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Newborn screening (NBS) results in a surplus of blood samples in the form of dried bloodspots (DBS). Texas's "opt-in" policy requires mothers' permission for the state to store DBS samples for research. A cross-sectional study was performed on post-partum mothers in North Texas to determine the effect of the mothers' demographics, knowledge, attitudes, and decisions about NBS and DBS storage on trust in Texas' ability to make good decisions regarding bloodspot research.

The aforementioned trust in the Texas government was strongly associated with trust in Texas to keep the babies' information private, belief that using DBS for public health was beneficial, and trust in Texas to de-identify their babies' DBS. Medicaid coverage also showed a slight association with this trust. Overall, mothers who are supportive of public health research using de-identified specimens such as DBS are more confident in the Texas's ability to make the right choices regarding DBS storage.

A CROSS-SECTIONAL STUDY ON FACTORS
AFFECTING MATERNAL TRUST IN TEXAS
GOVERNMENT TO MAKE GOOD DECISIONS
ABOUT NEWBORN SCREENING AND DRIED
BLOODSPOT STORAGE

THESIS

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Huy David Dang Nguyen, B.A.

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LIST OF ABBREVIATIONS

NBS = newborn screening

DBS = dried bloodspots

TDSHS = Texas Department of State Health Services

MAK-NBS = Maternal Attitudes and Knowledge about Newborn Screening Survey

S9 = Statement 9: “I know what newborn screening bloodspots are.”

S12 = Statement 12: “I wish I had more information about newborn screening.”

S13 = Statement 13: “I trust the people in the Texas Lab to keep my baby’s name and other information private.”

S14 = Statement 14: “I trust the state of Texas to make good decision about who should get to use my baby’s bloodspots for research.”

S15 = Statement 15: “Doing research on public health problems is a good way to use infant bloodspots from newborn screening.”

S17 = Statement 17: “It would be OK for the state to share my baby’s bloodspots with researchers if my baby’s name or other private information is not connected to the blood sample.”

S22 = Statement 22: “I GAVE THE STATE PERMISSION TO STORE MY BABY’S BLOODSPOTS AND SHARE THEM WITH RESEARCHERS.”

THFW = Texas Health Harris Methodist Hospital Fort Worth

THPL = Texas Health Presbyterian Hospital Plano

THAM = Texas Health Arlington Memorial Hospital

CHAPTER 1

INTRODUCTION AND BACKGROUND

Newborn screening (NBS) is a medical procedure and public health program that identifies potential conditions that can affect a child's long-term health. This mandatory process, unless rejected for religious reasons, is conducted in all 50 states and the District of Columbia. Early detection, diagnosis, and treatment of 55 genetic, metabolic, and endocrine diseases via NBS can prevent death and disability (Newborn Screening, 2015). Potential diseases tested include cystic fibrosis, sickle cell disease, phenylketonuria, and fatty acid disorders (Quick Reference, 2013). Children born with these conditions normally appear healthy at birth and come from healthy families, so parents who are carriers of these diseases may not expect any problems. However, detection of these diseases, many of them incurable but treatable, by NBS can have a tremendous effect on a child's quality of life (Newborn Screening - Frequently Asked Questions, 2015).

NBS involves pricking the heel of the infant and collecting blood samples, in the form of dried bloodspots (DBS), onto a bloodspot card. This process, usually performed out of sight of the parents, is harmless and does not disrupt the baby's safety. In Texas, two blood samples, one collected 24 to 48 hours after birth and the other collected one to two weeks after birth, are sent to the Texas Department of State Health Services (TDSHS) public health laboratory in Austin to analyze the samples and release the results to the baby's doctor. If an abnormal lab result is detected, the baby's physician will notify the parents and provide directions regarding immediate care and additional testing for the child (Newborn Screening - Frequently Asked Questions, 2015).

Since 2002, after routine DBS testing for potential diseases is complete, TDSHS securely stores the bloodspot cards until it is required to destroy them. The department may use the bloodspot cards to develop new tests, perform quality assurance checks, and conduct public health studies inside TDSHS. However, in order to conduct public health studies outside of TDSHS, parents must give permission. The bloodspots in these cases would not include any identifiable information from the baby or the parents. If the parent gives permission, the state of Texas would store the baby's bloodspots for up to 25 years for use in research outside of TDSHS. Otherwise, the bloodspot card would be stored only for up to two years before being destroyed (Newborn Screening - Frequently Asked Questions, 2015).

While NBS is clearly beneficial and mandatory for parents for the long-term health of their newborn babies, DBS had until recently been stored for years without parental consent, and it has been a controversial topic in recent years, especially in Texas. In 2009, a federal lawsuit was filed by the Texas Civil Rights Project on behalf of five plaintiffs against defendants TDSHS and Texas A&M University. The plaintiffs alleged that neglecting to provide parental consent for indefinite DBS storage was an act of unlawful search and seizure, and they feared their children's personal health information may be misused by the state. The resulting settlement forced Texas health authorities to destroy more than five million blood samples that were stored without parental consent between 2003 and 2009. The Texas government would soon provide legislation in response to this lawsuit to ensure proper consenting procedures for DBS usage outside of TDSHS. In 2010, Texas passed an "opt-out" policy on NBS and DBS, informing parents of newborns about DBS storage and giving them the option to refuse permission for the state to store their baby's DBS for research (Root, 2010).

After one year with the “opt-out” policy, Texas Legislature wanted to improve the DBS collection program by increasing transparency and the accountability of TDSHS. In 2011, the government changed the NBS policy, choosing to enforce an “opt-in” method starting in 2012. With this policy, parental permission is required for the state to store their baby’s DBS for up to 25 years. Other regulations were enacted to ensure proper handling of the bloodspot samples. For instance, de-identified blood samples may only be released for “public health purposes” related to cancer, infectious disease, and chronic disease. Additionally, the DBS biobank can only be accessed by researchers outside of TDSHS with explicit approval from the TDSHS Commissioner and the department’s Institutional Review Board. Finally, TDSHS must state every approved disclosure on its public website (New Law, 2011).

The change from an “opt-out” to an “opt-in” policy has been driven by two factors. First, an “opt-out” strategy tends to have a higher subject turnout than an “opt-in” strategy, and it is the recommended default strategy for low-risk studies; however, the subjects’ understanding of the intervention via the “opt-out” strategy may be poorer as a result of diminished awareness and knowledge (Junghans, 2005). Second, parents may perceive NBS and DBS storage as a high-risk procedure, which will affect their decision to allow DBS storage in Texas. This point of view may also increase their understanding of NBS. For example, a study conducted in an emergency department with computerized kiosks for nontargeted rapid HIV screening concluded that the high risk of HIV resulted in patients demonstrating a higher understanding and turnout of the procedure through an “opt-in” consent despite having a lower agreement rate than that of the “opt-out” consent method (Haukoos et. al., 2012). Therefore, it could be argued that a better understanding and awareness of the benefits and risks along with a more positive attitude of DBS

storage may influence parents' trust in the state of Texas to make good decisions regarding its policies on NBS and DBS.

The 2009 lawsuit and the two policy changes suggest that maternal knowledge and attitudes regarding NBS and DBS storage remain lacking. In 2013, a study using the Maternal Attitudes and Knowledge about Newborn Screening Survey (MAK-NBS), a questionnaire with statements about knowledge, attitudes, and opinions on NBS and DBS storage, examined Texas post-partum mothers' knowledge about NBS and their attitudes toward state retention of DBS for research purposes. The study determined that basic education about NBS and DBS was inadequate, with the bulk of education provided by the post-partum nurses. Also, the mothers tended to believe that DBS storage for research was beneficial. However, being Hispanic or African-American/Black predicted disagreement with many of the attitude statements regarding the sharing of DBS with researchers (Newcomb et. al., 2013).

Although the previous study focused on general maternal knowledge of NBS and DBS storage, it did not report on mothers' trust in the process. Because it took many years of storing bloodspots without parental consent before Texas legislation was passed, post-partum mothers may be wary of the state government's ability to enforce good policies on giving non-TDSHS researchers access to these specimens. This research project hoped to expand on this subject by gauging mothers' trust in the Texas government on DBS storage and determining potential factors that may affect it.

CHAPTER 2

PROBLEM

The objective of this project was to assess the strength of association between post-partum mothers' trust in the state of Texas to make good decisions regarding access to their babies' bloodspots for research, versus several factors potentially impacting such trust, including these mothers' demographics, knowledge, attitudes, and decisions on NBS and DBS storage.

Specifically, the question was as follows:

How was the outcome variable, the level of trust of mothers of newborns in the state of Texas to make good decisions about who should get to use their babies' bloodspots for research, correlated to the following predictor variables?

- Age
- Race/ethnicity
- Level of education
- Health insurance
- Best source of information about newborn screening
- The extent of the mothers' knowledge about newborn screening
- The extent of the mothers' desire to learn more about newborn screening
- Trust in the TDSHS laboratory to keep the babies' name and other information private
- The degree to which the mothers believe that doing research on public health problems is a good way to use infant bloodspots from newborn screening
- Agreement that Texas can share bloodspots with researchers if the babies' name and other information are not connected to the blood sample

- The mothers' decisions whether or not to give Texas permission to store their babies' DBS for research purposes

Some demographics have been shown to have an effect on agreement or disagreement of various statements of the MAK-NBS in the 2013 study on maternal knowledge of NBS and DBS storage (Newcomb et. al., 2013). It was expected that the same would occur in this study towards the outcome variable with respect to age, race/ethnicity, level of education, and health insurance.

The suggestion that mothers are not well informed of NBS and DBS storage may also have an effect on trust in the Texas government regarding DBS access from non-TDSHS researchers. Perhaps mothers who have more knowledge of the procedures may have increased trust while those who wish for more NBS education may have decreased trust.

The remaining predictor variables have been chosen based on the idea that if mothers are accepting of the system in place to administer NBS and DBS retention, they may be more likely to have trust in the Texas government regarding DBS storage decisions.

