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# Evaluation of the New Onset Diabetic Education Program for Navajo Adults

Denise S. Bartley  
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**Evaluation of the New Onset Diabetic Education Program for Navajo Adults**

**by**

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DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy in Nursing**

The University of New Mexico  
Albuquerque, N.M.  
May 2019

## **Dedication**

Dedicated to the ones I love, in this world and the next.

My family is my world; this work is dedicated to my family members, who unconditionally supported and encouraged me during this long journey. To my husband, Howard, thank you for your unwavering love, support, and patience. To my parents, John and Darline, for always telling me I could do anything and truly believing it. To my dad, John, who never doubted me. To my sister, Cindy, who is one of the smartest and strongest women I know. To my sons, Anthony (Rachel) and Clifford (Amanda), and grandchildren, Jacob, Brooklyn, and Katelyn, who complete my world. Thank you all for your love and support. Each of you have inspired me and I am truly blessed.

In memory of

John H. Hamilton II, Dec. 26, 1965 – May 2, 2015

Kyle Brandon Galyon, Feb. 12, 1988 – Aug. 24, 2018

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I would especially like to thank the people of the Navajo Nation, Beverly Becenti-Pigman, and the members of the Navajo Nation Human Research and Review Board for supporting this study, for without them, it would not have come to fruition.

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## **Abstract**

The prevalence of diabetes mellitus (DM) is higher in American Indians/Alaska Natives (AI/AN) than in any other racial or ethnic group in the United States (U.S. Department of Health and Human Services [USDHHS] Centers for Disease Control and Prevention [CDC], 2018). In response to this escalating health issue, the U.S. government funded a number of DM education and treatment programs focusing on AI/AN populations. The purpose of this study was to evaluate the New Onset Diabetes Education Program (NODEP) based at Northern Navajo Medical Center (NNMC) in Shiprock, N.M.

The Navajo philosophy of learning was used as a guiding framework. This two-phase study examined the effectiveness of NODEP using medical records and survey data. In Phase I, glycosylated hemoglobin (HbA1c) levels and body mass index (BMI) data were collected via retrospective chart reviews on Navajo adults (n = 480) diagnosed with DM and referred to NODEP from January 1, 2010, to December 31, 2015. Study participants were assigned to one of four groups (n = 120): (a) attended a full three-day course; (b) attended a one-day course; (c) began the three-day course but did not complete it; and (d) people who were referred but did not attend any portion of NODEP.

During Phase II, a researcher-designed survey was administered prospectively to capture participants' perspectives on the strengths and weakness of the program as well as on barriers and facilitators to attendance.

Participants who attended and completed either version of NODEP at NNMC showed significantly improved levels of HbA1c over 24 months. Participants who completed the three-day course showed a clinically meaningful improvement from a mean of 10.0% at the time of referral to  $\leq 7.0\%$  from six to 24 months. Similarly, those who completed the one-day course had a mean HbA1c of 9.3% to  $\leq 7.3\%$  from six to 24 months. In contrast, mean HbA1c was never less than 8.0% for those who did not complete or never started the program. Moreover, study participants who did not attend any portion of NODEP showed a statically significant worsening HbA1c level over 24 months.

Responses to the survey indicated that a large majority (90.9%) of participants who attended NODEP to completion ( $n = 77$ ) thought that the most helpful information was "understanding what DM is" and that the least helpful information included discussion of DM medications (9.1%). The most significant barrier to attending NODEP was that it was not held in the outlying communities. Themes from the participants' comments comprised prevention, management, variation in teaching strategies, self-reliance, outreach programs and challenges. Further, participant recommendations included making NODEP more accessible by teaching the course in rural communities and by providing access to a counselor, traditional healer, or to community support groups.

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# **CHAPTER 1**

## **INTRODUCTION**

Diabetes mellitus (DM) is one of the most pervasive and challenging health problems in the modern world. According to the World Health Organization (WHO) (2016), approximately 8.5% of the global adult population is chronically afflicted with DM. While no country is spared, the prevalence of diabetes is rising faster in low- and middle-income countries compared to high-income countries (WHO, 2016). Despite this, the number of individuals diagnosed with DM continues to rise in high-income countries as well. In the United States, the prevalence of DM in adults older than 18 is 12% (U.S. Department of Health and Human Services [USDHHS] Centers for Disease Control and Prevention [CDC], 2018).

In the United States, the disease burden of DM is significantly higher in indigenous populations than it is for the White majority. Estimates from the CDC (2018) indicated that AI/ANs have more than twice the rate of DM (15.1%) when compared to White populations (7.4%). The prevalence of DM, however, differs significantly among AI/AN populations, with the Alaska Natives being the least affected and the Pima Indians of the Gila River Community in Arizona having the greatest prevalence (Carter, Pugh, & Monterrosa, 1996; Gladwell, 1998). The Pima Indians have been studied longitudinally since 1962, and the prevalence of DM in the population increased 42% in the period between 1967 and 1977 (Carter et al., 1996; Gladwell, 1998). Like the Pima Indians, the Navajo population has experienced an astounding rise in the prevalence of DM since the 1960s.



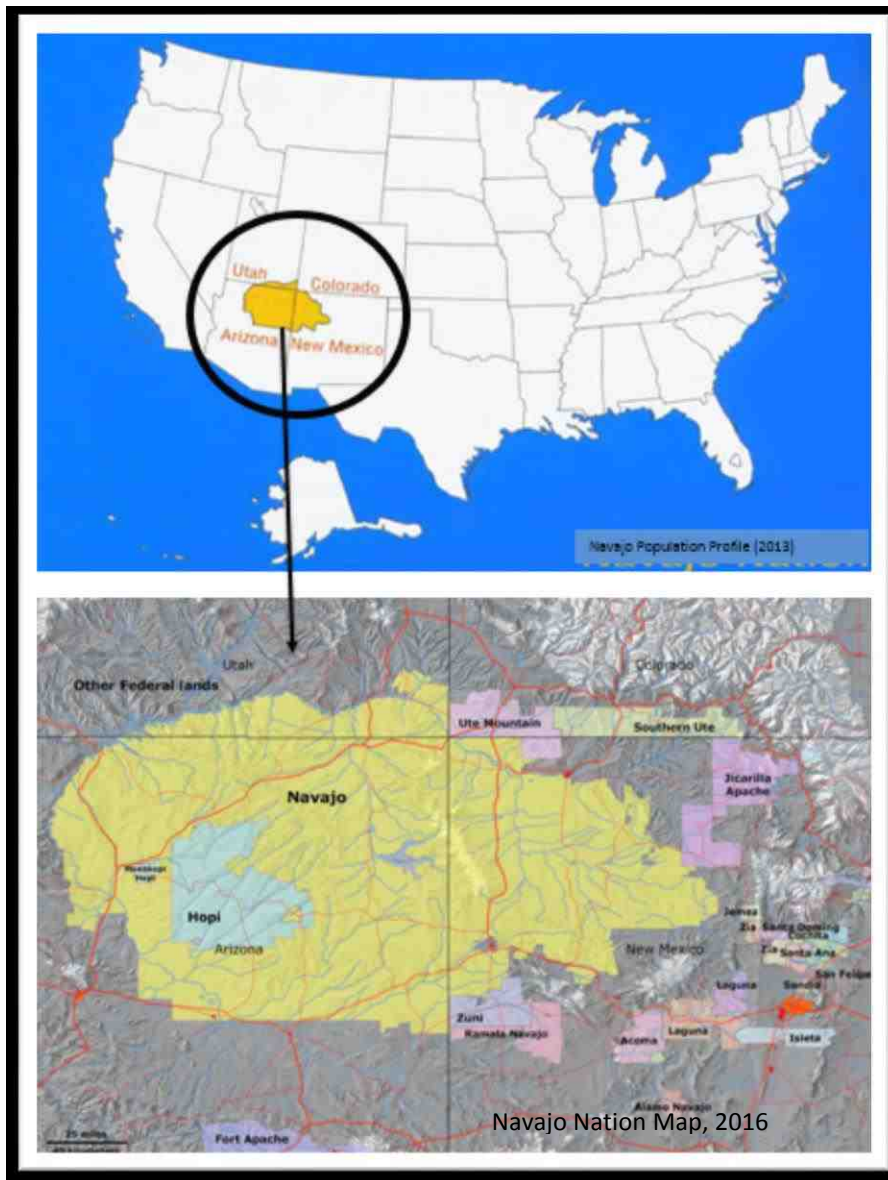
Prior to the 1960s, DM was virtually unheard of among the Navajo (Prosnitz & Mandell, 1967; Saiki & Rimoin, 1968). Even when greater numbers of people diagnosed with DM began to be noticed in the late 1960s, it was considered an isolated and benign abnormality (Saiki & Rimoin, 1968). Unfortunately, since the 1970s, the number of Navajo people with DM has grown to near epidemic proportions (Sugarman, Hickey, Hall, & Gohdes, 1990). In 2013, the prevalence of diabetes in Navajo adults 20 and older (16.3%) was higher than the national average for AI/AN (15.1%) (USDHHS, Indian Health Services [IHS], Division of Diabetes Treatment and Prevention [DDTP], 2015).

With the rapid increase in type 2 diabetes mellitus (T2DM) diagnosed among AI/ANs, the federal government was prompted to dedicate specific resources to combat this epidemic. Two major programs were put into place with a focus specifically on the treatment and prevention of DM among AI/ANs. In 1979, the IHS Division of Diabetes Treatment and Prevention (DDTP) was established (USHHS, IHS, DDTP, 2017; McLaughlin, 2010) and is based in Albuquerque, N. M. (McLaughlin, 2010; Sugarman, et al., 1990). The Special Diabetic Program for Indians (SDPI), established in 1997 enabled the IHS and other entities to develop diabetic education and treatment programs (USHHS, IHS, DDTP, 2017). Grant funds from this program were used to establish the Diabetic Education Program at NNMC, which in turn created the New Onset Diabetic Education Program to streamline the process for newly diagnosed diabetics to receive the necessary education on management--diet, exercise, preventative eye and foot exams, and glucose monitoring--and treatment options--lifestyle and medications. The NODEP is discussed in more detail further in this chapter.

## **The Navajo Nation**

The Navajo Nation, located in the southwestern United States. (Figures 1.1) in the states of New Mexico, Arizona, and Utah, consists of diverse topography, including high mountains and deserts. The Navajo Nation is known as Diné Bikéyahich, to the Navajo people, which mean Navajoland (Navajo Nation Government, 2011).

