch. After lunch, I met up with Randi and we went to the

resident's didactic training session to recruit them for the COPD study. While there, we completed informed consent and pre-surveys for about 9 of the residents. Once we returned to campus, we made sure all of the files were complete and everything was filled out in the study files. I then continued working on my term paper until it was time to leave for the day.

September 28, 2012

In the morning, Randi and I went to Seminary. While there, we recruited patients for the Diabetes study and spoke with clinic personnel regarding some recruiting issues we were having. We also spoke to another physician about completing the COPD study survey for us. After we returned, I continued working on my proposal draft and term paper for the rest of the day.

Week 7: October 1-5

October 1, 2012

In the morning, I spoke with Randi and we looked at the schedule for Seminary. Most of the appointments we needed were in the afternoon so I worked with a member of the research team and created more files for upcoming participants. I then continued working on my research proposal and surveys. I emailed the draft of the proposal and survey to Dr. Fulda for edits. After lunch, I went with a research team member to Seminary for recruiting. After recruiting, I continued working on my term paper for the rest of the afternoon.

October 2, 2012

I received my proposal and survey back with items that needed to be changed and corrected. I began working on those changes until lunch. After lunch, I continued working on those changes until 1:30. I then attended an IRB Full Board Review meeting until 4:30. After the meeting, I met Randi to help her gather research materials for a participant we had scheduled in the morning.

October 3, 2012

I arrived to the Patient Care Center early so we could prepare for participants we had at 8:00. We waited there until 8:30 and found out the participants wanted to reschedule. We gathered all of our materials and took them back to the EAD. I then continued working on my proposal and survey and emailed another draft to Dr. Fulda.

October 4, 2012

I continued working on my proposal and survey. I then took a break from that to help Randi with changing IRB paperwork for a study she is working on. After lunch, I continued helping Randi organize paperwork in her office. I created files for the DM MX study and completed recruitment forms. I then made copies of the flyer for the Diabetes study and created space in the study binder for them. I then helped Randi gather study materials for a participant that was scheduled for the following morning. I worked on my study documents until the end of the day.

October 5, 2012

Randi and I had an appointment scheduled at 8:30. We arrived at 8:00 and began setting up all of our paperwork and supplies for the appointment. We processed the participant until 10:30. After that, we processed blood until 11:00. We then cleaned our work spaces and brought our documents back to the EAD. I received the final comments from Dr. Fulda regarding my research proposal and survey. I worked on those corrections until lunch. After lunch, I continued working on changes to those documents. I then helped Randi get our materials together for the appointments scheduled on Monday. I then attended a staff meeting. After the staff meeting, I emailed the final changes to my research proposal and survey to Dr. Fulda and wrapped up a few things until it was time to leave for the day.

Week 8: October 8-12

October 8, 2012

We had participants scheduled all day. We began at 8:00 setting up for our first appointment which was at 8:30. We then called the patient and found out they would be unable to make it. We checked emails until our next participant which was 10:00. Our 10:00 appointment showed up so we processed them until 12:00. After that, I ate lunch and printed more aliquot tube labels while other members of the research team processed the next participant. After I finished, I relieved Randi and helped the other research team member with processing blood. Our last participant of the day was at 3:00. We waited until 3:30 and realized the participant was not going to show up. We cleaned the rooms and gathered all of our materials and headed back to the office. While there, I made the final changes to my proposal and survey and emailed the final draft to my committee members.

October 9, 2012

I went by Randi's office in the morning. I continued processing the charts for the participants we had on the previous day. After that, I gathered recruitment information for Seminary and additional COPD folders. I then worked on a literature review search for Dr. Fulda until lunch. After lunch, I went to Seminary to recruit two residents and pick up a survey from one of the physicians. I also screened a patient of theirs for the Diabetes study. After that, I returned to campus. I began researching the expedited review process for my thesis until it was time to meet another participant. I went to Randi's office and got all of our study documents and headed to the PCC. One of our participants called to reschedule and another participant was a no-show. I then headed back to my office where I worked on my IRB documents and daily log for the rest of the afternoon.

October 10, 2012

In the morning, I looked over the Seminary and PCC patient schedules to see if there were any patients meeting the criteria for the Diabetes study. I then reviewed the lab results for the last 3 participants to see if they were normal or abnormal. I received my proposal and survey back

from one of my committee members. I worked on making certain corrections to these documents. After lunch, I prepared the research study materials for our 4:00 participant. I then worked on my term paper until 3:30. At 3:30, I went with a member of our research team to get ready to process a participant.

October 11, 2012

In the morning, I checked the Seminary schedule for appointments. There were two appointments in the afternoon that might meet our criteria for the Diabetes study. I then worked on my IRB documents until 11:30. After that, I went to the PCC to have the results from our last three participants reviewed by one of the physicians listed on the study. Dr. Lund asked that I come back in the afternoon when he was free. I then continued working on corrections to my proposal and my study documents until 1:30. From 1:30-2:00, I met with Dr. Fulda and asked her a few questions regarding my required IRB documents. I then went back to the PCC to talk to Dr. Lund regarding the results for our participants. After that, I headed to Seminary to recruit. After I returned to campus, I finished making corrections to my proposal.

October 12, 2012

In the morning, I met with Randi to discuss the schedule for the day. I then went and worked on my IRB documents until lunch. After lunch, I continued working on my IRB documents until around 3:00. I then went with Randi to meet our participants. We processed our participants until it was time to leave for the day.