CHAPTER 3

DESIGN AND METHODOLOGY

The project was a cross-sectional study that used data from 12 questions listed on the Maternal Attitudes and Knowledge about Newborn Screening Survey (MAK-NBS) consisting of 31 items written in the English language. The first 21 items of the MAK-NBS contain statements about knowledge, attitudes, and opinions on NBS and DBS storage, and the survey asks subjects to express agreement for each statement on a 1-5 scale with 1 being “strongly disagree,” 2 being “disagree,” 3 being “not sure,” 4 being “agree,” and 5 being “strongly agree.” The 22nd survey item requests the subject’s prior decision whether or not to opt-in for Texas’s bloodspot storage policy. The final nine items elicit demographic information. The investigators of a previous study developed this survey to identify any problems with reading level, translation, or confusion with items. The study was conducted alongside Dr. Patricia Newcomb’s ongoing study, “Maternal Knowledge and Attitudes Regarding State Retention of Newborn Bloodspots for Research Purposes,” which was already approved by the Texas Health Resources Institutional Review Board. Dr. Newcomb’s study also uses data from the MAK-NBS.

Specifically, the outcome variable was the response to Statement 14 (S14): “I trust the state of Texas to make good decision about who should get to use my baby’s bloodspots for research.”

The predictor variables to be used in this project were as follows:

- “My age is”
- “My race/ethnic group is”
- “My level of education is”

- “My care for this birth will be paid for by”
- “I learned the **MOST** about newborn screening from”
- Statement 9 (S9): “I know what newborn screening bloodspots are.”
- Statement 12 (S12): “I wish I had more information about newborn screening.”
- Statement 13 (S13): “I trust the people in the Texas Lab to keep my baby’s name and other information private.”
- Statement 15 (S15): “Doing research on public health problems is a good way to use infant bloodspots from newborn screening.”
- Statement 17 (S17): “It would be OK for the state to share my baby’s bloodspots with researchers if my baby’s name or other private information is not connected to the blood sample.”
- Statement 22 (S22): “I GAVE THE STATE PERMISSION TO STORE MY BABY’S BLOODSPOTS AND SHARE THEM WITH RESEARCHERS.”

Using these eleven predictor variables and the outcome variable, multivariable regression modeling with ordinal and categorical variables was used on the data. Data analysis was conducted via SPSS Statistics software to determine correlations and the strength of the associations between the predictor variables and the outcome variable. Potential study sites from which data would be collected included the post-partum units of seven Texas Health Resources hospitals: Texas Health Harris Methodist Hospital Fort Worth (THFW), Texas Health Harris Methodist Hospital Alliance (THAL), Texas Health Presbyterian Hospital Denton (THD), Texas Health Presbyterian Hospital Plano (THPL), Texas Health Arlington Memorial Hospital (THAM), Texas Harris Methodist Hospital Southwest Fort Worth (THSW), and Texas Health Harris Methodist Hospital Cleburne (THC).

All human subjects who participated in the study completed a paper-and-pencil version of the MAK-NBS starting in August 2015. At least 650 participants are expected to respond to the survey for the duration of Dr. Newcomb's study, which will last beyond the time period of this internship. However, this practicum project utilized as many MAK-NBS responses as possible by late October 2015. With a desired statistical power level of 0.8 and a probability level of 0.05, the minimum required sample size to achieve an anticipated medium effect size (f^2) of 0.15 for a multivariable regression study with eleven predictor variables was 122.

Eligible participants were parents who received care in a post-partum hospital unit. Subjects were able to participate if they spoke and read English, their babies received newborn screening at the study site, and their babies were healthy. Parents were eligible if they were 18 years of age or older, regardless of health status. Parents of babies who were admitted to the neonatal intensive care unit were excluded to prevent increased stress on the parent. No population defined by regulations as "vulnerable" was included in this study.

The target population was mothers of newborns in North Texas from the three most widespread ethnic groups (African-American, Caucasian, and Hispanic). The survey was offered to all eligible mothers regardless of ethnic phenotype because the subjects defined ethnicity, thus, ethnicity was known only after completion of the survey. Previous work in the area indicated that the sample would be representative of the population (Newcomb et. al., 2013). Post-partum or nursery nurses accomplished recruitment of survey participants by handing each patient a survey or introducing the treatment patient to a research team member. The survey included a cover letter explaining the study. The nurses and research staff retrieved completed surveys from subjects any time during the admission up to and including discharge.

CHAPTER 4

DATA ANALYSIS AND RESULTS

Sample Characteristics

Data collection began in early August 2015 and concluded on October 27, 2015. The sample consisted of 176 post-partum mothers from THFW (58 responses), THAM (92 responses), and THPL (26 responses). The majority of the mothers were between 18-35 years old and either Caucasian/White (43.2%), African-American/Black, (22.2%) or Hispanic (31.8%). Approximately 72.2% stated their level of education as “Some college” or further; 46.6% were covered by Medicaid, and 25.6% had private health insurance. Over half of the mothers obtained their best newborn screening knowledge from nurses in the hospital after delivery.

Less than half of the mothers agreed that they knew what newborn screening bloodspots were, and 66.5% wished they had more information about the topic. Approximately 85.3% trusted the Texas Lab to keep their babies’ names and other information private, and 54.5% were agreeable with the state sharing de-identified bloodspots with researchers. Approximately 60.8% agreed that doing research on public health problems was a good way to use infant bloodspots, and 73.9% trusted the state of Texas to make good decisions about who should get to use the bloodspots for research. Regarding the opt-in procedure, only 26.7% gave the state permission to store their babies’ bloodspots for researchers to use; however, 34.7% did not remember their decision. Characteristics and responses of the sample are presented in Tables 1 and 2.

Table 1: Characteristics of Sample of Post-Partum Mothers in Study

Variable	Number	Percent of Total
<i>Study site</i>		
THFW	58	33
THAM	92	52.3
THPL	26	14.7
<i>Age</i>		
18-24 years	53	30.1
25-30 years	74	42
31-35 years	35	19.9
36+ years	11	6.3
<i>Race/Ethnicity</i>		
Caucasian/White	76	43.2
Hispanic	56	31.8
African-American/Black	39	22.2
Asian	9	5.1
<i>Education</i>		
Less than high school	10	5.7
High school diploma	36	20.5
Some college	69	39.2
Bachelor's degree	42	23.9
Master's degree or more	16	9.1
<i>Health insurance</i>		
Medicaid	82	46.6
Private	45	25.6
None	3	1.7
<i>Best source of newborn screening</i>		
Nurse in hospital	92	52.3
Family doctor or midwife	24	13.6
Internet	21	11.9
Baby's doctor or nurse practitioner	13	7.4
<i>S22: Gave state permission to store bloodspots for researchers</i>		
Yes	47	26.7
Don't remember	61	34.7
No	67	38.1
<p><i>Abbreviations: THFW = Texas Health Harris Methodist Hospital Fort Worth; THAM = Texas Health Arlington Memorial Hospital; THPL = Texas Health Presbyterian Hospital Plano; S22 = Statement 22.</i></p> <p><i>Total number of participants = 176</i></p>		

Table 2: Knowledge, Attitudes, and Opinions on Newborn Screening and Dried Bloodspot Storage

Statement	% Agree or Strongly Agree	Mean (Standard Deviation)
S9: I know what newborn screening bloodspots are.	48.3	3.45 (1.09)
S12: I wish I had more information about newborn screening.	66.5	3.76 (1.11)
S13: I trust the people in the Texas Lab to keep my baby's name and other information private.	85.3	4.21 (0.83)
S14: I trust the state of Texas to make good decisions about who should get to use my baby's bloodspots for research.	73.9	3.94 (0.98)
S15: Doing research on public health problems is a good way to use infant bloodspots from newborn screening.	60.8	3.76 (1.02)
S17: It would be OK for the state to share my baby's bloodspots with researchers if my baby's name or other private information is not connected to the blood sample.	54.5	3.43 (1.2)
<i>Scale is from 1 [Strongly disagree] to 5 [Strongly agree] with 3 = [Unsure]</i>		

Correlations

The outcome variable of trust in Texas was tested for correlation with all the predictor variables. No correlations were found between the outcome variable and the following predictor variables: knowledge of newborn screening, wishing for more knowledge in newborn screening, age, race/ethnicity, level of education, insurance, and best source of education about newborn screening.

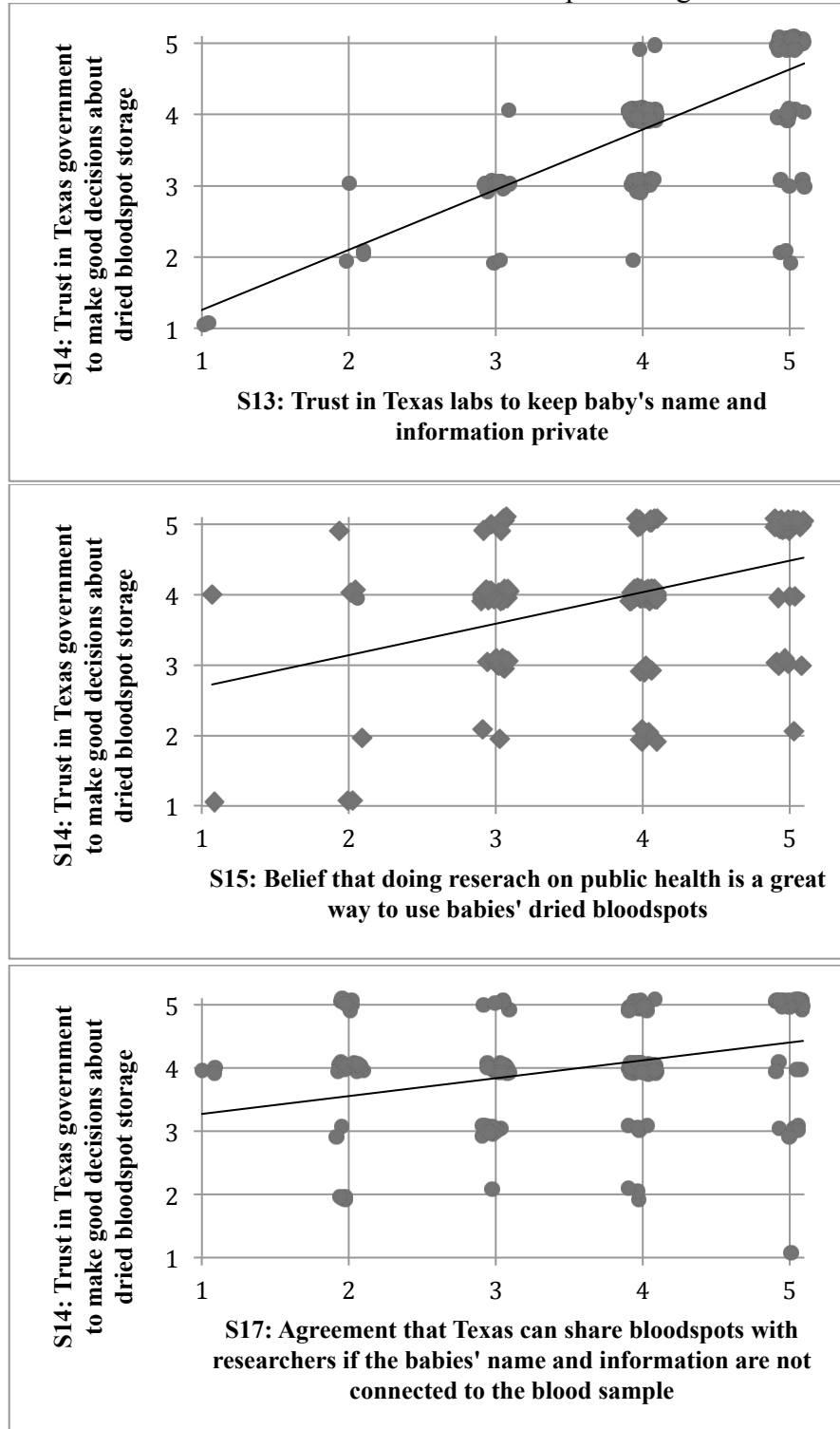
The outcome variable had a strong positive correlation with trust in the Texas Lab to keep the babies' name and other information private ($r = 0.682, p < 0.001$). Furthermore, a weak positive correlation was found between the outcome variable and believing that Texas could share bloodspots with researchers if the babies' information was removed from the blood sample ($r = 0.344, p < 0.001$). A moderate positive correlation was found between the outcome variable