Figure 1.1. Navajo Nation Located in the Southwest Region of the United States



According to Navajo oral history, the Navajo reservation is situated within the Four Sacred Mountains (Figure 1.2) that were created by the Holy People (Diyin Diné) (Acrey, 1988; Schwarz, 2001). In the east is Mount Blanca (Tsisnaajiní), near Alamosa, Colo.; in the south is Mount Taylor (Tsoodzil), near Grants, N.M.; the San Francisco Peak (Dook’o’oosłíid) is in the west, near Flagstaff, Ariz.; and in the north is Mount Hesperus (Dibé Nitsaa) in the LaPlata Mountains (McPherson, 1992; Schwarz, 2001).

Figure 1.2. Four Sacred Mountains Surrounding the Navajo Nation



Four Sacred Mountains (n.d.)

The Navajo Nation has increased in size since the U.S.-Navajo Treaty of 1868 (Ault, 2018; McPherson, 1947) to become the largest Indian reservation in the United States, encompassing 27,425 square miles (Navajo Population Profile, 2013). The Navajo

Nation is comparable in size to West Virginia (24,038 acres) (Navajo Population Profile, 2013; World Atlas, 2018).

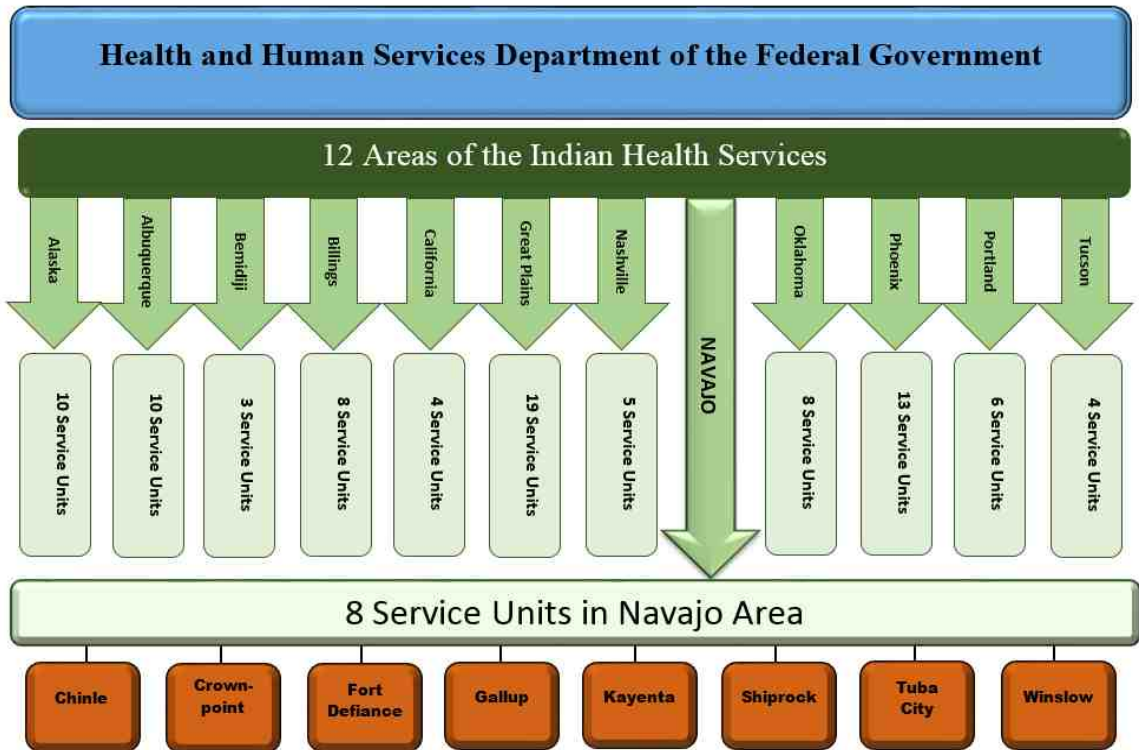
According to a report by Norris, Vines, and Hoeffel with the U.S. Census Bureau, (2012), the Navajo tribe is the second most populous in the United States, second only to the Cherokee. These figures include American Indian (AI) alone and AI combined race. However, the Navajo Nation has the largest number of enrolled members (287,000) who identified as belonging to a single race (Navajo), followed by the Cherokee tribe (284,000) (Norris et al., 2012). Forty seven percent of the Navajo population lives on Navajo tribal lands, 26% live in metropolitan areas, 10% live in border towns, and 17% live elsewhere (Navajo Population Profile, 2013). Most Navajo people seek healthcare through the IHS, which has hospitals, clinics, and health stations throughout the Navajo Nation (USDHHS, IHS, 2018).

## **MEDICAL CARE FOR THE NAVAJO**

### **Indian Health Services**

The IHS, a division of the U.S. Department of Health and Humans Services (U.S. HHS) (Figure 1.3) estimates there are 3.6 million AI/ANs in the United States (USDHHS, IHS, 2018). The IHS provides healthcare and disease prevention services to approximately 2.2 million AI/ANs through a system of hospitals, clinics, and health stations (USHHS, IHS, 2018). These facilities are managed by IHS, by tribal governments or tribal organizations under contract with the IHS, or by urban Indian health programs. As of 2013, there were 612 IHS-operated and tribally operated health facilities on or near Indian lands (USHHS, IHS, 2018).

Figure 1.3. Indian Health Services Hierarchy



**Navajo Area Indian Health Service**

The Navajo Area Indian Health Service (NAIHS) under the IHS is mainly responsible for the delivery of health services to AI/ANs in portions of Arizona, Colorado, New Mexico, and Utah. The NAIHS is primarily responsible to the healthcare of members of the Navajo Nation and Southern Band of San Juan Paiutes but also provides care to other AI/AN people (USDHHS, IHS, 2016a).

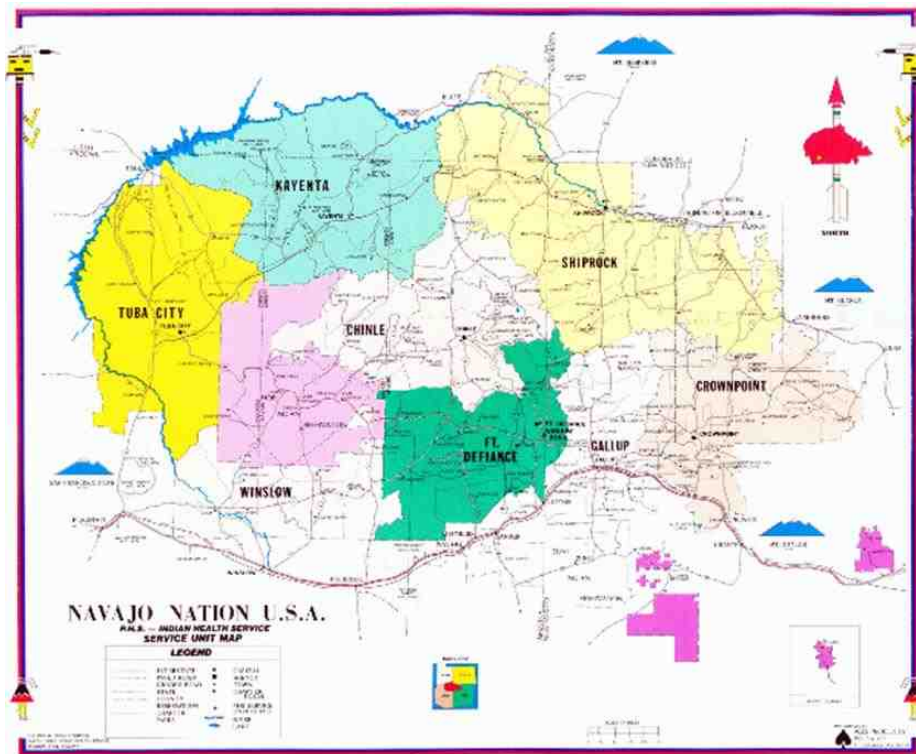
**Northern Navajo Medical Center**

The Northern Navajo Medical Center is in the Shiprock Service Unit in Shiprock, N.M. Shiprock is in the Four Corners area of the United States where New Mexico, Arizona, Colorado, and Utah share a boundary. NNMC is one of five facilities within the

Shiprock Service Unit. The Shiprock Service Unit is the largest service unit of the Navajo Nation (USHHS, IHS, 2016a) (Figure 1.4).

Approximately 81,000 people receive care at NNMC (USDHHS, IHS, 2016b). The inpatient capacity is 29 patients per day and the outpatient volume averages 600 patients per day (USDHHS, IHS, 2016b). NNMC has strong relationships with private providers in the Four Corners region, as well as at the University of New Mexico in Albuquerque, and Brigham and Women’s Hospital in Boston (USDHHS, IHS, 2016b).

Figure 1.4. Navajo Area Service Units



(USHHS, IHS, Navajo, 2016a)

## **Division of Diabetes Treatment and Prevention**

The objectives of the DDTP program are to address the epidemic of diabetes in Indian country in both clinical and public health settings by monitoring diabetes surveillance, improving and measuring clinical diabetes care, and promoting diabetes networks for rapid translation of research into clinical practice (USDHHS, IHS DDTP, 2016). The IHS DDTP included 301 grant programs in 2016; the programs are known as the Special Diabetes Program for Indians (SDPI) (USDHHS, IHS DDTP, 2016). Through the SDPI, the IHS was awarded approximately \$138 million to prevent and treat diabetes in AI/ANs. Grant funds go to tribes, tribal organizations, urban Indian organizations and IHS facilities. For fiscal year 2016, the Shiprock Service Unit received \$2,842,190 (USDHHS, IHS DDTP, 2016).

## **New Onset Diabetic Education Program at Northern Navajo Medical Center**

NODEP has been in existence since 2002. The program arose to serve the increasing number of newly diagnosed diabetic patients because there were a limited number of primary care providers. Initially, the program consisted of participants attending three group classes. The need for culturally competent educators was an early priority, and Navajo speaking educators were recruited and trained to provide culturally appropriate education in conjunction with Western medicine. The classes are taught in Navajo and/or English, depending on the request and needs of the participants.

NODEP strives to meet the needs of the participants at any given time. People enter NODEP at different levels of physical and mental well-being and with different levels of knowledge about diabetes. To provide a meaningful and educational experience for NODEP participants, the educators must be aware of these differences and address

them accordingly. Further, as the needs of the participants can change rapidly, the teaching strategies of NODEP educators must also change. This concept of adjusting to constant change, in order to obtain a life balance is not new to the Navajo people; it is called *hózhó* (Austin, 2009; Farella, 1984; Werito, 2014). For a person, family, and community to be in *hózhó*, they must be in balance and in harmony (Austin, 2009; Iverson, 2002; Werito, 2014). The Navajo philosophy of learning embraces the concept of *hózhó*; if a person is not in *hózhó*, it is more difficult for that person to obtain or develop the knowledge and skills they need to improve their situation or to restore balance and harmony (Austin, 2009; Benally, 1992, 1996). Benally (1992) described the Navajo philosophy of learning as a way of providing education in a circular and interconnected fashion. The Navajo philosophy of learning is utilized in NODEP; though the curriculum contains separate classes such as diet, exercise, medication management, monitoring DM, and preventing complications, each of these components is related and plays a role in the overall well-being of the individual with DM. NODEP aims to support people with DM to seek and obtain *hózhó*.