Week 9: October 15-19

October 15, 2012

In the morning, there was a participant. I worked over at the PCC then helped one of the research team members with the blood processing part of the study. We then cleaned up all of our materials and returned to my office. I then continued working on my term paper and IRB documents until lunch. After lunch, I went with another member of the research team to Seminary to recruit for the diabetes study. After we left Seminary, I continued working on my documents until it was time to leave.

October 16, 2012

In the morning, I helped make additional diabetes folders for our upcoming participants. I also helped pack all of our materials for our participants in the afternoon. I then worked on my IRB documents until 2:00. At 2:00, I went with Randi to the PCC to process another participant. We had a set of siblings to process and finished around 6:00.

October 17, 2012

We had another participant at 8:30. Another research team member was helping Randi with this participant. I worked in the computer lab at the PCC until the other research team member had to go to class. I then helped Randi finish processing the participant. I then returned to Randi's office and worked on doing the high/low risk assessment sheets and lab reports for the earlier participants. After lunch, I continued going through all of our previous folders and making sure all of the documents were in a particular order and that their file is complete. I then worked on IRB documents until 5:00.

October 18, 2012

In the morning, I continued auditing our charts. I also finished the lab results and high/low risk forms for the participant we had yesterday. I then continued working on IRB documents until lunch. After lunch, Randi and I discussed possible sites for recruitment and she asked that I compile a list of places we can recruit participants. I then worked on that list and my IRB documents until 5:00.

October 19, 2012

We had a participant scheduled for 9:00. We were unable to confirm this participant but I went to the PCC to look for them. While there, I screened a possible participant and then returned back to the office. I then checked the schedule for Seminary and found that there were two patients in the afternoon that might work for our study. I worked on my IRB documents until lunch. After lunch, I checked in with Randi to see if she had anything for me to work on. Since our afternoon participants rescheduled, I continued working on IRB documents and then went to Seminary to recruit.

Week 10: October 22-October 26

October 22, 2012

I checked in with Randi to see if there were any patients on the Seminary schedule that we could screen. There was an appointment at 11:00 and one at 2:40. I then worked on IRB documents until 10:30. I met up with a member of the research team and we went to Seminary. After lunch, I worked on IRB documents until 2:00. I then met up with the research team member and we went to Seminary again to screen the 2:40 patient. After recruiting, I worked on my documents until it was time to leave for the day.

October 23, 2012

In the morning, I took the lab value reports to the PCC to have one of the physicians review and sign them. After they were signed, I made copies of them and mailed them to the participant's parents. I also updated their charts with the new reports. After that, I worked on my protocol until the afternoon. After lunch, I continued working on my IRB documents until it was time to leave for the day.

October 24, 2012

In the morning, I met with Randi to look at the recruitment schedule. I then made additional flyers and cut out the phone numbers attached to the bottom. I then worked on IRB documents until late afternoon. I then went to Randi's office and help her gather all of the folders and supplies needed for our appointments for the following day. I then continued working on my documents until it was time to leave for the day.

October 25, 2012

We had several appointments on the schedule on this day. We met at the PCC early for a set of siblings that were coming in at 8:30. One of the siblings consented to participate so we processed her until 10:30. We then ate lunch and gathered materials for our 12:00 appointment. We then processed them until 2:30. We then returned to the office and I worked on my study documents until the end of the day.

October 26, 2012

In the morning, I gathered materials and documents for our participant at 12:00. I completed the conversions and forms for the participants on the previous day. I also worked on my study documents until 11:30. We then processed our participant until around 3:30. After that, we returned to the office and I continued working on my study documents until it was time to leave.

Week 11: October 29-November 2

October 29, 2012

In the morning, I went to Randi's office to look at the schedule at Seminary for recruitment. There was an appointment on the schedule in the morning and the afternoon. I went with another member of the research team to Seminary to recruit. After returning, I made copies of recruitment forms for the upcoming church carnival. I also made additional folders for the diabetes study. Later, the research team member and I went back to Seminary. After returning, I worked on my research study documents.

October 30, 2012

In the morning, I went through all of the diabetes study charts and made sure everything was consistent and in the same order. I also made sure all of the documents were filled out. I then completed the conversions for our charts and completed the high/low risk forms. In addition, I took the lab results to the physicians to have them reviewed and signed. The results were then copied and mailed to the participant's parents. I then worked on study documents until the end of the day.

October 31, 2012

In the morning, I helped Randi laminate and make additional flyers for recruitment at the carnival. I then gathered all of the materials needed for them to take to the carnival. I then worked on my study documents until lunch. After lunch, we met with Dr. Fulda to conduct a chart review. While auditing charts, we realized there were things we needed to correct and change in the future.

November 1, 2012

In the morning, Randi and I went through the charts to make sure we fixed the problems that were noticed during the chart review. We then worked on creating the memo that needed to be sent to the IRB. After that, we went to speak to Dr. Lund about how we needed to review results in the future. We also had him call the participants and explain the situation. After returning, I made copies of the corrected results and mailed them to the participants. After lunch, I worked on my study documents until 2:00. I then went with Randi to the PCC to process our afternoon participants.