and believing that conducting research on public health is a good way to use infant bloodspots from newborn screening ($r = 0.418, p < 0.001$). Finally, correlations were detected regarding the decision to opt-in to the bloodspot storage program; choosing “yes” had a weak positive correlated with the outcome variable ($r = 0.201, p = 0.008$), and choosing “no” had a weak negative correlation with the outcome variable ($r = -0.294, p < 0.001$). Table 3 shows an overview of the correlations, and the Figure 1 visualizes the three most positive significant correlations.

Table 3: Significant Correlations Related to Trust in Texas to Make Good Decisions About Dried Bloodspot Storage

Statement	Pearson coefficient <i>r</i>	<i>p</i> -value
S13: I trust the people in the Texas Lab to keep my baby's name and other information private.	0.682	< 0.001
S15: Doing research on public health problems is a good way to use infant bloodspots from newborn screening.	0.418	< 0.001
S17: It would be OK for the state to share my baby's bloodspots with researchers if my baby's name or other private information is not connected to the blood sample.	0.344	< 0.001
S22: [YES] I GAVE THE STATE PERMISSION TO STORE MY BABY'S BLOODSPOTS AND SHARE THEM WITH RESEARCHERS.	0.201	0.008
S22: [NO] I GAVE THE STATE PERMISSION TO STORE MY BABY'S BLOODSPOTS AND SHARE THEM WITH RESEARCHERS.	-0.294	< 0.001

Figure 1: Jitter Scatter Plots Showing Significant Positive Correlations Related to Trust in Texas to Make Good Decisions About Dried Bloodspot Storage



Scale is from 1 [Strongly disagree] to 5 [Strongly agree] with 3 = [Unsure]

Multivariable Regression

Three models of multivariable regression, summarized in Table 4, were used with the outcome variable at a significance level of 0.05. The first model included all the stated predictor variables. The second model utilized a stepwise approach using SPSS to determine the best fitting model for the scenario. The third model utilized four predictor variables: S13 (trust in Texas Lab to keep baby's info private), S15 (believing that doing research on public health problems is a good way to use babies' bloodspots), S17 (agreeing that Texas can share de-identified bloodspots with researchers), and Medicaid coverage.

The first model with all predictor variables was adequate (adjusted $R^2 = 0.457$, $F = 4.661$, $p < 0.001$). Of all the predictor variables, S13 ($p < 0.001$), S15 ($p = 0.022$), S17 ($p = 0.011$), and Medicaid coverage ($p = 0.044$) were found to be significant predictors of trust in Texas to make good decisions about DBS access for researchers. These four predictor variables would be used for the third multivariable regression model.

With the stepwise regression function in the second model, the best fitting model (adjusted $R^2 = 0.496$, $F = 50.867$, $p < 0.001$) had S13 ($p < 0.001$), S15 ($p = 0.006$), and S17 ($p = 0.001$) as significant predictors of the outcome variables. Unlike the first model, Medicaid coverage was not chosen as a significant predictor.

Finally, with the third model (adjusted $R^2 = 0.537$, $F = 48.496$, $p < 0.001$) involving S13, S15, S17, and Medicaid coverage, the significant predictors determined were S13 ($p < 0.001$), S15 ($p = 0.007$), and S17 ($p = 0.001$). Again, having Medicaid coverage was not significantly associated with the outcome variable in this model.

Table 1: Multivariable Regression Models (Significant Level = 0.05) with Outcome Variable = Trust in Texas to Make Good Decisions About Newborn Screening and Dried Bloodspot Storage

Multivariable Regression Model	Adjusted R ²	F statistic	Significant Predictor Variables
#1: All predictor variables were entered	0.457	4.661	S13 ($p < 0.001$), S15 ($p = 0.022$), S17 ($p = 0.011$), and Medicaid coverage ($p = 0.044$)
#2: Determined by stepwise regression, choosing S13, S15, and S17 as predictor variables	0.496	50.867	S13 ($p < 0.001$), S15 ($p = 0.006$), and S17 ($p = 0.001$)
#3: Predictor variables entered were S13, S15, S17, and Medicaid coverage	0.537	48.496	S13 ($p < 0.001$), S15 ($p = 0.007$), and S17 ($p = 0.001$)
<i>Abbreviations: S13 = "I trust the people in the Texas Lab to keep my baby's name and other information private."; S15 = "Doing research on public health problems is a good way to use infant bloodspots from newborn screening."; S17 = "It would be OK for the state to share my baby's bloodspots with researchers if my baby's name or other private information is not connected to the blood sample."</i>			

CHAPTER 5

DISCUSSION

The practicum project aimed to examine potential relationships between the outcome variable, post-partum mothers' trust in the Texas government to make good decisions about NBS and DBS storage, and various predictor variables including the mothers' demographics, knowledge, attitudes, and decisions regarding the process. Conclusions were made regarding sample characteristics, significant correlations between the outcome variable and various predictor variables via the Pearson correlation coefficient r , and the determination of significant predictors of the outcome variable via multivariable regression.

The research sample of 176, higher than the minimum number of 122 needed to achieve a medium effect size with eleven predictor variables in a multivariable regression model with a statistical power level of 0.8 and a probability level of 0.05, collected a variety of responses from mothers in the Fort Worth, Arlington, and Plano communities, resulting in an adequate representation of new mothers in the North Texas Area. As expected, mothers were between 18 to 35 years of age; however, the ethnic distribution of mothers in the sample suggests under-sampling of Caucasian/White mothers and over-sampling of African-American/Black and Hispanic mothers. This is not surprising as the Caucasian population is aging in the area, resulting in relatively less females capable of bearing a child (Ramsey et. al., 2011). Additionally, the over-sampling of the other two groups may be due to immigration trends since 2000 as well as the race/ethnicity profile of the residences surrounding the three hospitals (QuickFacts, 2014).

Results regarding general knowledge of NBS and DBS are similar to those reported in the previous MAK-NBS study. With less than half of the sampled mothers knowing what bloodspots

are and over half of them wishing to learn more about NBS, it is clear that education about the topic is still inadequate and, therefore, needs improvement. Despite the lack of general knowledge about NBS, most mothers seem to be trusting of the Texas labs and government to protect their babies' private information and make good decisions about DBS retention, respectively. This may be because NBS and obtaining bloodspots from the babies is a mandatory and relatively harmless procedure, resulting in mothers being more willing to let the state of Texas handle the blood samples.

All mothers in Texas are supposed to be educated on NBS and the opt-in process by the hospital staff in order to ensure a well-informed decision on DBS storage. However, it is surprising that over a third of the sampled mothers did not remember their decision. This may be yet another indication that education about NBS and DBS storage is lacking, but it is also possible that some nurses are not informing the mothers about the opt-in procedure at all, electing either to choose the decision themselves or to show an absence of a decision. This potential bypassing of parental consent would violate the Texas law set in 2012, suggesting that the original issue of storing DBS without consent is still prevalent. Perhaps the decision whether or not to "opt-in" (S22) was not shown to be a significant predictor of trust in the Texas government to make good decisions about DBS storage because of the large number of mothers not remembering their decision. It is worth noting that mothers who chose "yes" are slightly more likely to be trusting of the Texas government according to the weak correlation in Table 1 while mothers who chose "no" are more likely to have the opposite attitude.

The correlations and multivariable regression analyses clearly show that the outcome variable, trust in the Texas government to make good decisions about DBS storage, is associated with trust in Texas to keep the baby's name and other information private, a positive attitude

about using infant bloodspots for public health research, and agreement that Texas can use bloodspots if the baby's name and other info are not connected to the blood sample. In other words, mothers who are supportive of public health research using de-identified specimens such as DBS are more confident in Texas's ability to make the right choices in this area. The other possible important predictor variable, Medicaid coverage, was shown to be significant only in the first multivariable regression model. This would make sense since a mother that is covered by a governmental health care program for low-income individuals may be more trusting in another governmental policy regarding NBS and DBS storage. However, this relationship is still unclear as Medicaid coverage was shown to not have a significant association with the outcome variable in the other two models.

Finally, besides Medicaid coverage, none of the other demographic information seems to have any correlation or predictive indication for the outcome variable. This again may be affected by the lack of general knowledge of NBS and DBS, resulting in little difference between different demographic groups with respect to trust for the Texas government regarding this subject. However, in the previous study with the MAK-NBS, being Hispanic or African-American/Black predicted disagreement with a few statements in the survey (Newcomb et. al., 2013), so it seems that trust regarding DBS storage is not as sensitive of a topic as the other statements.