Currently, patients who are newly diagnosed with diabetes can receive diabetic education at the time of diagnosis. This initial, one-on-one session is designed to briefly cover the basics of diabetes and nutrition, but the educators also help the patients adjust to or accept the diagnosis so that the process of management and treatment might help ensure more-positive outcomes.

NODEP is designed as an interactive, didactic education program (NODEP, 2002). Participants visit local grocery stores and restaurants to help them identify good, better, and best food options; identify sources of hidden sugars; and obtain guidance in



reading and understanding food labels. The intent of this activity is to help participants make informed food choices and to help the family develop healthy habits as a cohesive unit (NODEP, 2002).

NODEP has been streamlined so that participants can obtain health screening and updates, including blood testing, electrocardiograms (EKG), retinal eye exam, updated vaccines, and dental screening. Participants also meet with a physician one-on-one to review medical history, lab findings, medications, and any other concerns (NODEP, 2002).

In addition, the program helps identify people who want primary care and are willing and able to attend clinic visits as scheduled. Thus, difficult to obtain appointments with a primary care provider are not as likely to be unused by scheduling a person who is not willing or able to utilize it. At the completion of the three sessions, a primary provider is assigned to the participant for the continuation of care (NODEP, 2002).

Between January 1, 2010, and December 31, 2015, 1,962 Navajo patients were referred to NODEP (NODEP Roster, 2017). Though NODEP has been recognized for its efforts in bridging the gap by providing early intervention for those newly diagnosed with diabetes, the effectiveness of the program in helping control glucose levels in the Navajo people had not been formally evaluated.

### **Purpose of the Study**

The purpose of this study was to examine the effectiveness of NODEP at NNMC in Shiprock, N.M. A two-phase design was used. Phase I examined glycosylated hemoglobin (HbA1c) values over six time points for Navajo adults 18 and older who were newly diagnosed with type 2 diabetes mellitus (T2DM) between January 1, 2010,

and December 31, 2015. Participants were grouped according to the educational program attended: Group 1 was comprised of those who attended and completed all three sessions of NODEP; Group 2 members were those who attended and completed a one-day course; Group 3's members had attended one or more classes in the traditional three-day course but did not complete the program; and, Group 4 was comprised of those who were invited, but did not attend NODEP.

Phase II of the study identified the strengths, weaknesses, and barriers to participating in NODEP program by surveying (Appendices A and B) Navajo adults at NNMC who were newly diagnosed with DM during the inclusion period. The survey data provided more-detailed and nuanced information about the acceptability, usefulness, and cultural appropriateness of NODEP from the perspective of Navajo adults diagnosed with T2DM.

This study provided the first comprehensive evaluation of a diabetic education program designed specifically for Navajo adults. Although a body of literature exists on DM among AI/ANs, a comprehensive review of more than 1,500 articles indicated that there is no previous published work in this area. Therefore, this study provided crucial information on appropriate management of DM for the Navajo people and their healthcare providers. It also provided a useful contribution for the larger community of AI/AN people seeking to improve DM management.

### **Research Questions and Hypotheses**

The research questions were:

#### **Research Question 1**

Is participation in either the three-day NODEP or the one-day NODEP associated with meaningful reduction in HbA1c compared with incomplete or no participation?

Hypothesis 1: Compared with newly diagnosed Navajo patients with DM who were referred to NODEP but did not participate, those who participated in either the three-day program or the one-day program will demonstrate clinically meaningful and statistically significant sustained improvement in HbA1c compared with those who did not participate and those with incomplete participation (began three-day program but did not complete). To test the hypothesis, HbA1c levels at diagnosis/referral and 3, 6, 12, 18, and 24 month follow-ups were obtained from existing records for four cohorts: full participation (three-days), accelerated/individualized participation (one-day), incomplete participation, and no participation in NODEP.

### **Research Question 2**

Is participation in either the three-day NODEP or the one-day NODEP associated with meaningful reduction in BMI compared with incomplete or no participation?

Hypothesis 2: Compared with newly diagnosed Navajo patients with DM who were referred to NODEP but who did not participate, those who participated in either the three-day program or the one-day program will demonstrate clinically meaningful and statistically significant sustained improvement in BMI compared with those who did not participate and with those with incomplete participation. To test the hypothesis, BMI levels at diagnosis/referral and at 12 and 24 month follow-ups were obtained from existing records for the same four cohorts as in the preceding research question.

### **Research Question 3**

What are the strengths of NODEP as perceived by participants who attended and completed the three-day course (Group 1) and those who attended and completed the one-day course (Group 2)?

Hypothesis 3: Participants who attended NODEP course to completion will identify course content as the main strength of NODEP. To test the hypothesis, quantitative and qualitative data will be examined from participants completing Survey A (Appendix A). Quantitative data will be obtained using percentages, while qualitative data will be examined using a theme system of analysis.

#### **Research Question 4**

What are the weaknesses of NODEP as perceived by participants who attended and completed the three-day course (Group 1) and those who attended and completed the one-day course (Group 2)?

Hypothesis 4: Participants who attended the NODEP course to completion will identify the locations where the course was taught as the greatest weakness. To test the hypothesis, quantitative and qualitative data will be examined from participants completing Survey A (Appendix A). Quantitative data will be obtained using percentages, while qualitative data will be examined using a theme system of analysis.

#### **Research Question 5**

What are the barriers to attending NODEP as perceived by participants who attended and completed the three-day course (Group 1), those who attended the one-day course (Group 2), those who began the traditional three-day course but did not complete it (Group 3), and those who did not attend any portion of NODEP (Group 4)?

Hypothesis 5: Survey respondents will identify transportation as the main barrier to attending NODEP. To test the hypothesis, quantitative and qualitative data will be examined from participants completing Survey A (Appendix A) and Survey B (Appendix B). Quantitative data will be obtained using percentages, while qualitative data will be examined using a theme system of analysis.

### **Scope of the Study**

The IHS is an agency within the U.S. Department of Health and Human Services (HHS). IHS is responsible for providing healthcare services to AI/ANs of federally recognized Indian tribes. The IHS is divided into 12 physical areas throughout the United States. The Shiprock Service Unit is in Navajo area of the IHS (USDHHS, IHS, 2016a). This study was conducted at NNMC in the Shiprock Service Unit (Figure 1.3).

Between January 1, 2010, and December 31, 2015, 1,961 Navajo adults were referred to NODEP at NNMC (NODEP Roster, 2017). Of those referred, 493 had completed the traditional three-day course, 179 completed the one-day class, 226 began the three-day course but did not complete it, and 1,064 people did not attend any portion of NODEP. Because Group 2 contained the fewest participants, the researcher reviewed all charts for this group. It was determined that 120 participants had a minimum of six data points (pre-intervention, 3, 6, 12, 18, and 24 months post-intervention). Thus, this study included those 120 participants and an equal number from each of the other three groups. Groups 1, 2, and 3 had a pre-intervention data point that was taken when they were referred to NODEP and at five post-intervention data points. Participants from Group 4 had a total of six data points at the same intervals as above, without attending the NODEP course.

Participants in Phase II of this study were given one of two written surveys. Participants from Groups 1 and 2 were given a survey that focused on identifying the strengths and weaknesses of NODEP. Participants from Groups 3 and 4 were given a survey that focused on barriers that interfered with them completing or participating in the program.

Study data were collected and maintained using Research Electronic Data Capture (REDCap) (Harris et al., 2009) tools hosted at the University of New Mexico's Health Sciences Center. The statistical analyses for the study were descriptive statistics and one-way repeated measures ANOVA with appropriate tests of assumptions and goodness of fit. Statistical analyses were conducted using IBM SPSS® 24.0 (2016). Open-ended questions in Phase II were analyzed using thematic content analysis.

### **Limitations**

Findings of the study are limited to Navajo adults receiving care at NNMC and might not be generalizable to all Navajo patients or to other AI/AN or non-native populations. Phase I of the study was retrospective, based on existing health records. Only patients newly diagnosed with DM and referred to NODEP for whom complete data were available over a two-year period were included.

Sampling was a limitation for Phase II of the study. A convenience sample of participants who were referred to NODEP during the time period of Phase I was recruited without regard to whether their data had been included in the Phase I analysis. Therefore, the extent to which the Phase II participants were representative of all who were referred to NODEP is uncertain.

Given that participants in Phase II were surveyed three to eight years after participating in NODEP, their recall about the strengths and weakness of the program might have been limited.

### **Significance of the Study**

The high prevalence of T2DM in the Navajo population requires that their healthcare providers develop culturally appropriate programs to help reduce the burden of disease. Using federal funds provided by the DDTP, NODEP was developed at NNMC to address this problem. While NODEP was designed with the goal of reducing the HbA1c levels of people who are newly diagnosed with DM, the program had not been examined previously to determine if it was achieving its goals. This dissertation reports the findings of an in-depth evaluation of NODEP in the following chapters.

## **CHAPTER 2**

### **REVIEW OF THE LITERATURE**

There are 573 (Fris, 2018) federally recognized AI/AN tribes in the United States, each with unique beliefs, cultures, and practices. However, AI/AN people residing on tribal lands are disproportionately affected by the social determinants of health, including living in poverty (Beckles & Truman, 2013; Poverty, 2016), as well as by cultural and social isolation (USDHHS, CDC, 2016a) and a lack of healthcare services (USDHHS, IHS, 2018; Mandal, 2014). AI/ANs also have substantially higher prevalence of obesity compared with White Americans (Amparo, Farr, & Dietz, 2011; Barnes, Adams, & Powell-Griner, 2010) and the highest prevalence of DM when compared to other racial and ethnic groups in the United States. (USDHHS, CDC, 2018).

#### **Key Findings from the Literature**

A literature review was conducted using PubMed and CINAHL databases along with generalized web-based searches on Google, Google Scholar, and MSN. For this literature search, the author used the key words "Native American," "American Indian," "Alaskan Native," "diabetes," "education," "diabetes education," and "Navajo," in a variety of combinations. Given the importance of history to the understanding of health among AI/AN people, a specific time frame was not used in the search criteria.