November 2

In the morning, I checked the recruitment schedule and organized the recruitment paperwork from the carnival. In addition, I completed the conversions and high/low risk forms for the participants on the previous day. I then worked on my study documents until 2:00. We then went to the PCC to wait for our afternoon participants. The participants did not show up so we returned to the office. I helped Randi set up the folders and materials for our Monday appointments. I then continued working on my study documents until it was time to leave for the day.

Week 12: November 5-9

November 5, 2012

We had 5 participants on the schedule for this day. In the morning, we processed one participant from 8:30-10:30. After that, we prepared all of the documents and materials for the second participant and went to lunch. After lunch, we processed another participant until 2:30. We then continued preparing documents and processed our last participant from 3-5:30.

November 6, 2012

In the morning, I took the charts from the previous day and made all of the conversions. After that, I took the lab results to Dr. Ball to have her review and sign. I then made copies of all of the results forms and mailed them to the participant's parents. After lunch, I made changes to my proposal until 2:30. I then went to the PCC to prepare all of the documents and materials for our participants at 3. They had to reschedule so I went back to the office and continued working on my proposal.

November 7, 2012

We had a participant at 8:30 so I went to the PCC at 8 to set up our materials. The participant rescheduled so I went back to the office. I continued making changes to my proposal and emailed the corrections to Dr. Fulda for review. After lunch, I made 20 folders for the Diabetes study. We then had a participant at 3:45. The participant did not show up so I went back to the office and continued working on my IRB documents until it was time to leave.

November 8, 2012

I worked on my IRB documents until 10:00. I then went to the PCC to prepare all documents and materials for our participant at 10:30. We then processed the participant from 10:30-12:30. After lunch, I worked on my daily journal and IRB documents until 2:30. I then went back to the PCC to prepare materials and documents for our participants at 3:00. We then processed them until 5:30.

November 9, 2012

In the morning, I completed the charts from the participants we had earlier in the week. I then worked on my IRB documents until it was time for our participant to arrive. I went to the PCC to set up the materials and documents for the participants but they did not show up for the appointment. After lunch, I made additional changes to my proposal and continued working on my IRB documents until it was time to leave.

Week 13: November 12-16

November 12, 2012

We had a participant on the schedule in the morning so I arrived early to help set up the documents and materials. The participant did not show up so we returned to the office. I then worked on my IRB documents until lunch. After lunch, I filled out the necessary forms for graduation and submitting my proposal and worked on my daily journal entries. I then met with Dr. Fulda to discuss all of my IRB documents. After our discussion, I made the final changes to my proposal and made changes to the IRB documents until it was time to leave for the day.

November 13, 2012

I came in late due to a doctor's appointment. After I arrived, I took the lab results to the PCC to have one of the physicians review them. The physician was busy and asked me to come back around 12:30. Randi and I took the results back to have them reviewed. Once they were signed, I made copies of them and mailed them to the participants. I then finished making corrections to my proposal and filling out the documents I needed to submit to the graduate school. I also continued working on my IRB documents so they can be sent to Anna to be reviewed.

November 14, 2012

In the morning, I met with Randi to look at the Seminary schedule. I noticed there were two appointments in the afternoon. I worked on my IRB documents and emailed the drafts to Dr.

Espinoza for review. I also continued working on my proposal documents needed to submit it to the graduate office. After lunch, I met with Dr. Kirchhoff to have her sign my proposal document and COI. I then went to Seminary to recruit subjects for the DMMX study and then returned to the office. I dropped off my paperwork to Dr. Gwirtz office for her signature on my proposal and intent to graduate forms. I then continued working on my practicum project until it was time to leave for the day.

November 15, 2012

In the morning, I continued working on my practicum project documents and daily journal. I took an early lunch and then returned in the afternoon. I continued working on my practicum project documents and term paper for my degree until the end of the day.

November 16, 2012

I checked in with Randi in the morning. I then continued working on my practicum project documents. I also worked on my daily journal entries and other items for my degree. We then had 2 Thanksgiving parties in the department and I attended those. After lunch, I continued working on those documents until 2:30. I then went to Randi's office and gathered the documents and supplies necessary to process our participant at 3:00. I then went with another member of the research team to process the participant until 5:00.

Week 14: November 19-23

November 19, 2012

I arrived at the PCC to begin processing our participant at 8:30. I set up all of the materials but the participant did not show up. There was another participant on the schedule for 9:30. I worked on my IRB documents in the student computer room while the other research team members waited for the 9:30 participant. That participant did not show up so we returned to the office. After lunch, I went to Seminary for recruitment with a member of the research team. After we returned, I continued working on my IRB documents until it was time to leave for the day.

November 20, 2012

We had a participant scheduled at 8:30 so I arrived and helped set up the documents and materials for that participant. We processed them until 10:30 then returned to the office. I then continued working on my IRB documents until lunch. After lunch, I went to Seminary to recruit patients for the Diabetes study. After I returned, I made additional edits to my IRB documents then turned them in to Dr. Fulda for review.

November 21, 2012

We had a participant scheduled at 8:30 so I arrived at the PCC to help set up the documents and materials needed. The participant did not show up so I returned to the office. I received

additional feedback on my IRB documents and then headed to lunch. After lunch, we had another participant scheduled for 1:00. We processed that participant until 2:30 and then had another participant on the schedule at that time. We processed the last participant and then left for the day.