CHAPTER 6

LIMITATIONS AND FUTURE WORK

Although the results are very conclusive, there are limitations and opportunities for improvement. One limitation is that while surveys were collected at three varying areas in North Texas, the inequality of surveys received from each site may impact the generalizability of the sample to new mothers in the North Texas area. Each post-partum unit had its own system in distributing the MAK-NBS to the mothers, and some systems were more effective than others. For example, the clinical nurse specialist at THAM was very diligent in passing out surveys in person to the majority of mothers in the post-partum unit during the data collection period, resulting in the largest number of responses out of the three study sites. On the other hand, THFW's post-partum unit opted to insert the MAK-NBS into every mother's newborn education packet, increasing the chances of the mother taking the survey home without ever filling it out and returning it; Dr. Newcomb eventually administered the surveys herself in person but not at the same frequency as the nurse scientist at THAM. It may be possible to create a protocol in which the nurse scientist or post-partum staff at each study site administers the MAK-NBS in a specific manner, but time constraints and staff awareness would make this difficult.

Since the MAK-NBS is a voluntary survey, mothers did not have to answer all of the questions, and some even neglected to answer certain demographic questions because they believed them to be irrelevant to the research study, leading to nonresponse bias. However, this was an uncommon occurrence, and the majority of post-partum mothers completed the entire survey. Also, there was the possibility that mothers may not be completely honest with their answers, disrupting the data analysis, but the overall models with the data were shown to be adequate.

Another limitation of this practicum study stems from the nature of the MAK-NBS item responses. Usually multivariable regression analysis is done with scale variables. However, all the variables on the MAK-NBS are ordinal. When doing multivariable regression on ordinal variables, one must assume that there is an equal degree of difference between the various categories, i.e., the difference between “strongly agree” and “agree,” is the same as that between “agree” and “not sure.” This may give slightly different results relative to what could have happened if one were to use a scale, e.g., a score of 1-10, for the items.

A major drawback of this study stems from the high number of mothers who did not remember their decisions to the opt-in policy for DBS storage. Again, this may be an indication that post-partum nurses are not informing the mothers about the DBS storage policy for non-TDSHS research and choosing the response themselves. Thus, the true percentage of mothers who chose to opt-in for DBS storage may be inaccurate. This problem would help explain the weak correlations between the decisions and the outcome variable as well as the lack of association with this predictive variable in the multivariable regression analysis. This can be improved by specifying that post-partum mothers may only be administered the MAK-NBS after making their decisions on whether to give the state permission to store their babies’ bloodspots for researchers. A future study may also explore this decision in more detail by determining the strength of association between the decision and other variables in the MAK-NBS.

Finally, the major conceptual limitation to using any kind of regression analysis is that while one can make conclusions about the correlations between the predictor and outcome variables, the cause-effect relationship will remain uncertain. For example, while trust in Texas labs to keep the baby’s personal information private is shown to be associated with trust in the Texas government to make good decisions about DBS storage via multivariable regression

analysis, there is no way to establish cause-and-effect between these two factors in a survey format. Perhaps determining potential cause-effect relationships like this via experimental-based research in a controlled environment would be a wise decision in future studies.

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Huy David Dang Nguyen

ID: 10992179

CRM Internship Daily Journal 2015

Monday, June 1

- 1) 8:00AM-10:30AM: Went to UNTHSC and LabCorp in the morning to fulfill remaining requirements to register for hospital badge (8:00AM-10:30AM)
 - a) Emailed Derrick for drug test results
 - b) Expected to finish requirements by Wednesday, then schedule orientation
- 2) 11:00AM-4:40PM: Data entry of clinical pastoral education survey from chaplain database, to be used for statistical analysis
 - a) Acknowledged the high frequency of missing data
- 3) 4:40PM-4:50PM: Discussed plan for the week
 - a) I have chosen the clinical trial to base my research thesis off of: "Maternal knowledge and attitudes regarding state retention of newborn bloodspots for research purposes"
 - b) Homework – Research the implications of missing data in statistical analysis as well as solutions to this problem
 - c) Wednesday – Go to UNTHSC to try to have Dr. Gwartz, Dr. Mallet, and Dr. Raven sign committee papers
 - i) Go to Harris Hospital to hopefully schedule orientation
 - ii) Attend "Budgeting: What Every Research Coordinator Needs to Know!" presentation at 6:00PM
 - d) Friday – Assist Dr. Newcomb with the newborn bloodspots research at Alliance Hospital

Tuesday, June 2

- 1) 8:00AM-9:30AM: Read websites – "Treatment of Missing Data" by David C. Howell from University of Vermont
- 2) 9:40AM-11:30AM: Read proposed project by Dr. Newcomb involving secondary analysis of data from electronic medical records of hospital while de-identifying the information
 - a) Main question to answer: Does this study constitute human subject research?
 - i) Pretty much the underlying question is: Does secondary data analysis constitute human subject research?
 - ii) My answer: Not for this particular study because according to 45 CFR 46.101, "the information will be recorded by investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects." Therefore, it is exempt from IRB approval.
- 3) 11:30AM-12:45PM – Met with Dr. Newcomb and Brenda McDonnell on Brenda's proposed study: "Essential Oils for Sleep"
 - a) Went over project details, IRB application questions
 - b) I have been assigned to assist Brenda in drafting the consent and HIPAA forms
 - c) Next meeting with her: June 11 at noon
- 4) 12:45PM-1:15PM – Went over chaplain data entered yesterday
- 5) 1:25PM-2:00PM – Discussed answer on previous secondary data analysis study not being human subject research
 - a) Typed response using 45 CFR 46 as source
- 6) 2:00PM-3:00PM – Read Brenda's study and started looking at consent form
- 7) 3:00PM-3:45PM – More data entry on yesterday's clinical pastoral education survey, this time on inter-rater reliability
- 8) 3:45PM-4:00PM – Brief meeting with Dr. Newcomb

- a) Learned about study regarding ICU care and its problem with obtaining informed consent from critically ill patients

Wednesday, June 3

- 1) 10:00AM-12:00PM – Went to UNTHSC
 - a) Was able to get Dr. Gwartz to sign Pre-Internship papers. Dr. Mallet and Dr. Raven were unavailable.
 - b) I am only missing the drug urine test results from Monday of last week. I tried calling around with little success.
- 2) 12:00PM-3:00PM – Worked on medical school applications. Submitted the TMDSAS primary.
- 3) 3:00PM-3:30PM – Reread Dr. Newcomb's newborn bloodspots study
 - a) Received email from Derrick that UNTHSC's HR department will forward my drug test results to Harris's Volunteer Center
- 4) 6:00PM-7:30PM – Attended "Budgeting: What Every Research Coordinator Needs to Know!" presentation by Jessica Derr at Texas Health Presbyterian Hospital Dallas
 - a) Key concept: Cost Coverage Analysis – a process/document that is a comprehensive analysis and review of all clinical related documents, procedures, and involved parties
 - i) Basis and the guide for your research billing process
 - ii) Determines and identifies who will pay, when they will pay, and how they will pay
 - iii) Can be your budget template
 - iv) Benefits: increased opportunities for revenue, builds trust and credibility with sponsors and administration, increased billing compliance

Thursday, June 4

- 1) 8:00AM-9:45AM – Looked at Brenda's sleep study proposal and started working on consent form
- 2) 10:00AM-11:30AM – Accompanied Dr. Newcomb to her meeting with Dr. Subhrangsu Mandal (Professor of Chemistry and Biochemistry) and Dr. Ajit Alles (Pathologist) over Dr. Mandal's research proposal
 - a) Epigenetics, noncoding RNA
 - b) Looking for biomarkers around genes related to asthma
 - c) Want to screen asthma patients for certain RNA by getting some tissue (blood or urine)
- 3) 12:00PM-2:00PM – More data entry on Chaplain survey, this time on peer inter-rater reliability
- 4) 2:00PM-3:45PM – Consent form for sleep study

Friday, June 5

- 1) 9:00AM-10:00AM – Prepared data entry tables for chaplain study
- 2) 10:00AM-11:30AM – Scoring PSQI surveys and making a data table of answers
- 3) 12:00PM-1:30PM – Sleep study consent form
- 4) 1:30PM-2:30PM – Accompanied Dr. Newcomb and Dr. Jo Wells for the final stages of filming of an informative newborn bloodspot video to be used for the newborn bloodspot research
 - a) Also learned a little more about the study as this will be useful for my research thesis

P. Newcomb

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Monday, June 8

- 1) 8:00AM-9:30AM – Began looking through CITI training for IRB at THR
- 2) 9:30AM-4:00PM – Finished rough draft of consent form for sleep study and emailed it to Brenda
 - a) Also took a look at protocol form for editing
 - b) Will collaborate more with Brenda in the next couple days before Thursday meeting

Thursday, June 9

- 1) 8:15AM-10:00AM – Online CITI training for eIRB account
- 2) 10:00AM-12:00PM – Finally did hospital orientation and obtained ID badge
- 3) 12:00PM-3:00PM – Did remaining CITI training
 - a) Submitted the required documents to THR IRB email
 - b) Will someday attend THR IRB meetings
- 4) 3:00PM-3:30PM – Sleep study consent form

Wednesday, June 10

- 1) 10:00AM-2:00PM – Worked on medical school applications
- 2) 2:00PM-4:00PM – Did some literature review on newborn bloodspots

Thursday, June 11

- 1) 9:00AM-12:00PM – Prepared for meeting with Brenda and Dr. Newcomb on sleep study
 - a) Read documents in progress by Brenda and made changes accordingly to consent form
 - b) Also did some data entry on chaplain questionnaire once that was completed
- 2) 12:00PM-1:30PM – Meeting with Brenda and Dr. Newcomb
 - a) Revised and proofread consent form
 - b) Will meet again with Brenda tomorrow morning
- 3) 1:30PM-3:00PM – Consent form on sleep study; data entry of chaplain questionnaire
- 4) 3:00PM-5:00PM – Accompanied Dr. Newcomb to meeting with breastfeeding research group and learned about cognitive interviewing for a questionnaire they made
 - a) Cognitive interviewing – a process in which the researchers evaluate what the participants think about the questionnaire instructions and questions in order to determine if they need revisions

Friday, June 12

- 1) 8:00AM-9:00AM – Finished chaplain survey data entry
 - a) Dr. Newcomb met with the survey creators and used the data to demonstrate that inter-rater reliability was extremely inadequate
 - i) She will need to meet with them later this year to discuss cognitive interviewing to improve the survey
- 2) 9:00AM-11:00AM – Worked on consent form and IRB protocol with Brenda
- 3) 11:00AM-12:30PM – Meeting with Dr. Newcomb and Brenda