The initial search yielded more than 5,000 articles. PubMed alone yielded 4,000 articles for review; of them, 3,150 were eliminated because they did not meet the search criteria or were duplicate articles. Due to the large number of articles retrieved by the search, publications that did not provide abstracts were also eliminated. Of the 764 articles that met the search criteria, 36 were specific to Navajo people.



Though many articles pertain to DM among AI/AN populations, most address the prevalence and incidence of diabetes (Dabellea et al., 2009; Prosnitz & Mandell, 1967; Saiki & Rimoin, 1968; Sugarman et al., 1990; Will et al., 1997). Despite this extensive search, the author did not locate any articles pertaining to diabetic education programs or more precisely, to the effectiveness of the Special Diabetes Program for Indians (SDPI) that were specific to the Navajo. To the best of the author's knowledge, this is the first study to address a comprehensive diabetic education program designed for members of an AI/AN tribe.

### **Impact of diabetes**

DM is a disease that affects people from all walks of life and in every country around the world. It is the fourth leading cause of death worldwide (WHO, 2011). The exact number of Americans with DM is unknown; however, it is estimated that DM affects more than 30 million Americans and that a higher burden of disease is carried by racial and ethnic minority populations (USDHHS, CDC, 2018). Being from a racial or ethnic minority group increases a person's risk for DM. Hispanic (12.1%) and non-Hispanic Black (12.7%) adults ( $\geq 20$  years) have a similar prevalence of DM (USDHHS, CDC, 2015) while AI/AN people (15%) have the highest percentage of adults with diagnosed DM compared with non-Hispanic Whites (7.4%) (USDHHS, CDC, 2018). Within the AI/AN group, the Pima Indians of the Gila River community in Arizona, who have been studied longitudinally since 1962, have the highest reported prevalence, at 38% (Schulz et al., 2006).

Approximately 95% of U.S. adult Pima Indians with diabetes are overweight (USDHHS, Office of Minority Health [OMH], 2015). The prevalence of type 2 diabetes

mellitus (T2DM) in the Pima was found to have increased from 42% during the decade between 1967 and 1977 (Carter et al., 1996). Carter et al. argued that changes in lifestyle, including lack of regular physical activity and an increased intake in highly refined, high fat, empty calorie foods, have had a significant influence on the prevalence of T2DM among the Pima. However, age- and sex-adjusted incidence rates for T2DM among U.S. Pima adults were relatively stable (20 to 25 incident cases per 1,000 patient years across three 13-year periods) between 1965 and 2003 (Pavkov et al., 2007).

In one of the earliest studies involving T2DM in the Navajo, Salisbury (1937) reviewed the cases of more than 6,000 Navajo adult hospitalizations at Sage Memorial Hospital in Ganado, Ariz., and found only one case of DM. But like the Pima, T2DM rose noticeably in the 1960s among the Navajo (Prosnitz & Mandell, 1967; Saiki & Rimoin, 1968). Unfortunately, T2DM was not recognized as being or becoming a major health concern at that time; in fact, it was considered to be an isolated and benign abnormality (Saiki & Rimoin, 1968).

### **Diabetes-Associated Morbidity and Mortality**

Diabetes is associated with multiple medical complications that decrease health-related quality of life and contribute to early mortality (Best et al., 2015; Sugarman, Hickey, Hall, & Gohdes, 1990). Complications include visual impairment and blindness (Bourne et al., 2013), amputations (Moxey et al., 2011; Sugarman et al., 1990), chronic kidney disease with kidney failure (Bourne et al., 2013; Bullock et al., 2017), heart disease (Mendlein et al., 1997; Will et al., 1997), and stroke (Bourne et al., 2013; Morrish, Wang, Stevens, Fuller, & Keen, 2001).

Diabetic retinopathy occurs because of long-term accumulative damage to the small blood vessels in the retina and can lead to blindness (Diabetic Retinopathy, 2015). In 2010, diabetic retinopathy caused 1.9% of moderate or severe visual impairment globally and 2.6% of global blindness (Bourne et al., 2013). In people with DM, small-vessel damage, such as retinopathy, is usually seen prior to larger vessel damage (Singh et al., 2013) that in the extremities can be demonstrated by slow or nonhealing sores which could lead to amputation, especially in the toes, feet, and lower legs (Bourne et al., 2013).

In the United States, nearly two million people have had a limb amputated for medical reasons. Vascular disease, including DM, is responsible for 54% of limb amputations, followed by trauma (45%), and cancer (approximately 2%) (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008).

In 2011, Moxey et al. reported that the rate of limb amputation among persons with diagnosed DM was approximately 10 to 20 times that of people who did not have DM. However, a dramatic decrease in the number of limb amputations was reported due to diabetes between 1996 and 2008, according to the CDC (2012a). In 1996, 11 of every 1,000 adults with DM required an amputation of a foot or leg compared to four of every 1,000 in 2008, an astounding decrease of 65% (USDHHS, CDC, 2012a).

The reduction in limb amputations of diabetic patients can be attributed to a combination of factors, including the FDA approval of new and more-effective medications in the treatment of DM. Metformin was approved for use in the United States in 1995, followed by repaglinide (Prandin) in 1998, exenatide (Byetta) in 2005, and sitagliptin phosphate (JANUVIA) in 2006 (American Diabetes Association, 2014). In addition to

pharmacotherapy, the use of HbA1c testing as a standardized method for diagnosing and consistent monitoring of glucose levels in diabetic patients (ADA, 2015; Suckow et al., 2016) and diabetic self-management education and diabetes self-management support (Diabetes education program, 2016) also might have contributed to the decrease in limb amputations among people with DM. Progress has also been made in other areas of diabetic-related complications, including end-stage renal disease (ESRD).

While the etiology of ESRD is mixed, diabetes is one of the most common contributing factors (Bourne et al., 2013; Bullock et al., 2017). Worldwide, the incidence of ESRD is up to 10 times higher in adults with diabetes as in those without (Bourne et al., 2013). In the United States, diabetes is the leading cause of kidney failure (Bullock et al., 2017).

In 2014, 120,000 people in the United States began treatment for ESRD; among them, 44% or 53,000 people listed diabetes as the primary cause (Bullock et al., 2017; Burrows et al., 2017). However, during a 15-year span from 2000 through 2014, there was a 33% decrease in the incidence of diabetic-related ESRD (Burrows et al., 2017). Even with this decrease, AI/AN populations continued to carry a disproportionately higher burden of diabetes-related ESRD (Burrows et al., 2017). According to claims data collected from the Centers for Medicare and Medicaid Services (CMS), the incidence of ESRD was three times higher among AI/ANs than among Whites, and the incidence of ESRD due specifically to diabetes was six times higher than among Whites (Burrows, Geiss, Engelgau, & Acton, 2000). As mentioned above, diabetes accounts for 44% of all new cases of ESRD in the United States (Burrows et al., 2017); however, a striking 69% of those cases are among AI/AN (Burrows et al., 2017). Having diabetes also contributes

to a higher incidence of morbidity and mortality related to cardiovascular disease (CVD) in AI/AN populations (American Heart Association, 2015).

CVD is a principal cause of death and disability among people with DM. Approximately 68% of those 65 and older with DM die from heart disease and 16% die of stroke (American Heart Association, 2015). People with DM have a two to six-fold increased risk of death from CVD than those without diabetes (Gu, Cowie, & Harris, 1999).

The Strong Heart Study (Howard et al., 1999) was a particularly well-known study that focused on AI populations. The researchers found that among AI men and women aged 45 to 75, having DM increased a person's risk for developing CVD. AI men were found to have a 2.2 times increased risk of developing CVD, while AI women had a 3.5 times increased risk of developing CVD compared to individuals without DM (Howard et al., 1999). Among all CVD events, DM accounted for 56% of death in men and 78% in women, indicating that coexisting DM was a strong predictor of CVD death (American Heart Association, 2015).

### **Physical Risk Factors for Developing Diabetes among the Navajo**

#### **Genetic Risk Factors**

The development of T2DM is usually a combination of factors including environment, lifestyle, and genetics (Ahlqvist, Ahluwalia, & Groop, 2011; Cheng, 2005; Das & Elbein, 2006; Leontis & Hess-Fischl, 2017), though the influence of each might vary from person to person. The role of genetics in the development of diabetes is still under investigation, but it is well-known that a person can inherit a predisposition for T2DM (Ahlqvist, Ahluwalia, & Groop, 2011; Das & Elbein, 2006; Leontis & Hess-

Fischl, 2017). Although a person might be genetically predisposed, lifestyle factors such as environment, healthy diet, and exercise might limit the development of T2DM (Cheng, 2005; Reue & Donkor, 2007; Sugarman et al., 1990).

While there is broad consensus that lifestyle plays a significant role in the development of T2DM among AI/AN populations, the questions concerning the influence of genetics in the development of T2DM remain unanswered for many groups, including the Navajo. In part, these unanswered questions relate to perceived violations of traditional Navajo practice and cultural laws. Although this violation might be unintentional, it widens the gap between a Navajo patient and a Western medical provider. In traditional Navajo culture, words are very powerful and are perceived to influence health outcomes. Therefore, it is important for healthcare workers to keep conversations positive and speak in third-party references, such as, “It is important to take this medication every day. If a person with DM takes this medication every day it will help control their blood sugar, help protect their vision, their kidneys, and help prevent limb amputations.” Though perceived violations to Navajo tradition often are unintentional, there are historical events that have heightened the mistrust among AI/ANs of the medical and research communities (Blakemore, 2017).

In 2004, the Havasupai Tribe of northern Arizona was awarded a \$700,000 settlement when researchers from Arizona State University and the University of Arizona collected blood samples from Havasupai tribal members to try to determine if a link existed between genetics and T2DM (Blakemore, 2017). However, when the results of the study were presented, the participants were horrified to learn their blood samples had also been used to study schizophrenia, inbreeding, and ancient migration patterns.

The Havasupai people were not informed that their blood would be studied for anything other than a possible link to diabetes. They believed the discussions involving schizophrenia and inbreeding were stigmatizing and that information concerning the migration patterns was in contrast to their origin beliefs (Blakemore, 2017).

Navajo people have faced similar exploitations of medical testing in the not too distant past. During the Cold War years from the 1940s through the 1980s, millions of tons of uranium was extracted from Navajo lands (Eichstaedt, 1994; Pasternak, 2010). Approximately 15,000 people worked in the uranium mines, and about one quarter of them were Navajo (Eichstaedt, 1994). The U.S. government knew that people exposed to radon in uranium mines had a greater risk of developing and dying of lung diseases, including cancer, 10 to 20 years after exposure (Eichstaedt, 1994; Pasternak, 2010). However, the government still had questions concerning the effects of uranium exposure on the human body, so in 1954, research teams traveled across the Navajo Nation with a medical and mobile X-ray unit to obtain data on the health of uranium miners (Pasternak, 2010). The research team obtained chest X-rays, blood and urine for laboratory testing, a work history, and a medical history. Members of the research team would inform the miner if something was wrong at the time of the exam, but the uranium workers were not informed that they were at an increased risk over time for developing lung cancer (Pasternak, 2010). At the end of the first data collection period (summer of 1954) 1,319 uranium workers had been examined (Pasternak, 2010).