November 22-23

I was out of the office on these days due to the Thanksgiving holiday.

Week 15: November 26-30

November 26, 2012

In the morning, I spoke to Randi and received the Seminary schedule from her. I noticed that there were 4 appointments in the afternoon. I then went to my office and finished the lab results and high/low risk form for one of our participants. I then worked on corrections to my IRB documents until lunch. After lunch, I went to Seminary to recruit for the diabetes study. After recruitment, I returned to the office and continued working on the lab results and high/low risk forms for two of our participants last week. I gave the charts to Dr. Fulda for review. After that, I made additional copies of some of the forms needed for the diabetes study and worked on my daily journal entries. I then finished the corrections and printed them for Dr. Fulda's review.

November 27, 2012

In the morning I made final changes to my IRB documents and sent to Dr. Fulda and Dr. Espinoza for the final review. While they were reviewing those documents, I created a sign in sheet for the COPD training session on Wednesday. I then received the corrections to my documents and made the changes. I then made copies of the IRB documents for me, Dr. Espinoza and the IRB. After lunch, I walked the documents down to the IRB. I then worked on creating the Master list for the diabetes study. I then went home because I was not feeling very well.

November 28, 2012

In the morning, I went to Randi's office and got the charts that needed to be reviewed and signed by a physician. I took them to the PCC and had Dr. Ball review them. Once I returned, I made copies of the lab results and mailed them to the participant's parents. After lunch, we had a training session for the COPD study at the PCC. I took the sign in sheet and attended the training session until 2:30. After that, I went back to my office and created lab requisition sheets for the diabetes study.

November 29, 2012

In the morning, I met with Randi and looked at the recruitment schedule. In addition, she gave me the correct responses for the COPD study surveys. Later that morning, I received an email from the IRB regarding changes that needed to be made on my study documents. Dr. Fulda said she would call them after lunch to get clarification. After lunch, Dr. Fulda informed me of what

needed to be changed on my documents so I began making those changes. Once they were complete, I emailed them back to Dr. Fulda for her review.

November 30, 2012

We had a participant on the schedule at 10:00. We arrived at the office and looked at the Seminary schedule. Dr. Fulda also asked me to start scoring the COPD surveys and writing down the areas where each participant needs more information for the PACE office. I worked on that until 9:30 then went to the PCC to set up for our participant. They did not show up so we went back to the office and I continued to work on the COPD surveys until lunch. After lunch, I continued to work until 2:30 because we had another participant on the schedule at 3. We then processed that participant until 5:00.

Week 16: December 3-7

December 3, 2012

In the morning, the research team met with Dr. Fulda to discuss data entry for the Diabetes study. Also, Dr. Fulda told me that my documents were approved and ready for pick up so I walked down to the IRB and picked up the originals of my study documents. I then made copies of them and gave the originals to Dr. Fulda. I then continued working on the COPD surveys until lunch. After lunch, I did my journal entries for the previous week. I also continued working on the COPD surveys until it was time to leave for the day.

December 4, 2012

In the morning, I began typing out the responses on the COPD surveys. I took a small break to finish my journal entries and give a copy to Dr. Fulda for review. I then continued working on the COPD surveys until late afternoon. After I finished, I emailed the information to Dr. Fulda. Once that was complete, I put all of the COPD folders back in the cabinet and began working on my research project. I made copies of my survey and cover letter. I then helped Randi get the materials ready for our next participant which was coming in on Wednesday morning.

December 5, 2012

In the morning, I met Randi at the PCC to process our participant. The participant did not show up so we returned to the office. I then put my surveys together so that they would be ready for me to start the recruitment process. I then went through the charts from the Diabetes study to make sure everything was complete before our chart review on Thursday. Randi then asked that I help her with grades for the Clinical Medicine course. We worked on that until late afternoon. After returning to the office, I continued going through all of the documents in the diabetes folders until the end of the day.

December 6, 2012

I arrived at work around 11:00 following a doctor's appointment. I met with Randi and we discussed what I needed to work on for the day. I then went to the PCC to get the COPD sign in sheet and the diabetes folders. Upon returning, I made hanging folders for our Diabetes

participants and organized them in Randi's office. I then got a COPD folder and training session sign in sheet to take with me to Seminary. Around 1:30, I headed to the Seminary clinic. While there, I discussed the COPD study with one of the new physicians and administered his consent documents and pre-survey. Once they were complete, I made sure all of the residents signed in for the COPD training session and then headed back to the office. I gave the sign in sheets and information to Randi before leaving for the day.

December 7, 2012

In the morning, I met with Dr. Fulda and Randi to do another chart review for the Diabetes study. Once we completed the review, we attended a department Christmas party. After lunch, I made changes to the COPD survey results document until 1:00. I then went to Seminary to recruit patients for the Diabetes study. After returning, I finished the COPD survey results and emailed the document to Randi and Dr. Fulda.

Week 17: December 10-14

December 10, 2012

In the morning, Randi and I met with Dr. Fulda to discuss what she wanted us to work on for the week since she would be attending a conference. I then talked to Randi about places we can use for recruitment. In the afternoon, Randi and I went to Seminary to recruit for the Diabetes study. We also went to the Tarrant County Public Health Office to drop of flyers for the Diabetes study. After we returned to the office, I called some of the Fiesta grocery store locations to see if we can recruit subjects there.