- a) Revised the IRB protocol form for sleep study
- b) Set protocol completion deadline for Tuesday, June 16

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Monday, June 15

- 1) 9:00AM-3:00PM – Working with Brenda on sleep study protocol and consent form in preparation for 3:00PM meeting with Dr. Newcomb
- 2) 3:00PM-4:15PM – Meeting with Dr. Newcomb
 - a) Consent form is nearly finished, just needs proofreading
 - b) Protocol form is nearly finished; Brenda will work on it more for deadline tomorrow

Tuesday, June 16

- 1) 9:00AM-10:15AM – Finished consent form and emailed to Dr. Newcomb and Brenda for review
- 2) 10:30AM-12:00PM – Attended cognitive interviewing session #2 for breastfeeding survey group
 - a) Dr. Newcomb gave advice to two of the survey members as they practiced cognitive interviewing with two practice subjects on their survey
 - i) Told me that I would eventually be conducting a cognitive interviewing session myself, with the chaplain survey group, in August
- 3) 12:30PM-1:45PM – Attended seminar on Leaf Healthcare
 - a) Hospital wants to implement a pilot study for a sensor that monitors turns in patients
 - b) Ultimate goal is to reduce pressure ulcers

Wednesday, June 17

- 1) 9:00AM-2:00PM – Medical school applications
- 2) 2:00PM-4:00PM – Did literature review on informed consent regarding newborn bloodspots
 - a) Also looked into the concept of implied consent

Thursday, June 18

- 1) 8:30AM-9:30AM – Worked on proposal
- 2) 10:00AM-11:45AM – Dr. Newcomb introduced me to an ongoing ED study regarding narcotics use in patients
 - a) Assigned me to organize some data
- 3) 12:00PM-2:00PM – Accompanied Dr. Newcomb to IRB meeting at Cook Children's Hospital
 - a) Concepts reinforced: assent vs. consent, vulnerable populations
 - b) New issues learned: going against manufacturer guidelines for the sake of higher benefit vs. risk
- 4) 2:15PM-3:00PM – Organizing ED narcotics data
 - a) Will continue this tomorrow morning
- 5) 3:00PM-4:00PM – Attended Research Council meeting and took notes for Dr. Newcomb
 - a) Basically planning for Research Symposium event in the coming months

Friday, June 19

- 1) 9:00AM-10:00AM – Continued to work on organizing ED narcotics data, but came across a problem
 - a) Discussed with Dr. Newcomb, and she told me to scratch the project as she will look over it this weekend and tell me a better way to organize it
- 2) 10:00AM-11:15AM – Meeting with Kimberly (a PT) and Michelle on new research proposal that I will assist in
 - a) Pusher syndrome in stroke patients
 - i) Can go away, not a permanent effect
 - b) Want to realign misaligned patients by training them
 - c) Want to apply protocol to acute care patients like in the ICU
 - d) Benefits: decrease inpatient time, increase quality of life compared to giving attention patients at a later stage
 - e) Protocol: Teach nurses how to observe, how to correct
 - f) Design: Dr. Newcomb recommends prospective study, randomized trial, association
 - g) A brand new theory that has not been studied yet, so this study has a lot of potential!
- 3) 12:00PM-1:00PM – Worked on data entry project for Vaginal Delivery Safety Checklist questionnaire
- 4) 1:30PM-4:30PM – Cleaning up ED narcotics data



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Monday, June 21

- 1) 8:30AM-12:00PM – More cleaning up of ED narcotics data
 - a) Database is too large, so I just took the first 1000 patients, and roughly 600 of them were applicable to what Dr. Newcomb was looking for
- 2) 12:30PM-1:00PM – Meeting with Dr. Newcomb and Brenda on sleep study
 - a) Everything is nearly complete, but now we need to fill out the eIRB application online
 - b) Will communicate with Brenda over the next few days to make sure we get this done
- 3) 1:00PM-4:00PM – Worked on eIRB application for sleep study

Tuesday, June 22

- 1) 8:45AM-10:00AM – Added Dr. Newcomb's protocol changes on sleep study to the eIRB application
- 2) 10:00AM-10:30AM – Dr. Newcomb showed me how to fill out the eIRB application for continuing reviews
- 3) 10:30AM-11:00AM – Looked through the ED narcotics data we currently have in preparation for meeting at 11:00AM
- 4) 11:00AM-11:45AM – Attended THFW Chronic Pain / Narcotic Abuse Continuing Improvement Committee meeting with Dr. Newcomb
- 5) 12:30PM-3:30PM – Worked on ED narcotics data

- a) Out of 157 patients that I looked through so far, only 3 submitted Press Ganey surveys...
- 6) 3:30PM-5:00PM – Went over entire eIRB application on sleep study with Dr. Newcomb
 - a) Emailed Brenda our progress and told her to look through everything

Wednesday, June 24

- 1) 10:00AM-2:00PM – Medical school applications
- 2) 2:00PM-4:00PM – Reread Dr. Newcomb's protocol on ongoing newborn bloodspots screening and tried to brainstorm various questions regarding implied consent

Thursday, June 25

- 1) 8:15AM-10:30AM – Looked over Brenda's changes in eIRB application and made corresponding changes to consent form
 - a) Also proofread entire application
 - b) I think it's almost done!
- 2) 10:30AM-10:45AM – Met briefly with Erik Soliz in preparation for attending THR's IRB meeting on July 10
- 3) 10:45AM-12:00PM – Continued work on ED narcotics data
- 4) 12:30PM-2:00PM – Med school secondary essays
- 5) 2:00PM-4:15PM – Continued work on ED narcotics data

Friday, June 26

- 1) 8:45AM-1:00PM – Continued work on ED narcotics data
 - a) Much faster now!

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Monday, June 29

- 1) 8:15AM-12:00PM – ED narcotics data
 - 2) 12:30PM-4:00PM – ED narcotics data
- FINISHED! Thank goodness.

Tuesday, June 30

- 1) 10:00AM-3:00PM – Worked on formatting tables regarding demographics of managers/directors and their feelings about work-related stress, expectations from coworkers and bosses, etc.
- 2) 3:00PM-4:00PM – Worked on literature background for research proposal

Wednesday, July 1

- 1) 10:00AM-12:00PM – Medical school applications
- 2) 1:00PM-3:00PM – Started looking more into literature regarding opt-in vs. opt-out policies since that was mentioned in Dr. Newcomb's protocol on newborn bloodscreens

Thursday, July

- 1) 8:00AM-9:00AM – Finally received the Maternal Attitudes and Knowledge about Newborn Screening (MAK-NBS) survey from Dr. Newcomb's bloodspot study
 - a) Realized that my research proposal will be taking data from this questionnaire
- 2) 9:00AM-4:00PM – Started preparing packets with the MAK-NBS survey for eventual distribution to study partners at the other THR hospitals involved in the newborn bloodspot study
- 3) 4:00PM-4:30PM – Sought advice with Dr. Newcomb on formulating a research proposal question based on MAK-NBS

Friday, July 3

- 1) 8:00AM-9:00AM – Looked over MAK-NBS and thought of a question, but Dr. Newcomb said results from that question would mainly just be descriptive rather than statistical
 - a) Gave me more advice on forming a unique question, i.e. deciding which items would be predictive variables to perform multivariable regression analysis vs. an outcome variable
- 2) 9:00AM-3:00PM – Continued preparing packets with MAK-NBS survey
 - a) Eventually ran out of envelopes, so went home early

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Monday, July 6

- 1) 8:00AM-9:00AM – Spent more time looking at MAK-NBS and finally decided on nine predictor variables for one outcome variable on the survey
- 2) 9:00AM-9:30AM – Discussed research question with Dr. Newcomb, and she agreed that it was a good question
- 3) 10:00AM-2:00PM – Worked on literature background for research proposal
- 4) 2:00PM-4:00PM – Attended meeting with group regarding pusher syndrome
 - a) Much more complex than Brenda's sleep study, but it is very much on its way
 - b) Dr. Newcomb may put me on this study as study staff

Tuesday, July 7

- 1) 8:00AM-9:00AM – Worked on Research Design and Methodology section of research proposal
- 2) 9:00AM-10:00AM – Went to a meeting at a cancer registry regarding publishing a breast cancer study from previous year's intern
 - a) Dr. Newcomb has lost touch with intern, so a new first author was assigned; however, new first author is hesitant on publishing the manuscript because she wants second opinions from others and physicians
 - i) Therefore, others will read the manuscript and hope to provide feedback by next week
- 3) 11:00AM-12:00PM – Visited Allison to help her with her eIRB application
 - a) Then a coworker of Allison's came in, and Allison gave a 30-minute intense crash course on catheter UTIs
 - i) Best crash course I've had yet

- 4) 12:00PM-1:30PM – Attended “lunch” meeting at Clinical Pastoral Education (CPE) department (the department with the unreliable questionnaire tool)
 - a) Dr. Wayne Menking, the potential PI, admitted that the questionnaire was too wordy, was too unreliable, and needed to be shortened
 - i) Presented a new version of the questionnaire with less questions but not necessarily better wording
 - (1) Questionnaire will undergo cognitive interviewing next month
 - ii) Explained that his boss wants to see “results” on how well CPE is doing on educating its students and residents, hence why he wants to use the questionnaire for a potential study
- 5) 2:00PM-4:00PM – Was assigned to draft a protocol about cognitive interviewing process on CPE questionnaire
 - a) Wording on some parts is similar to that of the breastfeeding cognitive interviewing study, so I was given a copy of that protocol

Wednesday, July 8

- 1) 8:00AM-12:00PM – Worked on Problem/Hypothesis and Significance section on research proposal
- 2) 1:00PM-3:00PM – Medical school applications

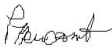
Thursday, July 9

- 1) 8:00AM-12:00PM – FINISHED preparing MAK-NBS packets (400 in total)
- 2) 1:00PM-2:00PM – Worked on updating newborn bloodspot newsletter to send to the other study sites
- 3) 2:00PM-3:00PM – Did a little more work on CPE cognitive interviewing proposal
 - a) Went home early to get some rest before attending THR IRB meeting tomorrow morning