With events such as the one described above, it is not surprising that the Navajo are hesitant to trust researchers. As a result, in 2002, the Navajo leaders and community

members decided not to participate in any research studies that involved genetics (Blakemore, 2017).

## **Obesity**

Obesity increases a person's health risks for high blood pressure, T2DM, heart disease, dementia, and certain cancers, including breast (in post-menopausal women), colon/rectum, endometrial, pancreatic, gallbladder, kidney, and liver (Story et al., 1999). Further, people who are obese also have a higher mortality rate from cancer compared to people of normal weight (National Cancer Institute, 2017). In the United States more than one in three adults (40%) and one in six children between the ages of 2 and 19 (18.5%) are obese (USDHHS, CDC, 2017).

According to the 2009 IHS Government Practices Results Act (GPRA) report, which assessed each of the eight NAIHS service units the percentage of Navajo people who were considered overweight (BMI between 25.1 and 29.9) ranged from 17% to 39% while an additional 23% to 60% were in the obese category (BMI  $\geq$  30) (Navajo Nation Memorandum, 2014). In some of these areas on the Navajo Nation, up to 60% of adults have been diagnosed with T2DM (Toppa, 2015).

## **Social Risk Factors for Developing Diabetes among the Navajo**

### **Geographic Isolation**

The sheer size and remote nature of the Navajo Nation presents unique challenges that can influence a person's range of choices and behavior, beginning in childhood and potentially affecting them for years. There are more than 18,000 miles of roads on the Navajo Nation and only 3,000 miles are paved (Chaco, 2012). Most Navajo households are located miles from a paved road (Chaco, 2012) and many of these roads become



impassable during windy periods that can bring dust and sandstorms and during times of rain or snow. Most of these unpaved roads are tribally maintained, but the Navajo Nation Department of Transportation (NNDOT) does not have the manpower or equipment to keep all of these roads passable, leaving many families stranded for days to weeks at a time (Chaco, 2012; Vock, 2017).

The normality of poor road conditions on the Navajo Nation make it difficult, if not impossible, for Navajo children to regularly attend primary and secondary school, for individuals to obtain medical care, and for Navajo people to obtain healthy food choices including fresh fruits and vegetables. According to a 2014 report from the Diné Policy Institute there are only 10 full-service grocery stores on the entire Navajo reservation and the U.S. Department of Agriculture (USDA) has identified nearly all of the Navajo Nation as a food desert. Further, because a road can become impassable at almost any time, many Navajo families maintain a supply of nonperishable and highly processed foods, such as canned goods, boxed meals, canned and bottled drinks, many of which have high sugar and chemical content.

## **Education**

Disparities in primary and secondary education are associated with multiple social and health problems. Health disparities related to inequities in education are apparent in the Navajo. Recent data show that one of four AI/AN youth do not graduate from high school in four years (University of Wisconsin Population Health Institute [UWPHI], 2018) and have the lowest graduation rate of approximately 72%, compared to other racial groups (National Center for Education Statistics, 2018). In comparison, Asian/Pacific Islander youth have the highest graduation rates at greater than 91%,

followed closely by White youth at 88% (National Center for Education Statistics, 2018). Further comparisons of graduation rates by state shows that New Mexico, which is a minority majority state, has the lowest graduation rate of 67.9% (National Center for Education Statistics, 2018), while Nebraska, with 88.6% of the population being White (U.S. Census Bureau, 2017), has the highest graduation rate at 93.7% (National Center for Education Statistics, 2018).

There are eight types of educational entities on the Navajo Nation: Arizona public schools, New Mexico public schools, Utah public schools, Bureau of Indian Affairs schools, Grant schools, Association of Navajo Controlled Schools, chartered schools; and private schools (Navajo Nation Department of Diné Education, 2016). The variety of schools and the fact that the Navajo Nation has land in three states--Arizona, New Mexico, and Utah--make it difficult to obtain overall graduation rates for Navajo students attending school on the reservation. However, the information that is available shows the dropout rate per school varied greatly, ranging from 2.04% at the Rock Point Community School, in Rock Point, Arizona to 38.3% at Alamo Navajo School in Magdalena, N.M. (Navajo Nation Department of Diné Education, 2016).

People with less education are more likely to experience an increased number of health risks, including obesity, sedentary lifestyles, substance abuse, and intentional and unintentional injury, compared with individuals who have more education (Beckles & Truman, 2013; USDHHS CDC, 2012b; Zimmerman, Woolf, & Haley, 2015). People with higher education levels tend to live longer and have an increased chance of obtaining and understanding health information and services that help them make

appropriate health decisions (Beckles & Truman, 2013; USDHHS CDC, 2012b; Zimmerman et al., 2015).

### **Poverty/Unemployment**

In 2016, the national, annual (unadjusted) unemployment rate for the U.S. population 16 and older was 4.9%, (U.S. Department of Labor, 2018). African American and AI/AN adults experienced the highest unemployment rates in 2016 of 9.9% and 10.5%, respectively, (UWPHI, 2018) while Asian and White adults experienced lower rates 3.5% and 4.2%, respectively (UWPHI, 2018). The Navajo Nation unemployment rate increased over the past decade and was 47% in 2015 (Navajo Nation, 2016) compared to 42% in 2004 (Navajo Nation Economic Development, 2004). A report released by the U.S. Census Bureau (2013) ranked two communities on or adjacent to the Navajo reservation within the top five among Native American communities for the percentage of residents living the below poverty level. Shiprock, N.M., where this study was conducted, ranked third in the nation in the percentage of AIs living below the poverty level and Gallup, N.M., was ranked fourth. According to the 2010 Census, AIs account for 96% of the population in Shiprock (U.S. Department of Commerce, U.S. Census Bureau, 2013). Census figures showed that the median per-capita income of Shiprock residents was \$13,307, which is much lower than the New Mexico state average of \$23,948 and is less than half of the national average of \$28,555 (U.S. Department of Commerce, U.S. Census Bureau, 2016b).

### **Historical Influences on the Navajo**

The forced removal of the Navajo from their homelands by the U.S. government beginning in 1864 is known as the Long Walk (Acrey, 1988; Iverson, 1981). From 1864

through 1866, more than 8,500 Navajo men, women, and children, already weak from starvation, were gathered and marched more than 300 miles to Bosque Redondo in eastern New Mexico, where the military had an outpost at Fort Sumner, N.M. (Acrey, 1988; Iverson, 1981). Fort Sumner was referred to by the Navajo as hwéeldi, which means “the place of suffering” (Blair, 2018; Schwarz, 2001). The Navajo people were finally released from Bosque Redondo in 1868 and returned on foot to their original homeland encompassed by the four Sacred Mountains (Acrey, 1988; Bruchac, 2002; Iverson, 1981).

In the internment camp at Bosque Redondo, the military did not adequately feed the Navajo people; provided were canned goods, white flour, processed sugar, and lard (Iverson, 2002). Using these ingredients, the Navajo made a flatbread that was fried; it became known as frybread (Donovan, 2018). Frybread became a staple food that is frequently served even today.

A typical piece of frybread, which is usually the size of a large dinner plate, can contain as many as 750 calories and 25 grams of fat (Donovan, 2018). During the time the Navajos were detained, and for some time after their release, the high caloric and fat content of frybread provided necessary sustenance. However, frybread has remained a staple food in many traditional households; it is frequently served at family and community gatherings, official meetings (usually with lunch), and celebrations. Frybread is also offered on the menus of many restaurant and fast food chains across the reservation and town adjacent to reservation boundaries.

### **Traditional Navajo Philosophy**

The strength and resilience of the Navajo are demonstrated in the traditional creation story. The creation story is a complex origination story that includes elements of well-being and health (Griffin-Pierce, 2000; Zolbrod, 1987). The people who orient their lives through traditional philosophy value harmony, beauty, wellness, and balance in life as well as the environment; this is called hózhó (Austin, 2009; Kahn-John, 2010; Werito, 2014). Hózhó is a strength that one must strive to attain at all times (Benally, 1992, 1996; Griffin-Pierce, 1992, 2000; Werito, 2014). The struggle to obtain and maintain hózhó dates to the origins of the Navajo people.

The creation story continues to be important to many Navajo. Many of the themes from the creation story are still acknowledged and respected, regardless of where individuals are on the spectrum of traditionalism (Iverson, 1981; McPherson, 1947; Lindig & Teiwes 1993). Themes that arise from the creation story began in the first world and continued throughout the journey to this, the fourth world. These themes consist of symmetry, balance, harmony, wellness, and beauty. These ways of being are collectively known as hózhó.

### **Hózhó**

The word hózhó is comprised of the prefix ho- and the stem -zho. Ho- refers to the environment or the world and -zho to balance (Witherspoon, 1977) and all things good (Austin, 2009; Benally, 1987; Witherspoon, 1977; Wyman, 1970). Hózhó cannot be translated into a single English word (Witherspoon, 1977; Wyman, 1970); hózhó is a concept that is complex (Kahn-John, 2010). The commonly used descriptions such as beauty, harmony, and wellness do not fully represent the concept hózhó (Austin, 2009; Benally, 1987); each of these positives must be in balance with their negative opposites

(Austin, 2009; Kahn-John, 2010). Seeking balance is an important aspect in the Navajo way of life and is so ingrained that it cannot be removed from daily living (Austin, 2009; Werito, 2014).

Hózhó is the continual goal of traditionally oriented Navajo people; hózhó is integrity, purity, and wholeness that is an essential guiding force that many strive toward during their lifetimes (Austin, 2009; Farella, 1984; Kahn-John, 2010; Reichard 1950; Werito, 2014). As Farella (1984) described it and Austin (2009) expounded on it, hózhó is the “main stalk,” and everything else is derived from it. The concept of hózhó is all inclusive. It includes knowledge, behavior, thought, language, people, gods, and ritual (Farella, 1984).

Hózhó is not something that can be held in status; the universe, environment, community and people are in constant motion; therefore, people must continually strive to adjust to restore balance and harmony (Farella, 1984; Werito, 2014). If disharmony and imbalance persist then hóchxó can lead to physical or mental illness (Austin, 2009; Farella, 1984; Kahn-John, 2010). Kahn-John (2010) asserted that despite the best efforts of the Navajo, some are in hóchxó, as evident by the increased rates of mental illness, violence, heart disease, cancer, and all other illnesses among the Navajo, including diabetes.