December 11, 2012

In the morning, I went with a member of the research team to Seminary to recruit for the Diabetes study. We were there until lunch. After lunch, I went to the PCC with Randi to help her move some of the blood samples from one freezer to another. We also had to continue watching the freezer to make sure the temperature was correct. By the time we finished moving the samples, it was time to leave for the day.

December 12, 2012

In the morning, I went to Randi's office to get the Seminary schedule in order to recruit for the Diabetes study. Randi and I then discussed what needed to be done during the day. I then went to the library to get a keyboard for a study she is working on. I then continued working at my desk until lunch. After lunch, I attended the December birthday office party. After that, Randi and I went to the PCC to get the last of the blood samples and move them to the EAD. After finishing that, I continued working at my desk for the rest of the day.

December 13, 2012

In the morning, I began working on recruitment for the diabetes study. I began researching Catholic churches in the area. I gathered information from their website on upcoming events and church services. I also compiled a list of stores and other places for recruitment. I also passed out surveys to people employees at the PCC and in our office. In the afternoon, I called a few of the locations on my list and asked a few questions regarding recruitment. I gave the information to Randi and we called Dr. Fulda regarding questions about recruitment. When I finished with recruitment, I gathered surveys from all of the participants in our office and the PCC.

December 14, 2012

In the morning, I checked the Seminary schedule and saw an appointment on the schedule for the afternoon. I then continued working on recruitment for the diabetes study by researching more Catholic churches. After lunch, I presented the information to Randi. We then began brainstorming more places for recruitment. I then left to go to Seminary for the late afternoon appointment. The appointment was a no-show and I went home after the appointment.

Week 18: December 17-21

December 17, 2012

In the morning, I looked at the clinic schedules to see if there were any patients that would work for the Diabetes study. I then went with Randi to recruit at the Pediatric clinic in the PCC. We found two people who were interested in participating in the study. One did not show up but the other one came around 2:30. We processed that participant and left for the day after we finished.

December 18, 2012

In the morning, I finished processing the paperwork from the participant on Monday. I completed the high/low risk form and results form and gave them to Dr. Fulda for review. I then looked at clinic schedules for recruitment. There weren't any appointments so I continued working on my research project until the afternoon. After lunch, Dr. Fulda completed reviewing the chart so I took it to the clinic to have the results form signed. After it was signed, I mailed the document to the participant's parent. After that, I continued working on my research project until the end of the day.

December 19. 2012

In the morning, I looked at the schedules for Seminary and the PCC. They did not have patients on the schedule so I began calling some of the Catholic churches. I worked on this until lunch. After lunch, I made a sign in sheet for the COPD training and went to the training to have all of the participants sign in. After that, I continued calling more churches until it was time to leave for the day.

December 20, 2012

In the morning, I began looking for Dr. Fulda's breastfeeding documents so we can start on the IRB submission. I did this until 9:30 and then went to the PCC to process another participant. After processing them, I attended the team Christmas luncheon until 1:30. After that, I continued working on the IRB documents for Dr. Fulda.

December 21, 2012

In the morning, I called more Catholic churches for Diabetes recruitment. A few of them asked for copies of the flyers so that they could get them approved by their Pastors or administrative offices. I then worked with Randi on the email and emailed the documents to them. After that, I worked on the breastfeeding protocol until lunch. After lunch, Randi and I processed a participant until the end of the day.

December 24-January 1

School closed: Christmas Vacation

Week 19: January 2-4

January 2, 2013

We had two participants scheduled on this day so we went to the PCC to process them at 8:30. It took us until 12:00 to finish processing these participants. After lunch, I briefly met with Dr. Fulda and discussed what I needed to work on for the rest of the week and for my thesis project. After that, I finished processing the charts from the appointments before the break so they could be filed. After finishing that, I completed my travel vouchers so they could be processed. In addition, I completed my daily journal and gave a copy to Dr. Fulda for review.

January 3, 2013

In the morning, we looked at the clinic schedules for the day. We then gathered all of the materials and documents to process sibling participants at the PCC. I went with a member of our research team to process participants at 10:00. We finished processing these participants by lunch. After lunch, I completed the charts from the appointments on the previous day. I then made some research binders for Randi and worked on Dr. Fulda's protocol until it was time to leave for the day.

January 4, 2013

In the morning, I went to the Pediatric clinics to recruit participants for the Diabetes study. The participants agreed to participate after their appointment in the Pediatric clinic. We processed them from 10:30 until 1:00. After lunch, I completed the charts from the previous day and mailed the results to them. I also called one of the Catholic churches to follow up with them about a possible recruitment opportunity. After that, I worked on Dr. Fulda's breastfeeding protocol until the end of the day.

Week 20: January 7-11

January 7, 2013

In the morning, I looked at the clinic schedules and discussed the items I needed to work on with Randi and Dr. Fulda. I then went with a member of the research team to move blood samples from a freezer in the PCC to a freezer in the EAD. After completing that, we went to the Pediatric clinic to screen and possibly recruit participants. There was a patient that met our criteria later in the afternoon so we went back to the office. We completed more tasks until it was time to go back to the PCC. After screening, I went to lunch then headed to Seminary to do more recruitment. After returning, I completed the charts from Friday's appointment so they can be reviewed by Dr. Fulda. I also completed a note to file for the Diabetes study.