Friday, July 10

- 1) 7:30AM-9:30AM – Attended THR IRB meeting
 - a) Substantially more members
 - b) Cases were more complex than those at Cook Children’s Hospital
 - c) Overall was interesting
- 2) 10:00AM – Was told by Dr. Newcomb to meet Dr. Jo Wells at Texas Health Alliance hospital to trial the newborn bloodspot screening video
- 3) 11:00AM-12:00PM – Looked over video with Dr. Newcomb and Dr. Wells
 - a) Took notes on good and bad parts of video
 - b) Ultimately want to cut length (currently 8 minutes) down to 3-5 minutes
- 4) 12:00PM-1:00PM – Met with staff at Texas Health Alliance

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Monday, July 13

- 1) 9:00AM-12:00PM – Was given task by Dr. Newcomb to compile all nursing schools in Texas that offer a BSN as well as all medical schools

- a) Then search each school's website for faculty emails
- b) Ultimately want to create a sample frame for a complaints study
- 2) 12:30PM-3:00PM – Continued work on complaints study task
 - a) Was overwhelmed by all the faculty members from the medical schools, so we decided to only stick with schools in the DFW region

Tuesday, July 14

- 1) 8:00AM-4:00PM – Continued work on compiling faculty emails from nursing and medical schools in DFW
 - a) Too much typing
 - b) Learned that the study only needed a sample size of nine
 - i) Ended up compiling list of 688 names and emails
 - (1) Faculty from all DFW nursing schools, internal medicine staff of UT Southwestern

Wednesday, July 15

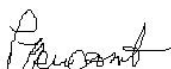
- 1) 10:00AM-2:00PM – Completed summary section of research proposal
- 2) 2:00PM-4:00PM – Added more information to literature review section of research proposal

Thursday, July 16

- 1) 10:00AM-12:00PM – More work on research proposal
- 2) 1:00AM-2:00PM – Took a look at IRB response to Brenda's sleep study and made some changes
 - a) Brenda is still on vacation, so we will not be able to properly submit the changes until about the end of the month
- 3) 2:00PM-5:00PM – More fixing on research proposal

Friday, July 17

- 1) 8:00AM-8:30AM – More fixing on research proposal
- 2) 9:00AM-12:30PM – Attended Core Nurse Science meeting with Dr. Newcomb at THR Corporate in Arlington
 - a) Nurse scientists provided updates on their studies at the meeting
 - b) Passed out paper surveys to the other nurse scientists present at the meeting
 - c) Other sites that may be interested
 - i) Kathy Baldwin – may use Martha's cover letter instead
 - ii) Sam at Stephenville
 - d) Other topics: social media policy, THR research symposium, HR delays in reviewing research, etc.
 - e) Also showed the shortened 6-minute version of the newborn screening video
- 3) 1:30PM-4:00PM – Reviewed research proposal draft with Dr. Newcomb and submitted it



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Monday, July 20

- 1) 8:30AM-11:30AM – Worked on proposal revisions based on Dr. Mallet’s feedback
- 2) 12:00PM-3:30PM – Prepared the majority of the 200 additional packets of MAK-NBS surveys
- 3) 3:30PM-4:30PM – Added section in proposal with an example of multivariable regression analysis

Tuesday, July 21

- 1) 8:30AM-11:00AM – Worked on edits on Brenda’s sleep protocol
- 2) 12:00PM-2:00PM – Prepared the remainder of the MAK-NBS packets
 - a) Still need more envelopes
- 3) 2:00PM-2:30PM – Read Dr. Newcomb’s 2013 NBS study, then deleted it from hard drive
- 4) 3:00PM-4:00PM – Doing a little more literature review on my research project

Wednesday, July 22

- 1) 10:00AM-2:00PM – Med school applications
- 2) 2:00PM-3:00PM – Read through Dr. Newcomb’s edits on sleep study documents

Thursday, July 23

- 1) 9:00AM-11:00AM – Made appropriate edits on sleep study protocol and emailed them to Brenda for her to review
- 2) 11:30AM-3:45PM – Worked on antepartum data entry for Joy
 - a) Finished most of it and submitted spreadsheet to Dr. Newcomb

Friday, July 24

- 1) 9:00AM-10:00AM – More literature review on research project
- 2) 10:15AM-10:15AM – Read through pending journal article of Dr. Newcomb’s colleague about delivering hand massage with essential oils to critically ill patients
- 3) 11:30AM-12:30PM – Worked on remainder of Joy’s antepartum data entry spreadsheet and submitted completed spreadsheet to Dr. Newcomb
- 4) 1:00PM-2:00PM – Med school applications
- 5) 2:00PM-3:30PM – Was given a research review assignment by Dr. Newcomb as the employee at Azle who normally does the task for July is no longer employed there
 - a) Found article in American Journal of Medicine entitled “Long-term Adherence to Healthy Dietary Guidelines and Chronic Inflammation in the Prospective Whitehall II Study”
 - i) Read through the article, will do the research review next week



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Monday, July 27

- 1) 8:30AM-10:30AM – Reread research review article, annotated it, and took notes in detail
- 2) 10:30AM-3:00PM – Worked on research review assignment for the article

- 3) 3:00PM-3:30PM – Briefly did more data entry for Joy’s antepartum study
- 4) 3:30PM-5:00PM – Attended Dr. Newcomb’s meeting with Joy regarding her antepartum study
 - a) Also worked through research review assignment during meeting and submitted it to Dr. Newcomb
 - b) I’ll be helping Joy make a poster on this topic

Tuesday, July 28

- 1) 9:00AM-10:30AM – Worked a little on research project
- 2) 11:00AM-12:45PM – Sat in with Dr. Newcomb’s session with Amanda over study regarding Leaf Healthcare
 - a) I may eventually be part of the study staff, but right now they’re working on the protocol
- 3) 2:00PM-2:45PM – Attended update meeting on Pusher Syndrome study
- 4) 3:00PM-4:30PM – Worked with Dr. Newcomb and Brenda to finalize changes to IRB documents for sleep study
 - a) I made a mistake and did not save a “track changes” version of those documents last week, which is what the IRB wants along with a clean version
 - i) Thankfully Dropbox retains previous copies of your files, so I found an earlier version with the track changes still available
 - ii) LESSON LEARNED – don’t mess with the IRB
 - b) Revised documents have been uploaded to eIRB application and submitted

Wednesday, July 29

- 1) 10:00AM-3:00PM – Med school applications

Thursday, July 30

- 1) 9:00AM-12:00PM – Dr. Newcomb told me we should get started on completing amendment to her bloodspot study to add TH Cleburne, TH Southwest, and TH Stephenville to the study while adding Dr. Samantha Pehl and Dr. Kathy Baldwin as study staff
 - a) Began work on revising protocol to account for new changes
 - b) Also started amendment on eIRB website
- 2) 1:00PM-4:00PM – Received email from Dr. Wells at Alliance Hospital regarding newborn bloodspot video
 - a) Needed popup link at the very end to direct participants to the electronic survey

Friday, July 31

- 1) 8:00AM-11:00AM – Continued working on protocol changes for bloodspot project
 - a) Emailed a final copy to Dr. Newcomb
- 2) 10:30AM-2:00PM – Arrived at Alliance Hospital to view video with Dr. Newcomb and Dr. Wells
 - a) Watched video a few times and documented the cuts we needed to make the video under six minutes in length
 - b) Also wanted to add captions or bulletpoints to scene with a still picture and Emily talking about the participants rights as a human research subject
 - c) Still could not figure out how to add link to survey at end

- i) But spoke to Rudy Loremo of IT at the hospital, and he suggested uploading it to YouTube
- (1) Task has been assigned to me



Mentor Signature: _____

Monday, August 3

- 1) 8:00AM-11:00AM - Obtained signatures from all three committee members for research proposal and degree plan and turned it into administration office
- 2) 11:00AM-12:00PM – Notified Jason Noles (coworker who did the bloodspot video) of the changes needed, and we sat together to work on the video changes for a little bit
- 3) 1:00PM-4:00PM – Was assigned a task to do a literature search on alcohol and elderly trauma
 - a) Did an initial literature search and only found four articles

Tuesday, August 4

- 1) 9:00AM-2:00PM – Continued work on literature search and created a pinch table of sources on the topic as well as their summaries and findings
- 2) 2:15PM-4:00PM – Found a detailed paper called “Alcohol and injuries in elderly people” from the 1990s with lots of information and cited studies, so will read that the next day

Wednesday, August 5

- 1) 10:00AM-2:00PM – Secondary applications and reading the detailed paper from yesterday


Thursday, August 6

- 1) 8:00AM-9:00PM – Spoke to Kimberly Williams of post-partum unit about the administering of MAK-NBS surveys
 - a) YES! We can now finally collect samples for my research project!
- 2) 9:00AM-12:00PM – Continued literature review of alcohols and injuries in elderly people
- 3) 1:00PM-5:00PM – Sat down with Jason and made final changes to bloodspot video, including adding the captions
 - a) Eventually created an unofficial “Bloodspot Study” YouTube account and uploaded the video, setting it to private
 - b) Created an annotation to add MAK-NBS survey link for participants to click
 - i) However, in order to link to a SurveyMonkey link, you need to own the website, and since THR does not own SurveyMonkey, this would be a problem to be discussed

Friday, August 7

- 1) 7:30AM-9:30PM – Attended IRB meeting at THR
 - a) Very productive meeting with many different studies approved
 - b) Lots of drug trials and continuing reviews
- 2) 10:00AM-12:00PM – Researched ways to add annotation to end of bloodspot video

- a) Had to suffice with adding a text annotation with a link to survey that participants can copy and paste
 - i) But this may be difficult to enforce since the video would be viewed on bedside tablets
- b) Told Dr. Newcomb about problem, and she agreed that this would be a problem
- 3) 12:00PM-3:00PM – Drove to Alliance Hospital to meet with Dr. Wells, show her the final video, and present video to Research Council meeting there
 - a) Dr. Wells and I thought the video looked as good as it could be
 - i) We acknowledged the annotation problem and emailed Rudy from IT about it
 - b) Bad news... IT department at Alliance did not think video met marketing standards of the hospital, so they will not allow us to show the video on their bedside tablets
 - i) Came during Research Council meeting, so I was disappointed as well
 - ii) Still showed video to council, and they thought it was good as well
 - c) Now I understand what Dr. Newcomb and Dr. Wells meant when they said there were too many steps of approval for this video, from the script to marketing standards (even though the project is not even for marketing)
 - d) Told Dr. Newcomb about this
 - i) She was also disappointed but okay with it, said we would remove Alliance from the intervention site list and use a portable DVD player at Fort Worth instead, where we wouldn't have to worry about marketing standards