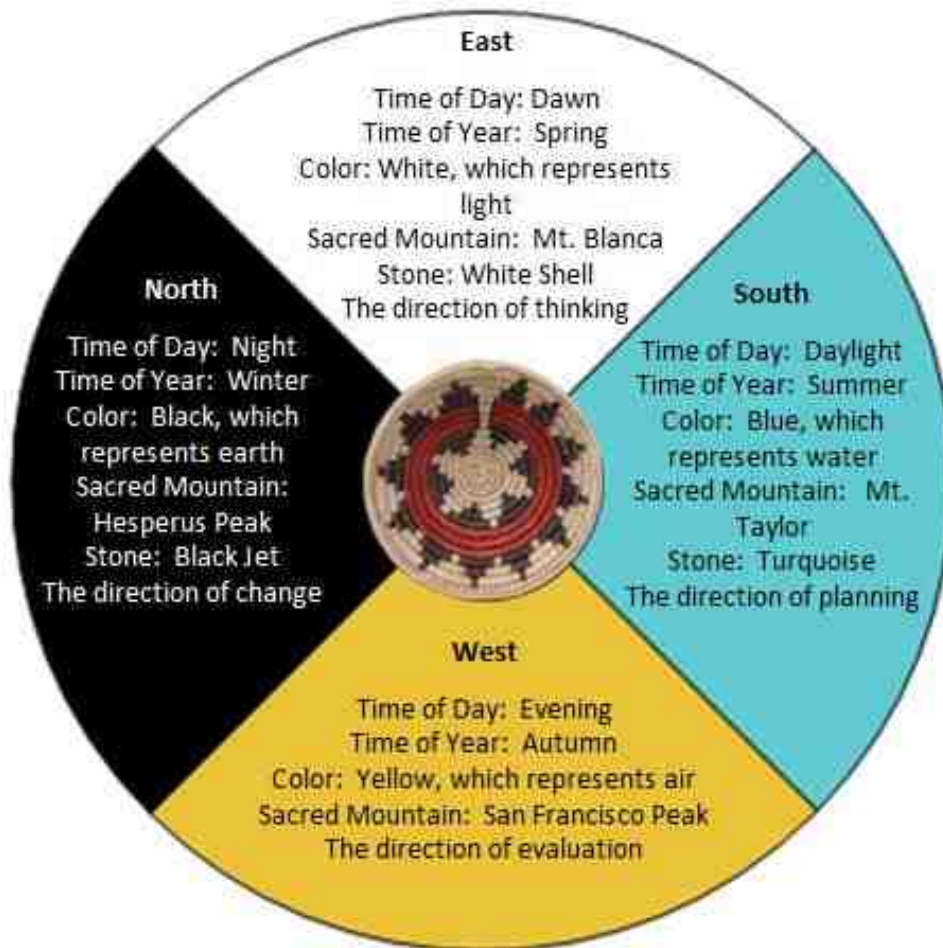
Living in hózhó means continually restoring, finding, and practicing balance in one’s life (Werito, 2014). Hózhó can be restored in many ways including having pure and positive thoughts, blessing one’s homes with cedar or sage, and through traditional ceremonies (Farella, 1984; Wyman, 1970).

### **Navajo Philosophy of Learning**

Hózhó and the Navajo philosophy of learning are linked because both utilize the knowledge of the four directions to help the individual obtain and maintain this state of serenity. Hózhó cannot occur if any portion of an individual's life is not in balance (hóchxó) (Benally, 1992, 1996; Iverson, 2002; Kahn-John, 2010).

The source of Navajo traditional knowledge is found in the philosophy, origin stories, songs, and prayers of the Navajo people (Benally, 1992, 1996; Iverson, 2002; Lindig & Teiwes, 1993). Navajo traditional philosophy emphasizes circularity and balance (Benally, 1992; Link, 1998; Locke, 2002); thus, many sacred items and beliefs are represented in sacred pairs or fours (Link, 1998; Benally, 1992). Examples of these include First Man and First Woman; the two superior bodies of Father Sky and Mother Earth; and the four directions, beginning in the east and moving clockwise to the south, west and finally the north. There are four sacred outer mountains--Mount Blanco, Mount Taylor, San Francisco Peak, and Hesperus Peak. The day consists of four parts--dawn, daylight, twilight, and night--and there are four seasons--spring, summer, autumn, and winter. There are also four sacred colors to the Navajo: white, which represents light; blue, which represents water; yellow, which represents air; and black, which represent the Earth (Benally, 1996; Iverson, 2002) (Figure 2.1).

Figure 2.1. Traditional representations of the four directions



Acrey, 1988; Benally, 1992, 1996; Navajo Nation Government, 2011; Reichard, 1950.

Each direction holds specific knowledge that is important for survival. Mother Earth is credited with placing this knowledge and linking it with the elements of the four directions (Locke, 2002; Benally, 1996). The east is associated with giving people a



direction to their lives; south is associated with making a living; the theme of the west is social well-being; and the north is associated with respect for nature and all creation (Benally, 1996; Carey, 2015).

### **Knowledge Associated with the East**

The knowledge associated with the east gives a person, family, community, or nation a direction to their lives. Knowledge from the east relates to wisdom, the means of understanding, keen discernment and sound judgment. It will guide a person to develop good character and soundness of the heart and mind (Benally, 1992, 1996; Link, 1998; Locke, 2002).

Traditional Navajos believe that the Diyin Diné passes over the country at dawn and that if a person is up and about, they will be blessed with health and prosperity (Carey, 2015; Benally, 1992, 1996). Dawn is also the time when one should pray. This early-morning prayer helps one clear the mind, purify the heart, and prioritize life, which begins anew at the dawn of each day (Benally, 1992, 1996; Link, 1998; Locke, 2002).

It is also believed that one should run at dawn. Running each day at dawn is not only a form of exercise that promotes physical well-being, but is also an exercise that contributes to mental and spiritual well-being (Benally, 1992; Locke, 2002). Running each day at dawn requires discipline that in turn strengthens the body, mind, and spirit.

If one does not follow the guiding principles provided by the east and dawn, one runs the risk of being unable to fully experience life or to develop a genuine appreciation for themselves, others, and nature (Benally, 1992). They would lose the standards by which traditionally oriented Navajo evaluate the value of their thoughts and actions (Benally, 1992, 1996). The lack of knowledge from the east could result in disharmony,

greed, social maladjustment, hunger, illness, poverty, and other social difficulties (hóchxó) (Iverson, 2002; Benally, 1992, 1996).

In education, knowledge from the east encompasses sound judgment, sound teaching practices, resilience, maintaining standards of conduct and appreciation for life and all living things. If sound values, morals, and ethics are not utilized, the family structure deteriorates, which in turns leads to a breakdown of society. The knowledge from the east is crucial in providing standards by which people can judge the effectiveness of their thoughts and actions (Austin, 2009; Benally, 1992, 1996).

### **Knowledge Associated with the South**

The knowledge obtained from the south is associated with making a living and the knowledge and activities that go with it. Knowledge from the south encourages one to achieve self-sufficiency, provide for one's family, and to be a contributing member of society (Austin, 2009; Benally, 1992). Work is traditionally not just a physical or technical endeavor; it also has a spiritual dimension (Benally, 1992, 1996; McPherson, 1992). Before one can achieve self-sufficiency, one must acknowledge work and all the aspects associated with it. During work, one must consider the ethical issues, social interactions, and environmental impact that are interwoven and cannot be separated from the process of achieving and maintaining self-reliance and providing for the family (Benally, 1992, 1996; McPherson, 1992).

An important and basic concern in Navajo philosophy is the balance between moderation and excessiveness (Benally, 1992). To ensure harmony; one must recognize that power, strength, and wealth come from the environment and the people, not from

material goods or monetary gains. It is believed that to live in excess is an evil that will lead to strife and illness (Austin, 2009; Benally, 1992, 1996).

In education, the knowledge from the south is essential to attain a central balance in one's education. Without this central balance, a person is not able to provide for oneself, the family, or the community. It is thought that a person who cannot contribute to the self, family, and community has lost direction in life (Benally, 1996).

### **Knowledge Associated with the West**

Knowledge from the west is associated with the gathering of families, thinking, planning, and teaching. Young people are believed to need some understanding of their history to understand the world as it is now and to help prepare them for the future. History and storytelling contain instructions for acceptable behavior of the individual, family, and community (Austin, 2009; Benally, 1996; Link, 1998; Locke, 2002).

Knowledge from the west promotes a connectedness among family members. This is accomplished in several ways, one of which is by using kinship names when talking to or referring to a family member (Benally, 1992; Carey, 2013). Calling a family member by a given name in the home is rarely done and is a sign of disrespect (Benally, 1992). The use of kinship terms helps to strengthen positive family connections (Benally, 1992; Carey, 2013).

Another important aspect of kinship is the Navajo clan system. Being able to identify the clans from which a person comes helps provide a sense of belonging by connecting them to their lineage and ancestry (Benally, 1992, 1996; Reichard, 1950). In traditionally oriented families the clan system is cherished and taught to children at a young age (Benally, 1996; Carey, 2013).

It is also during this time that children are taught their roles, communication skills, and appropriate behavior by observing, listening to, and assisting others (Benally, 1992, 1996; Carey, 2015). The knowledge associated with the west begins in the home but is lived in the community.

In education, knowledge from the west is associated with social well-being. This includes family gatherings to discuss and plan events for the following day and other future activities (Benally, 1996). Knowledge for the west nurtures positive human relations in the home and community and stresses the need for teaching and planning to help overall well-being among Navajo people.

### **Knowledge Associated with the North**

Knowledge from the north is associated with respect for all things in nature (Benally, 1996; Werito, 2014) rest, and reflection (Carey, 2015). This knowledge stresses awareness and understanding of the interrelatedness and interdependence of all life. If any area of knowledge is out of balance, there is hóchxó; the individual must recognize this imbalance in order to correct it (Benally, 1992, 1996). When this balance is upset, it usually affects other elements that threaten the well-being of the self, the family and the community (Benally, 1992, 1996; Carey, 2015).

In education, the north is associated with respecting the earth, the celestial bodies, and all living things. This reverence includes both the physical and spiritual aspects of nature and one must protect and work with nature to ensure its benevolence. If mistreated, nature will respond by inflicting sickness and misfortune creating hóchxó (Werito, 2014).