January 8, 2013

I checked in with Randi in the morning. We looked at the Seminary schedule and PCC schedule to see if there were any possible appointments. The appointments were in the afternoon so I updated my daily journal. After completing that, I finished my timeline for Dr. Fulda and emailed it to her for her review. After lunch, I talked to Dr. Fulda about my timeline. She suggested that I email my committee members to check their availability and then schedule a room. I emailed my committee then went to Seminary to recruit and screen participants for the Diabetes study. After that, I updated my daily journal until it was time to leave.

January 9, 2013

In the morning, I checked Seminary's schedule and found someone that meets our criteria in the afternoon. I then received emails back from my committee regarding their availability. I began working with Keith on finding an available room that meets the availability of my group. Once I secured a room, I sent an appointment to my committee members. After lunch, I went to Seminary to recruit for the Diabetes study. After I returned, Randi asked that I work on creating a schedule for the research assistants. I also updated the aliquot tube and Quest payment spreadsheets.

January 10, 2013

In the morning, I checked the Seminary schedule and found a few morning patients that might work for our Diabetes study. I then worked on my daily journal and created my Declaration of Intent to Defend form. After finishing those, I went to Seminary to do recruitment for the Diabetes study. After lunch, I began reading archived theses to figure out how I need to write my paper. I also continued helping Randi catch up on other paperwork until it was time to leave for the day.

January 11, 2013

After arriving at work, I checked the Seminary schedule and noticed a morning appointment that might work for our Diabetes study. I left at 9:00 and went to Seminary. After recruiting at

Seminary, I continued planning out my thesis final report and completing the necessary paperwork for my practicum project. After that, I attended the TPI and School of Public Health Works in Progress (WIPS) meeting from 12:00-1:00. After attending that meeting, I went with Randi and Dr. Fulda to the Pediatric study meeting to learn about their progress. After that, I went back to the office to get recruiting materials and went to the Peds clinic to try to recruit participants. They did not have anyone on the schedule that met the Diabetes study requirements so I went back to the office. Randi asked that I begin making regulatory binders for our different studies. I worked on that until it was time to leave for the day.

Week 21: January 14-18

January 14, 2013

Randi was out sick on this day so Dr. Fulda asked that I email her to get the Seminary schedule and email the research coordinator on the Pediatric diabetes study to get the recruitment schedule for the Peds clinic. After doing both of those items, I worked on my practicum project. The research coordinator emailed me back and let me know that she would not be screening from 12:00 until the end of the day. I went to lunch early and then went back to the Peds clinic to look at their schedule. They had 2:15, 3:45 and 4:15 appointments that would work for our study. I then went back to the office and worked on my practicum project until it was time to go back to the Peds clinics for these appointments. After screening, I returned the screening forms and recruitment materials to the office and talked to Dr. Fulda about what I needed to work on tomorrow.

January 15, 2013

There was inclement weather on this day so I arrived at the office late. Dr. Fulda and I then discussed my database for my thesis project. She showed me how to create a database in SPSS and how to enter data in the database. I then worked on creating my database until it was time to go home for the day.

January 16, 2013

In the morning, I continued working on my thesis project while I waited for the Seminary schedule to be forwarded from Randi. Later that morning, I began doing some recruitment for my practicum project. Once I finished, I went to lunch. After lunch, I went to the PCC to get a screening form from another research coordinator. I then worked with Dr. Fulda to coordinate all of the research assistant's schedules and sent out appointments to everyone. I then went to talk to one of my committee members. I had my declaration of intent to defend form signed and I returned to the office. I finished up a few things and headed home for the day.

January 17. 2013

In the morning, I checked the Seminary schedule and went to the Pediatric clinic in the PCC to check their schedule. I waited for a few patients to show up but they did not show up for their

appointments so I returned to the office. I then worked on my practicum project until the next appointment. I then went to the clinic around 11:50 and screened two potential participants. After lunch, I sent a schedule to all of the DM MX study research assistants and updated my daily journal.

January 18, 2013

In the morning, I checked the Seminary schedule and saw a few morning appointments that met the criteria for our Diabetes study. I went to Seminary and recruited participants until 10:00. I then took an early lunch. After lunch, I checked in with Randi and gathered materials for an appointment we had on the schedule at 1:00. The participants did not show up so we went back to the office. I then worked on data entry for my research project until 3:00. I left early to take my daughter to an appointment.

Week 22: January 21-25

January 21, 2013

School closed due to MLK Holiday

January 22, 2013

In the morning, I talked to Randi about the participants that were processed on the 18th and 21st. I also checked the schedules for the PCC and Seminary. After that, I began finishing up processing the previous participants' charts. Once they were complete, I gave them to Dr. Fulda for review. I then updated my daily journal and updated my travel reimbursement document. After lunch, I continued working on my daily journal and continued entering data for my thesis project into my database. I then went to Seminary at 3:30 to recruit possible participants for the Diabetes study.

January 23, 2013

In the morning, I checked in with Randi and discussed recruitment for the Diabetes study. I then checked the PCC and Peds schedules for possible participants. I then worked on entering data into my database for my thesis project for about an hour. I then did some recruitment for my thesis project and went to the Peds clinic to screen a patient of theirs before lunch. The patient wanted to stay and participate in the study after their appointment at the Peds clinic. We processed that participant from 1:30-3:30. We then moved blood samples from the PCC to the EAD freezer and put all of the materials back in Randi's office. I then worked on data entry for my thesis project until it was time to leave for the day.