Mentor Signature: _____

Monday, August 10

- 1) 9:00AM-12:00PM – Dr. Newcomb is on vacation this week, so she gave me permission to have a light week as well
 - a) Went up to post-partum unit to start collecting surveys
 - b) No surveys were administered yet, but I reminded Kimberly and the staff about their task
 - i) Dr. Newcomb told me that when she did this in the past, the post-partum unit was historically difficult to cooperate with since they would often be too busy to pass out surveys

Tuesday, August 11

- 1) 9:00AM-11:00AM – Went up to post-partum unit to check on surveys
 - a) Two surveys were collected, and I started an Excel spreadsheet to enter in data
- 2) 11:00AM-12:00PM – Went to UNTHSC Student Health Clinic to clear up remaining hold on account regarding vaccinations

Wednesday, August 12

- 1) Took day off

Thursday, August 13

- 1) 9:00AM-10:00AM – Retrieved two surveys from post-partum unit, entered them into database

Friday, August 14

- 1) 9:00AM-10:00AM – No surveys today
 - a) Received email from Brenda about “Study Coverage Analysis” for her sleep study



Mentor Signature: _____

Monday, August 17

- 1) 8:30AM-9:00AM – No surveys from post-partum unit
 - a) Reminded staff about study and protocol
- 2) 9:00AM-10:00AM – Recapped with Dr. Newcomb regarding situation with bloodspot video not meeting “marketing standards” even though it is a research tool
 - a) Decided to remove Alliance Hospital from intervention site and add Fort Worth instead
 - b) Also had to change wording of protocol and all the different cover letters for each site
- 3) 10:00AM-4:00PM – Worked on revising amendment, protocol and cover letters

Tuesday, August 18

- 1) 9:00AM-10:00AM – Retrieved three bloodspot surveys and entered them into database
- 2) 10:00AM-3:00PM – We were running out of blank surveys and envelopes, so I started a new batch

Wednesday, August 19

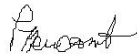
- 1) 10:00AM-1:00PM – Did a little literature review for research project

Thursday, August 20

- 1) 9:00AM-12:00PM – Met with Joy Thompson regarding her antepartum study involving timing of different catheter procedures
 - a) She needs to make a poster for the Research Symposium coming up in a couple weeks
- 2) 1:00PM-3:00PM – Did my own literature review on topic to prepare myself for future meeting with Joy

Friday, August 21

- 1) 9:00AM-10:00AM- Collected three surveys
- 2) 10:30AM-12:00PM – Continued literature review on antepartum study
 - a) Most of the literature on the topic is from the 90s



Mentor Signature: _____

Monday, August 24

- 1) 9:00AM-10:00AM – Collected five surveys (!!!)
- 2) 10:00AM-12:00PM – Contacted Joy regarding her poster, as her deadline is quickly approaching
- 3) 12:45PM-4:00PM – Worked with Joy on her poster
 - a) Completed introduction, background information, and methods section
 - b) Need analysis of data from Dr. Newcomb since I don't have SPSS

Tuesday, August 25

- 1) 9:00AM-10:00AM – Collected three surveys
- 2) 10:00AM-12:00PM – Proofread what Joy has so far for her poster sections
- 3) 12:45PM-5:00PM – Helped Joy finish her poster after receiving data analysis from Dr. Newcomb
 - a) Study is entitled “Outcomes related to persistent intravenous access in long-term antepartum patients”
 - b) I was listed as the second author
 - i) First time working on research poster since undergrad

Wednesday, August 26

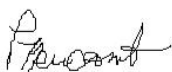
- 1) 10:00AM-12:00PM – Did more work on literature review for research thesis
 - a) Learned a lot more about newborn screening in the process

Thursday, August 27

- 1) 9:00AM-10:00AM – Collected one survey
 - a) Collecting surveys at a really low rate... we may need to attend a staff meeting or do the surveys ourselves
- 2) 10:00AM-4:00PM – Update on bloodspot video: Dr. Newcomb said that Clint at Alliance Hospital is willing to have someone else do professional editing for the video to make it meet “marketing standards,” but that would require paying out of pocket
 - a) So we won't be administering the current video to Fort Worth; we'll have someone else edit the footage for us, but that would take a while
 - b) Also, it turns out the amendment was never submitted from before, so we spent today working on revising the protocol once again
 - c) Submitted the amendment at the end of the day

Friday, August 28

- 1) 9:00AM-10:00AM – Collected two surveys
- 2) 10:30AM-12:00PM – Worked on introduction section of research thesis
- 3) 1:00PM-2:00PM – Collected two surveys
 - a) Will now start collecting surveys and reminding staff in the afternoon as well
 - b) Currently at 23 total surveys, which is not a lot at all
 - i) Hoping for help at other study sites as well



Mentor Signature: _____

Monday, August 31

- 1) 9:00AM-10:00AM – Collected two surveys
- 2) 10:00AM-3:00PM – Met with a nurse who was working on an Active Listening study and fixing her eIRB application for submission
 - a) It was similar in format to the bloodspot study in that informed consent was not needed, but a cover letter would be used instead, so I helped her answer various questions regarding informed consent in the eIRB application
- 3) 4:00PM-4:30PM – Collected one survey

Tuesday, September 1

- 1) 9:00AM-10:00AM – Collected one survey
- 2) 10:30AM-4:00PM – Received protocol file of Active Listening Study
 - a) Began work on drafting an informed consent form in case IRB requests it and rejects the cover letter idea

Wednesday, September 2

- 1) 10:00AM-2:00PM – Worked on new secondary applications

Thursday, September 3

- 1) 9:00AM-9:30AM – No surveys collected
- 2) 10:00AM-3:00PM – Continued work on informed consent form
- 3) 3:00PM-3:30PM – No surveys collected

Friday, September 4

- 1) 7:30AM-9:00AM – Attended eIRB meeting for THR
 - a) Business as usual, with plenty of interesting clinical trials approved
- 2) 9:00AM-10:00AM – No surveys collected
- 3) 10:00AM-10:30AM – Spoke to Dr. Newcomb about bloodspot video
 - a) Update: Clint agreed to cover the cost of the video so we wouldn't have to worry paying out of pocket
 - i) The bad news is we still have to wait, once again...
- 4) 11:00AM-2:00PM – Finishing touches on informed consent form


Mentor Signature: _____

Tuesday, September 8

- 1) 9:00AM-9:30AM – No surveys collected (!!!)
 - a) Told Dr. Newcomb about this problem
 - i) She said we may have to administer the surveys ourselves if the post-partum staff will not cooperate

- 2) 10:00AM-11:00AM – Went up to post-partum unit with Dr. Newcomb and spoke to Kimberly about the surveys
 - a) She suggested that we attend a UBC meeting next week to make a formal presentation on the study and to remind the staff to pass them out to the mothers
- 3) 12:00PM-3:00PM – Began a very rough draft of background info on research thesis

Wednesday, September 9

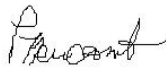
- 1) 10:00AM-2:00PM – Continued work on new secondary applications
- 2) 2:00PM-3:00PM – More literature review on research project

Thursday, September 10

- 1) 9:00AM-10:00AM – One survey collected
- 2) 10:00AM-4:00PM – More literature review on research project
 - a) Completed background info section and started work on introduction section
- 3) 4:00PM-4:30PM – No surveys collected

Friday, September 11

- 1) 9:00AM-10:00AM – One survey collected
- 2) 10:00AM-12:00PM – Dr. Newcomb told me that Barbara True at TH Arlington Memorial has been administering surveys for the past month, and she has 37 surveys (!!!)
 - a) Drove to Arlington Memorial to pick up surveys
- 3) 1:00PM-3:00PM – Entered surveys from Barbara and filed them
 - a) Now at a grand total of 64 surveys, which is very good so far



Mentor Signature: _____

Monday, September 14

- 1) 9:00AM-10:00AM – Collected one survey
- 2) 10:00AM-10:30AM – Finalized thesis defense date as November 10 at 10:30AM
- 3) 11:00AM-3:00PM – New task regarding different study
 - a) Dr. Newcomb wanted me to rewrite seven scenario cases of difficult interactions between hospital staff and patients
 - b) Finished three of the seven scenarios

Tuesday, September 15

- 1) 9:00AM-10:00AM – Collected one survey
- 2) 10:00AM-4:00PM – Continued work on scenario rewriting
 - a) Finished the remaining four scenarios and proofread/revised them
- 3) 5:00PM-6:00PM – Attended UBC meeting that had post-partum nurses in it, and I made a presentation of the bloodspot meeting and emphasized that all mothers should be receiving the surveys
 - a) The staff seemed to get the message, so I felt the meeting went very well

Wednesday, September 16

- 1) 10:00AM-2:00PM – Finished secondary applications
- 2) 2:00PM-3:00PM – Finished introduction section
 - a) Decided to merge introduction and background info together into one section prior to data and methods section

Thursday, September 17

- 1) 9:00AM-10:00AM – Collected two surveys
 - a) Progress seems to have returned to normal so far
- 2) 10:00AM-3:00PM – I was told by Dr. Newcomb and Gail Voncina, chair of the Research Council that they would like for me to present the research article I did for Azle back in July, so I reread the article, created a PowerPoint presentation based on my research review chart, and practiced my presentation
- 3) 3:00PM-4:00PM – Attended Evidenced Based Practice and Research Council meeting and presented the research article
 - a) It went well
- 4) 4:30PM-5:00PM – Collected two surveys
 - a) Grand total is now 69
 - i) Hoping to reach 100 by end of study

Friday, September 18

- 1) 9:00AM-10:00AM – Collected one survey
- 2) 10:00AM-12:00PM – Started work on methods section of thesis
- 3) 1:00PM-2:00PM – Noticed that the amendment from a few weeks ago was still unapproved
 - a) Emailed Erik from IRB about it
 - i) He answered back and said that it is in the process of being reviewed
 - b) It is important that the amendment be approved ASAP so that we can administer the MAK-NBS to the new study sites
- 4) 2:00PM-3:00PM – Collected one survey

Mentor Signature:  _____

Monday, September 21

- 1) 9:00AM-10:00AM – Collected one survey
- 2) 10:00AM-3:00PM – Continued work on methods section of thesis
 - a) Also revised introduction and background info a little bit
- 3) 3:00PM-3:30PM – No surveys collected