### **Diabetes Education**

Diabetes is a chronic disease that requires a person to continually make decisions to ensure appropriate daily self-management of the disease. Therefore, providing education for patients with diabetes is a cornerstone in the effective management of diabetes to improve health outcomes. Diabetes education programs usually cover the following topics: general information about diabetes and its treatment, psychological adjustments to life with diabetes, setting goals and solving problems, setting and following a meal plan, increasing exercise, blood glucose monitoring, managing sick days, and identifying and preventing complications (ADA, 2018).

Diabetes self-management education is the process of enabling the individual to manage diabetes by providing the knowledge, skill, and ability necessary to do so (Powers et al., 2015). Diabetes self-management support refers to the support that an individual or caregiver might need in order to sustain the skills and behaviors necessary to manage diabetes on an ongoing basis (Powers et al., 2015). Diabetes self-management education and diabetes self-management support programs are intended to address the patient's health beliefs, cultural needs, current knowledge, physical limitations, emotional concerns, family support, financial status, medical history, health literacy, and other factors that influence one's ability to meet the challenges of managing diabetes (Powers et al., 2015).

The American Diabetes Association (2018) strongly encourages all individuals with diabetes to receive diabetes self-management education and diabetes self-management support at diagnosis and as needed thereafter. In general, the participation in diabetes self-management education and diabetes self-management support programs has

been shown to be beneficial. This study will help determine if this is the case with NODEP at NNMC as well.

NODEP is only one part of a complete program intended to serve the diabetic patients at NNMC. NODEP has not formally been evaluated to determine its effectiveness among Navajo adults with diabetes.

### **The Navajo Philosophy of Learning and the New Onset Diabetes Education Program**

The Navajo philosophy of learning is an organized way of learning that is categorized into four inseparable areas. This is one of the biggest differences between Western knowledge and the sacred knowledge of the four directions in Navajo philosophy. Western knowledge is fragmented (Gilliland, 1992; McCarty, 2002), and one topic might have nothing to do with the next (Benally, 1992, 1996; Gilliland, 1992), whereas, in the Navajo philosophy of learning, balancing the knowledge of the four directions is paramount. It provides people with a foundation that is needed to make appropriate and wise decisions for the self, the family, and the community. Based on the Navajo philosophy of learning, the knowledge obtained from each of the four categories promotes learning that encompasses and nurtures all aspects of an individual, directing them toward harmony or hózhó (Benally, 1992, 1996).

The goal of NODEP is to provide the knowledge and skills necessary to help those with diabetes regain balance, physically, mentally, and spiritually. The knowledge obtained from the east involves building a strong foundation in order to build a good life. One of the elements associated with the knowledge from the east is the need to exercise daily. Exercising not only provides physical fitness, it also helps one clear the mind. In

association with diabetes, exercise is one of the cornerstones for prevention and treatment.

To the south is the knowledge of work and self-reliance. If a person or community lives in excess, disharmony can result, causing *hóchxó* (Austin, 2009; Kahn-John, 2010). Knowledge associated with the south—avoiding excesses—can be applied when teaching about appropriate food portions and in avoiding excesses in sugary foods and drinks and of alcohol and sedentary activities.

To the west is the knowledge that is obtained from the home and family. In the home a person with diabetes can rely on the support and encouragement of other family members. The family can grocery-shop, prepare meals, and exercise together. In this setting, children learn from the actions of other family members; therefore, it is important to provide a good example by preparing and eating healthy foods, and by engaging in physical activity.

The knowledge obtained from the north includes self-fulfillment and respect (Austin, 2009; Benally 1996). This knowledge stresses the interdependence of all aspects of knowledge, the self and life. This is a time to recognize imbalance, excess, or deficiencies that influence the being and the importance of striving to correct them. Relating this to NODEP, participants are encouraged to keep logs and records; by reviewing these logs, they might find areas of diet, exercise, and/or medication adherence that could be improved; if any area is out of balance, the whole will suffer. Knowledge associated with the north includes recognition that if any of these areas are out of balance the whole being is affected and in disharmony.

### **Summary**

This chapter summarizes the relevant literature on DM as a chronic disease and its impact on the Navajo in the context of historical trauma (Acrey, 1998; Iverson, 1981). Importantly, this chapter also describes the theoretical framework that has guided this study, including the Navajo philosophy of learning, and central concepts of hózhó and hóchx.

Utilizing these concepts, NODEP was developed at NNMC to help restore hózhó in the individual, family, and community through diabetes education and improved diabetes self-management. Given the high prevalence of T2DM among the Navajo, this study provided evidence for the effectiveness of this culturally sensitive DM education program. The following chapter describes the methods used in the study.



## **CHAPTER 3**

### **METHODS**

#### **Design**

The purpose of this study was to examine the effectiveness of NODEP at NNMC in Shiprock, N.M. A two-phase design was used to determine the effectiveness of NODEP. Phase I used a retrospective cohort design of pre-referral and follow-up HbA1c and BMI values of Navajo adults diagnosed with T2DM and referred to NODEP between January 1, 2010, and December 31, 2015. The four groups were: (a) those who attended and completed NODEP (three-day program); (b) those who attended an accelerated/individualized NODEP class (one-day program); (c) those who attended part of NODEP but did not complete it; and (d) those who did not attend NODEP. Data were abstracted from existing IHS electronic health records (EHR) via the Resource Patient Management System (RPMS).

Phase II used a descriptive, exploratory design to evaluate the strengths and weaknesses of the program, as well as the barriers to participation, as perceived by Navajo adults who were referred to NODEP between January 1, 2010, and December 31, 2015. These data were obtained using two surveys that were developed by the researcher. One survey (Survey A, Appendix A) was designed for who attended and completed either the three-day or one-day program (Groups 1 and 2), and the second survey (Survey B, Appendix B) was designed for those who either began but did not complete the three-day program or who did not attend NODEP (Groups 3 and 4).

The two-phase cohort design was appropriate for several reasons. First, a retrospective cohort design allows for the utilization of pre-intervention and post-

intervention measurements in multiple groups and can use time-series data (Harris et al., 2006; Shadish, Cook, & Campbell, 2002). In this study, the participants already belonged to existing groups or cohorts by virtue of the type of program they attended. Phase I data came from existing health records, and Phase II data were from administered surveys.

While cohort designs are often more feasible than true experimental research designs (Shadish et al., 2002), they have disadvantages. The groups themselves can have inherent differences from the beginning that can bias the results of a study (Harris et al., 2006; Shadish et al., 2002) and increase threats to internal validity (Harris et al., 2006).

The descriptive, exploratory design was appropriate for Phase II, because patient perceptions regarding barriers to participation and the strengths and weaknesses of the program had not been captured previously. The members of the Navajo Nation Human Research Review Board (NNHRRB) were clear in their recommendation that any evaluation of NODEP must also include the perspectives of the Navajo people so that the findings of the study would be useful to the tribe. Thus, Phase II provided a more nuanced, in-depth assessment of the program than Phase I alone.

### **Research Question 1**

Is participation in either the three-day NODEP program or the one-day NODEP associated with a meaningful reduction in HbA1c compared to partial or no participation?

Hypothesis 1: Compared with newly diagnosed Navajo patients with T2DM who were referred to NODEP but did not participate, those who participated in either the three-day program or the one-day program will demonstrate clinically meaningful and statistically significant sustained improvement in HbA1c compared with those who did not participate and those with incomplete participation (began three-day program but did

not complete). To test the hypothesis, HbA1c levels at diagnosis/referral and 3, 6, 12, 18, and 24 month follow-ups were obtained from existing records for four cohorts: full participation (three-day), accelerated/individualized participation (one-day), incomplete participation, and no participation in NODEP.

### **Research Question 2**

Is participation in either the three-day NODEP or the one-day NODEP associated with meaningful reduction in BMI compared with incomplete or no participation?

Hypothesis 2: Compared with newly diagnosed Navajo patients with DM who were referred to NODEP but did not participate, those who participated in either the three-day program or the one-day program will demonstrate clinically meaningful and statistically significant sustained improvement in BMI compared with those who did not participate and those with incomplete participation. To test the hypothesis, BMI levels at diagnosis/referral and at 12 and 24 month follow-ups were obtained from existing records for the same four cohorts as in the preceding research question.

### **Research Questions 3 and 4**

What are the perceived strengths and weaknesses of NODEP as identified by past participants? What are the perceived barriers to attendance at NODEP as identified by participants who began, but did not complete the program and participants who did not attend any portion of the program? These questions were answered by providing an analysis of the responses to Survey A (Appendix A) and Survey B (Appendix B). Descriptive statistics, consisted of means, standard deviations, frequencies, and percentages were calculated for all survey response items. Open-ended questions were

analyzed and summarized using thematic content analysis, which will be described later in this chapter.

### **Research Question 5**

What are the perceived barriers to attending NODEP at NNMC? These questions were answered by providing an analysis of the responses to Surveys A (Appendix A) and B (Appendix B). Descriptive statistics, consisted of means, standard deviations, frequencies and percentages were calculated for all survey response items. Open-ended questions were analyzed and summarized using thematic content analysis, which will be described in this chapter.

### **Setting**

All of the participants received care at Northern Navajo Medical Center (NNMC) in Shiprock, N.M. NNMC is one of five facilities within the Shiprock Service Unit (Figure 3.1), which is the largest service unit of the Navajo Nation (USDHHS, IHS, 2016a).

### **Participants**

Inclusion criteria were as follows: persons who were legally recognized as Navajo; 18 and older; newly diagnosed with DM; pre-referral HbA1c value of 6.5% or higher with at least two follow-up HbA1c values during the subsequent 12 months; and referred to NODEP between January 1, 2010, and December 31, 2015. During this time, 1,962 people met the diagnostic criteria for diabetes as defined by the ADA (2015) of having an HbA1c of  $\geq 6.5\%$  and were subsequently referred to NODEP. This study did not include any adults who were unable to consent, anyone younger than 18, pregnant women, or any incarcerated persons.

## Sample for Phase I

Of the 1,962 participants who met inclusion criteria during the designated time frame, 898 began the program. See Table 3-1 for the assignment criteria and number of participants in each group.

Table 3-1

*Group Population for NODEP from January 1, 2010, to December 31, 2015*

<b>Group</b>	<b>Program</b>	<b>Total Number in Sampling Frame</b>
Group 1	Attended the traditional three-day course to completion	493
Group 2	Attended an accelerated/individualized one-day course	179
Group 3	Attended some portion of the traditional three-day course, but did not complete it	226
Group 4	Did not attend any portion of NODEP	1064

## Sample Size

Statistical power is a function of several factors: sample size, effect size, and alpha (Type I) error rate (Field, 2009). Power is the complement of the Type II ( $\beta$ -) error rate and corresponds to the probability that a statistical test would reject the null hypothesis if the null hypothesis were not true (Field, 2009). By convention, an alpha

error level is usually set at 0.05 (Hazard-Munro, 2005), and power is set at 0.80 or higher (Field, 2009; Hazard-Munro, 2005). Ideally, effect size is based on preliminary data or clinical judgment on what a meaningful difference would be because of the intervention.