January 24, 2013

In the morning, I got the clinic schedules from Randi. There was an appointment on the schedule at 10:50 so I finished processing the paperwork and lab results from the participant on Wednesday. I then went to Seminary to do recruiting for the Diabetes study. After lunch, I

updated my travel spreadsheet and daily journal and continued my data entry until 4:00. I then helped Randi with a few items before leaving for the day.

January 25, 2013

In the morning, I went to the Peds clinic to recruit for the Diabetes study. I spoke to one patient and then returned to the office. I then worked on my thesis project until I returned to the Peds clinic around 10:30. The patient wanted to participate in the study after their appointment so I returned to the office to get all of the materials. We processed the participant from 10:30-12:30. After lunch, I updated my travel reimbursement spreadsheet and daily journal. I also sent my thesis database to Randi and showed her how to enter the data into it for double data entry.

Week 23: January 28-February 1

January 28, 2013

In the morning, I checked in with Dr. Fulda. She asked that I check the clinic schedules. There was a morning appointment on the schedule at Seminary so I went by there to recruit participants for the Diabetes study. When I returned, I had the charts from last week signed by a physician at the PCC. I then finished the lab results form and high/low risk form for the participant we had on Friday. After lunch, I got all of the signed lab results ready and mailed them to the participant's parents.

January 29, 2013

In the morning, I checked in with Randi. There were a few morning appointments at Seminary so I went there around 9:45. I spoke to 3 patients before returning to the office. After lunch, I went to the PCC to make copies Randi needed for a meeting. I then brought them back to the office. I later returned to the PCC to make additional copies, get supplies for Dr. Fulda's breastfeeding study and get charts to bring back to the office. I then returned to the office and put the IRB copies in the correct order. Later, I updated my daily journal and travel reimbursement spreadsheet. I also entered new surveys into the database and began planning my thesis final report.

January 30, 2013

In the morning, I went to the PCC to check the schedule. They had a 9:15 and 9:45 on the schedule so I stayed and tried to recruit those patients for the Diabetes study. I then returned to the office and saw that Seminary had a patient that might work for our study so I worked on my thesis project for 30 minutes and then went to Seminary. After returning from Seminary, I went to my advisor's office to drop off paperwork and then went back to the Peds office to screen more patients. After lunch, I went back to the Peds clinic to get the afternoon schedule, make copies of IRB documents and get a chart signed. Upon returning to the office, I sent the lab results to our previous participant and then returned to the Peds clinic to screen the 2:30 and 3:00

appointments. I then worked on my thesis and discussed job options with Dr. Fulda before leaving for the day.

January 31, 2013

In the morning, I went to the Peds clinic to look at their schedule. They did not have any patients that would work for the Diabetes so I returned to the office. I then worked on my thesis project until lunch. After lunch, I continued working on my thesis project until 2:00. I then went back to the Peds clinic to check the afternoon schedule. I then went back to the office to make copies and put together folders for the Diabetes study. One of the research assistants also came to the office to start the double data entry for my thesis project. I worked with her on that and continued putting together folders. After finishing the folders, I helped Randi gather recruitment materials for the following day.

February 1, 2013

In the morning, I checked the Seminary clinic for available appointments and checked emails. I then gathered all of the materials and went to the PCC to process the 10:00 appointment. I processed that participant until 11:30. I then helped Randi set up the materials for the 12:00 appointment. After lunch, I went back to the PCC to process another participant at 1:30. That participant did not show up so I returned to the office to work on my thesis project until it was time to leave for the day.

Week 24: February 4-8

February 4, 2013

I was not in the office on this day due to my child being sick.

February 5, 2013

I checked in with Randi and looked at the clinic schedules for the day. I then went to the office and finished processing the charts from Friday and Monday. I then gave them to Dr. Fulda for review. After lunch, I updated my travel reimbursement form and daily journal and turned them in for review. I then worked on my thesis until 2:30. At 2:30, I went to the PCC to process two participants. After waiting for 30 minutes, we realized the participants were not going to show up so we returned to the office and I continued working on my thesis until the end of the day.

February 6, 2013

I went to the Peds clinic in the morning to look at their schedule. I went back to the office to check emails and then returned to Peds to screen some of their patients. After screening, I went to the office to get some charts and then returned to the PCC to have them signed. I then mailed them to the participants' parents. After lunch, I helped one of the research coordinators and assistants to move blood samples from one freezer to another. I then went to the PCC to process a participant at 3:00. This participant did not show up, so I returned the materials to the office and then continued working on my thesis until the end of the day.

February 7, 2013

I arrived a little late on this day due to a doctor's appointment. When I arrived, I helped Randi process a participant until 1:30. I then moved our blood samples from the PCC to the EAD to be stored in the freezer. After lunch, I took some paperwork to the IRB and updated my daily journal. I then worked on updating my timeline for Dr. Fulda's review.