Tuesday, September 22

- 1) 9:00AM-9:30AM – No surveys collected
- 2) 9:30AM-12:00PM – Amendment for site and staff change on bloodspot study was finally approved, so we were given the go-ahead to administer the surveys to other sites
 - a) Dr. Newcomb and I contacted the various nurse scientists at the other sites
 - i) Dr. Wells said Betty Haywood would be there on Thursday to pick up surveys

- ii) Dr. Kathy Baldwin was unavailable
- iii) Dr. Samantha Pehl was unavailable
- 3) 1:00PM-3:00PM – Continued work on methods section of thesis
- 4) 3:00PM-3:30PM – No surveys collected
 - a) Told Dr. Newcomb... We're definitely going to administer the surveys ourselves when we can

Wednesday, September 23

- 1) Was feeling tired, took day off
- 2) Received email that Sam started surveys without permission at Stephenville
 - a) It will take a month before she would get approval from new OR supervisor, so Stephenville has been crossed off the study site list
- 3) Kathy is going on a month-long vacation, so we will need to contact the staff at Southwest ourselves for surveys

Thursday, September 24

- 1) 8:00AM-8:30AM – Met Dr. Newcomb in the post-partum unit to pass out surveys
 - a) However, Dr. Newcomb told me that some mothers were not fully clothed, so she said it was best that I don't actually administer the surveys myself
 - i) She will do her best to do them herself every morning
- 2) 9:00AM-1:30PM – More work on research thesis
- 3) 2:00PM-3:00PM – Finally attended meeting with ER Narcotics group
 - a) Gave summary of the data findings I found regarding the very low return rate of Press Ganey surveys
 - b) Dr. Ralph Baine, the principal investigator, however, wanted to go further with the results a bit more
 - c) Found out that they have been giving two scribes the task of manually going through every ED patient encounter from 2013 at THFW to see if they qualify as chronic pain patients
 - i) Over 11000 patients to sort through!
- 4) 3:00PM-4:00PM – Entered the two surveys that Dr. Newcomb obtained from earlier this morning

Friday, September 25

- 1) 8:00AM-10:00AM – More work on research thesis
- 2) 10:00AM-11:00AM – Entered in two surveys from Dr. Newcomb
- 3) 11:30AM-3:00PM – New task
 - a) I was given access to SharePoint site containing the ED Narcotics data
 - b) My goal was to sort through all the patients and determine how many unique patients were there
 - i) Lots of duplicates, and the IDs were long, so this would be a long task



Mentor Signature: _____

Monday, September 28

- 1) 8:00AM-4:00PM – Decided that it would be too much to go through and sort out duplicate patient IDs by hand, so I decided to relearn how to program in MATLAB
 - a) Focused on basic syntax and extracting data from Excel files
 - b) Also no surveys were collected today

Tuesday, September 29

- 1) 9:00AM-10:00AM – Two surveys were collected
- 2) 10:00AM-3:00PM – Spent rest of day writing and debugging code on sorting out duplicates from ED Narcotics data
- 3) 3:00PM-3:30PM – No surveys collected

Wednesday, September 30

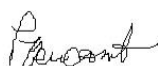
- 1) 10:00AM-12:00PM – Worked on research thesis

Thursday, October 1

- 1) 9:00AM-10:00AM – Two surveys were collected
- 2) 10:00AM-2:00PM – Completed code to extract unique patient MRNs from ED Narcotics data
 - a) Uploaded datasheet to SharePoint site

Friday, October 2

- 1) 7:30AM-8:30AM – Attended IRB meeting at THR
 - a) Short and relatively quick
- 2) 9:00AM-9:30AM – No surveys were collected
- 3) 10:00AM-11:00AM – Attended another ED Narcotics meeting regarding quality check of data from the two scribes
 - a) There were 1362 unique Patient IDs who are defined as chronic pain patients in the database, as calculated from my coding
 - b) Now the next goal is to find out how many of those patients were given Press Ganey surveys
 - c) Was told we would not be able to get the data until end of October



Mentor Signature: _____

Monday, October 5

- 1) 9:00AM-10:00AM – Picked up one survey
- 2) 10:00AM-1:00PM – Worked on research thesis, at least the limitations section
- 3) 1:00PM-5:00PM – Was told that we would be visiting TH Southwest this week for bloodspot surveys, so I made new batches (about 300 survey packets this time)
 - a) Delivered 100 to post-partum unit at THFW
 - b) Didn't pick up any completed surveys

Tuesday, October 6

- 1) 9:00AM-10:00AM – Entered in six surveys from Dr. Newcomb
- 2) 10:00AM-1:00PM – Met with Brenda and Dr. Newcomb regarding sleep study

- a) Study is finally starting in the cardiac rehabilitation unit, so we will finally be administering informed consent to potential participants!
- b) Went over procedures, documents, etc. one more time to make sure we are all on the same page
- c) Watched Dr. Newcomb do informed consent on one participant first
- 3) 2:00PM-3:00PM – More work on research thesis

Wednesday, October 7

- 1) 10:00AM-2:00PM – Finished up preliminary version of limitations section
 - a) Downloaded free software equivalent of SPSS called PSPP
 - i) Began data analysis on the data we currently have

Thursday, October 8

- 1) 9:00AM-9:30PM – No surveys collected
- 2) 10:00AM-10:30AM – Registered for Office for Human Research Protection (OHRP) Town Hall Meeting for October 20
- 3) 11:00AM-3:00PM – Worked on research thesis
- 4) 4:00PM-5:00PM – Practiced giving informed consent
 - a) Took a couple tries under Dr. Newcomb's supervision before I was finally approved
 - b) Need to work on not talking too quickly

Friday, October 9

- 1) 8:00AM-11:00AM – Obtained all the required signatures for the Intent to Defend form and turned it in to Dr. Gwartz
- 2) 11:00AM-12:00PM – Picked up one survey
- 3) 1:00PM-3:00PM – Went to TH Southwest to deliver surveys and tell them about the project
- 4) 3:00PM-5:00PM – Informed consent on sleep study participants at THFW



Mentor Signature: _____

Monday, October 12

- 1) 8:00AM-1:00PM – Picked up 30 more surveys from Barbara at TH Arlington Memorial!!!
 - a) Then entered in the survey data
- 2) 1:30PM-4:00PM – Worked on data analysis and typing results section of research thesis

Tuesday, October 13

- 1) 9:00AM-10:00AM – Picked up one survey
- 2) 10:00AM-12:00PM – Informed consent with some participants on sleep study
- 3) 1:00PM-3:00PM – Worked on results sections of research thesis
- 4) 3:00PM-5:00PM – Informed consent with participants on sleep study
 - a) Definitely getting better!

Wednesday, October 14

- 1) 10:00AM-12:00PM – Work on results section of research thesis

Thursday, October 15

- 1) 9:00AM-9:30AM – No surveys picked up
- 2) 10:00AM-1:00PM – Continued work on thesis
- 3) 1:30PM-3:00PM – Received email from Barbara about adding error bars on bar graph on Excel
 - a) Took a look at her error bars and spent a little time trying to do it myself
- 4) 3:00PM-3:30PM – No surveys picked up

Friday, October 16

- 1) 9:00AM-9:30AM – No surveys picked up
- 2) 10:00AM-1:00PM – Continued work on thesis, this time on the problem section
- 3) 2:00PM-3:00PM – Bloodspot video update
 - a) Clint decided not to cover the entire cost of hiring video editing staff like he said, so Dr. Newcomb will have to pay half of it out of pocket
- 4) 3:00PM-4:00PM – Conducted informed consent for sleep study participants
 - a) Encountered first rejection of consent from participant

Mentor Signature: _____



Monday, October 19

- 1) 9:00AM-9:30AM – One survey collected
- 2) 10:00AM-12:00PM – Work on research thesis
 - a) Finishing up problem section
 - b) Still working on data analysis
- 3) 1:00PM-5:00PM – Drove to TH Arlington Memorial to pick up 25 surveys from Barbara and then to TH Corporate to pick up a surprising 26 surveys from Plano!
 - a) Apparently a nurse scientist was passing out the surveys there as well!
 - b) Now at 166 surveys!
 - c) Spent rest of time entering in surveys

Tuesday, October 20

- 1) 9:00AM-9:30AM – No surveys picked up
- 2) 10:00AM-12:00PM – Met with Brenda regarding sleep study
 - a) Big problem: Brenda broke the blind because she accidentally switched the treatment and placebo oils
 - i) The only way she knew was because of the smells
 - ii) So now Dr. Newcomb will re-randomize the oils again, and Brenda will have to note that she messed the blind for the first 24 participants
- 3) 1:00PM-2:00PM – Spoke more to Brenda regarding entering in data for sleep study
- 4) 2:00PM-3:00PM – Managed to catch a little bit of the OHRP Town Hall Meeting webcast about improving the protection of human rights subject

- a) One interesting question asked was whether “human subjects” would include biospecimens like teeth
 - i) Answer is that it depends on the type of research you are doing
- 5) 3:00PM-5:00PM – Informed consent for sleep study participants

Wednesday, October 21

- 1) 10:00AM-2:00PM – Almost results section of research thesis

Thursday, October 22

- 1) 9:00AM-9:30AM – One survey collected
 - a) Grand total of 167 participants
 - b) I decided to stop the sampling here so I can complete the full data analysis and make tables for the results section
- 2) 9:30AM-3:00PM – Worked on research thesis
- 3) 3:00PM-4:00PM – Informed consent for sleep study participants

Friday, October 23

- 1) 10:00AM-4:00PM – Finished results section of research thesis and began working on discussion section and editing limitations section
- 2) 4:00PM-5:00PM – Discussed results with Dr. Newcomb to make sure I’m on the right path, and she agreed
 - a) Ended up finishing discussion section over weekend


Mentor Signature: _____

Monday, October 26

- 1) 8:00AM-4:00PM – Revising and proofreading research thesis
 - a) Added abstract section
 - b) Entered in seven surveys

Tuesday, October 27

- 1) 7:30AM-4:30PM – Revising and proofreading research thesis
 - a) Turned in thesis
 - b) Inputted one last survey and updated tables in thesis prior to submission
 - c) Grand total of 176 surveys, which is much better than the 100 I was expecting at the beginning!


Mentor Signature: _____