February 8, 2013

In the morning, I checked the Peds clinic schedule and Seminary schedule. I stayed in the Peds clinic and tried to recruit patients for the Diabetes study. I then left the clinic and returned to Randi's office to gather the materials for a participant we had on the schedule at 10:30. I then went to the PCC to process that participant. They did not show up so I called the participant's mother and rescheduled their appointment. I then returned to the office to continue working on my thesis project before lunch. After lunch, I checked the Peds schedule for the afternoon. They did not have any patients that would work for our Diabetes study so I returned to the office. I worked in the office until 2:30 then headed to the PCC to help another research assistant process a participant. We processed them until 4:30. We then put the materials back in Randi's office and headed home for the day.

Week 25: February 11-15

February 11, 2013

I checked all of the clinic schedules in the morning. There were not any appointments that would work for the Diabetes study so I went to the office to begin working. I updated my timeline for my thesis project and emailed it to Dr. Fulda. I then finished processing our participant's chart from Friday and gave it to Dr. Fulda for review. After lunch, I made a reminder call to the participant scheduled on 2/12/13. They rescheduled so I changed the appointment on the calendar. I then worked on recruiting for my thesis project and writing my thesis final report until the end of the day.

February 12, 2013

In the morning, I checked the clinic schedules for the day. I then called Seminary to check on two of the appointments on their schedule. The 10:00 and 10:20 appointments would work for the Diabetes study so I went to Seminary to try and recruit them. The 10:00 did not show up and the 10:20 was not interested in participating so I headed back to the office. I recruited a few participants for my thesis project before lunch. After lunch, I continued recruiting for my thesis project and writing my thesis final report. I then met with Dr. Fulda to discuss my timeline and my thesis final report. I continued working on the report until it was time to leave for the day.

February 13, 2013

In the morning, I went to the Peds clinic to look at the schedule for the morning. They had a few appointments later in the morning so I came back to the office. I updated my travel reimbursement document and daily journal. I then went back to the Peds clinic to recruit participants for the Diabetes study. After that, I returned to the office to continue working on my thesis report until lunch. After lunch, I went back to the Peds clinic to recruit participants for the Diabetes study. After that, I went to Family Medicine and recruited participants for my research project and had the lab results from our participant signed. After returning to the office, I mailed the lab results to one participant and prepared the lab results for another participant and gave them to Dr. Fulda for review. I then continued working on my thesis project until it was time to leave for the day.

February 14, 2013

In the morning, I checked the schedules for the day. I did not notice any appointments that would work for us so I began working on recruiting for my thesis project. I went around to the clinics and office and asked people to complete my study. I then went back to the office and worked on my report until lunch. After lunch, I went back to the office and clinics to pick up as many surveys as I could. I then continued working on my thesis report until the end of the day.

February 15, 2013

I went to the Peds clinic in the morning to check their schedule for the day. I noticed a few appointments later in the morning. I went back to the office and started working on my thesis project. Randi then asked me to set up the new Tanita machine and weigh a few people to see if it was consistent with our old machine. We had a participant on the schedule at 10:00 so I returned to the PCC. The participant did not show up so I began working on setting up the new machine and weighing people on it. After lunch, I tried to collect the last of the surveys I was waiting on and worked on my thesis report. We had a participant at 3:00 so I went to Randi's office to get the materials for the appointment. I also talked to Dr. Fulda about the Tanita results. She asked that we weigh ourselves 3 times on each machine to check for consistency. I went back to the PCC and waited for our participant. They did not show up so I checked on the Tanita machine again and returned to the office with the results. Dr. Fulda was pleased with the consistency so she asked that I set up an appointment with the other members of the research team to train them. I emailed them and continued working on my thesis until the end of the day.

Week 26: February 18-22

February 18, 2013

In the morning I checked on the schedules for the clinics and did not notice any appointments that would work for us. I then went to the PCC to check on the freezer and model number for the new Tanita machine so that we can order supplies for it. I then returned to the office to work on my thesis until lunch. After lunch, I recruited a few participants for my study and continued working on my thesis report until the end of the day.

February 19, 2013

We had a participant scheduled on this day so I went to the PCC in the morning to process that participant. We processed the participant and blood samples until 11:20. I then moved the samples from the PCC to the freezer in the EAD. I then updated the Aliquot tube notebook. After lunch, I worked on writing my thesis for the rest of the day.

February 20, 2013

In the morning, I went to the Peds clinic to check the schedule. They had a few appointments closer to lunch so I headed back to the office. I then finished processing the participant's chart from the day before and took it back to Randi's office. I then went back to the office to work on my thesis report. Around 12:00, I went back to the Peds clinic to try to recruit for the Diabetes study. The patients did not show up. After lunch, I continued working on my thesis report until it was time to leave for the day.

February 21, 2013

In the morning, we had a participant on the schedule. I went to the Peds clinic around 9:00. The participant did not show up so I brought the materials back to the office. I then responded to a few emails. Around 10:00, I went back to the Peds clinic to wait for the 11:00 appointment to show up so that I could try to recruit them for the Diabetes study. While waiting, I recruited a few people for my thesis study. The patient did not show up so I headed to lunch. After lunch, I continued working on my thesis until 3:00. I then took the chart from the other day down to the Peds clinic to have it signed by a physician. The results were then mailed. I updated my daily journal until it was time to leave for the day.

February 22, 2013

In the morning, I checked the clinic schedules and went to the Peds clinic to recruit for my thesis study and the Diabetes studies. I stayed there until lunch. After lunch, I continued entering the questionnaires into the database and began doing double data entry on the questionnaires that were previously entered. I then worked on my thesis final report until the end of the day.