### **Power Analysis**

For a repeated measures ANOVA (within- and between-interactions) with four groups, assuming at least modest autocorrelation (0.4) among repeated measures, a total sample size of 192 (48 per group) would be sufficient for 80% power to detect a small effect size (Cohen's  $f = .10$ ) for group-by-time interaction with six measures (baseline and five follow-up), and a sample of 240 (60 per group) would be sufficient for 90% power (Faul, Erdfelder, Buchner, & Lang, 2014). The threshold for a clinically meaningful decrease in HbA1c was 0.5% (REPOSE Study Group, 2017).

### **Sample for Phase II**

During the second phase of the study, a convenience sample of participants who completed NODEP and a group of participants who did not complete or did not attend NODEP were selected to respond to the survey (Appendices A and B). Initially, the NNMC EHR was searched to determine which of the 1,962 patients in the sampling frame had scheduled appointments at NNMC during the three-month data collection period. The researcher identified the participant and the place and time of the scheduled appointment and delivered the surveys to the appropriate clinics on a weekly basis. The computer search and delivery of surveys was an ongoing process because most clinics are rarely scheduled more than a month in advance. Seventy-seven completed surveys were obtained from Groups 1 and 2 (participants who completed the program), and 49 surveys

were collected from Group 3 (participants who did not complete it) and Group 4 (participants who did not attend).

## **Procedures**

### **Data Collection**

**Phase 1, Retrospective Chart Review.** A data search was conducted via the NNMC EHR program iCare. Information queried included the subject's gender, age, all BMI measures, and HbA1c lab values since the time of diagnosis. To maintain an equal number of subjects in each group, data from the cohort with the smallest number of subjects (Group 2 = 179) was collected first. This initial review of charts also established the data intervals of 3, 6, 12, 18, and 24 months as feasible in terms of the number with complete data. During the chart review, it was determined that 120 subjects had HbA1cs from the six data points above.

Next, 120 people were randomly chosen by computer for inclusion in the sample from Groups 1, 3, and 4. If a participant did not meet inclusion criteria or did not have complete data for HbA1c, they were excluded, and another participant was randomly selected from the same group. This process was repeated until 120 participants with complete data were obtained for each group. Therefore, the final sample size for Phase 1 was  $N = 480$ . All data were entered into an Excel spreadsheet and stored on a secure NNMC-owned computer.

Co-morbidities (hypertension; cardiovascular disease; obesity; and chronic kidney disease, stage III or greater) were initially intended to be examined; however, this was not feasible because it could not be determined reliably when the diagnosis had been made in relation to the diagnosis of diabetes and referral to NODEP. It was possible to determine

when the diagnoses had been added to the problem list, but this did not necessarily coincide with the date the ailment was diagnosed. For this reason, co-morbidity data were not collected.

**Phase II, Survey Data.** Phase II of the study involved surveying a sample of participants from each group. Prior to the initiation of the survey, the researcher met with the outpatient clinic staff at NNMC to introduce the study; to explain its importance; and to ask for staff assistance with the distribution, explanation, and collection of the surveys. Clinic staff included people who were proficient in the Navajo language and who were willing to serve as interpreters. To identify potential participants for this phase, a data base was set up using the name and medical chart numbers of individuals from each group who met the study. Once this information was entered into the IHS iCare system, the researcher determined when potential participants were scheduled for routine clinic appointments at NNMC. The researcher wrote the person's name, chart number, date and time of scheduled visit, and the location where the appointment was scheduled on the written consent form (Appendix C), which was then stapled to the appropriate survey. The surveys were then delivered to each of the clinics and given to the contact person for that clinic.

The process for distributing the surveys began when the potential participant checked in for a scheduled appointment. While the original plan was to a receptionist place the survey in the patient's folder upon check-in, it was decided to eliminate that step to ensure that participant information was kept secure.

The surveys were given to the screening personnel for each clinic. After the potential participant was checked in for their appointment, the medical assistant (MA)



called the person into a private screening room. Once the person was screened and found to be free of acute illness or stress, the MA introduced the survey in either English or Navajo, as appropriate. The introduction of the survey followed a scripted dialogue (Appendix D), which further described the study.

The participant was reassured that the survey was confidential; the primary provider, the researcher, and the MA who conducted the survey with the participant would not know if the participant completed it. The participant was also informed that they could speak to the researcher if they had questions or concerns, but no one requested to do so. After the MA removed the consent form and gave it to the participant, the survey form and a writing utensil were provided, and the participant was then escorted to an exam room to wait for their provider.

The surveys that had been placed in the collection boxes were removed weekly, placed into large envelopes, and kept in a locked cabinet until the end of the three-month collection period. This process also helped to protect the participant's identity, because the researcher did not know which day or from which clinic the surveys had been collected.

At the completion of the three-month data collection period, the researcher entered the survey data into a REDCap account that was established prior to initiation of the study and that was stored on secure server at the UNM HSC. The paper surveys were kept in a locked file cabinet in the office of the researcher at NNMC and will be stored for three years following the study closure, per UNM HRPO policy.

## **Variables and Measures**

### **Phase I: Retrospective Chart Review**

In Phase I of this study, all information was obtained via intensive review of the participants' medical records from NNMC. Gender, age at the time of referral, the year of referral, and home community were obtained to provide demographic information about the sample. Age was recorded in years. BMI, which was calculated in the NNMC EHR, was rounded to one decimal place.

Hemoglobin A1c, also known as glycosylated hemoglobin, is the percentage of hemoglobin to which glucose is bound (Saudek, Rubin, & Donner, 2014). The laboratory blood test for HbA1c measures the amount of glycosylated hemoglobin in the blood (ADA, 2016). The higher the HbA1c, the higher the glucose concentration is in the blood. HbA1c is the most reliable measure of long-term glucose control (ADA, 2016); it is also useful in monitoring the effects of diet, exercise, and drug therapy on blood glucose in DM patients (Saudek et al., 2014). According to the ADA, the normal HbA1c for a person without DM should be between 4% and 6%, while the HbA1c goal for a person with DM is lower than 7% (ADA, 2016).

Hemoglobin A1c values in the EHR had been determined by venous or capillary blood samples. HbA1c values that were obtained via capillary sample were collected and processed by clinic staff that had been trained and received in-house (NNMC) certification in this procedure. Capillary samples were processed in the clinic, a procedure referred to as point-of-care testing. The point-of-care HbA1c analyzer at NNMC is a device certified by the Clinical Laboratory Improvement Amendments (CLEA).

Though venous samples are considered to be the reference standard for evaluating HbA1c (Egbunike & Gerard, 2012; Keramati, Razi, Tootee, & Larijani, 2014), point-of-

care capillary testing has been found to be comparable to venous samples when collected by properly trained personnel and when CLEA-certified equipment is used (Heylen et al., 2014; Keramati et al., 2014). For this study, a total of 2,880 HbA1c's were evaluated; of these 2,674 (93%) were from venous sampling and 7% were by capillary point-of-care testing.

## **Phase II: Surveys**

Two surveys were used in Phase II of the study. Survey A (Appendix A) was used for participants who completed NODEP (Groups 1 and 2), and Survey B (Appendix B) was given to participants who either did not complete NODEP (Group 3) or did not attend NODEP (Group 4). These surveys were developed by the researcher with assistance from dissertation committee members and Navajo staff members at NNMC. Navajo staff members consisted of two personnel from housekeeping, one from the maintenance/facilities department, one RN, one physician, two medical assistants, and three employees from the reception/clerical area. All personnel stated they understood the intent of the survey and that they believed the individual questions were clear and logical. This step was included to try to establish readability and face validity for the instruments and to ensure cultural appropriateness.

The first six items were identical on both surveys. These items included demographics (age, gender, year of DM diagnosis, and community) and course information (one-day or three-day course and the language used). The remainder of the surveys used multiple choice, "check all the items that apply," and several open-ended questions, which invited participants to comment further on the prior questions.

Survey A (Appendix A) focused on the contents of the course and recommendations for improvement, and Survey B (Appendix B) concentrated on barriers to attendance and suggestions for improved access to NODEP. The reading level for the surveys was evaluated using Microsoft word readability statistics. Survey A (Group 1 and 2: completed NODEP) was evaluated to be at a sixth grade reading level, while Survey B (Group 3: did not complete; and Group 4: did not attend) was at an eighth grade reading level.

### **Data Analysis**

IBM® SPSS® (v.24) was used for the statistical analysis. For descriptive analysis, the means, medians, and standard deviations were calculated for continuous variables (age, BMI). Categorical variables, i.e., gender (male/female) and community (Aneth, Bechabito, Burnham, Cortez, Cove, Cudii, Farmington, Fruitland, Hogback, Kirtland, Nahnedzad, Newcomb, Red Mesa, Red Valley, Rock Point, San Juan, Sheepsprings, Shiprock, Sweetwater, Toadlena/Two Gray Hills, Sanostee, Upper Fruitland, and others) were reported as frequencies and percentages. Phase II data from the multiple-choice questions also were reported as frequencies and percentages. Open-ended questions were analyzed qualitatively using thematic content analysis as described later in this section.

For inferential analysis, the primary dependent variable was HbA1c, and a secondary dependent variable was BMI. The primary independent variable was cohort/group based on type and extent of NODEP participation (three-day course; one-day course; started three-day course but did not complete; referred but did not start). A change from baseline HbA1c (initial diagnosis and referral to NODEP) was evaluated at

3, 6, 12, and 24 months after participation or after referral for those who did not participant. A change from baseline BMI was assessed at one and 24 months. A repeated measures ANOVA was used to determine if there was a difference in the magnitude or timing of a change in HbA1c levels between the groups (group x time interaction) or any main effects of group or time. For post hoc tests, Games-Howell correction was used for pairwise comparison of mean HbA1c values by group because homogeneity of variance across groups was not supported, except for the baseline HbA1c measurement. A similar approach was used for assessing change in BMI by group over time, except that Bonferroni correction was used for post hoc tests because the homogeneity of variance was supported across groups at all three time points.

### **Validity and Reliability**

Three main types of validity must be considered when conducting quantitative research: statistical conclusion validity, internal validity, and external validity. Statistical conclusion validity determines whether statistical inferences are valid and warranted by the data. Internal validity determines whether measures and results mean what they are claimed to mean. In a test of an intervention, internal validity refers to the extent to which the researcher can say that the results for an outcome were caused or influenced by the intervention, in this case NODEP. External validity determines the extent to which results might be generalizable to other persons or settings in addition to those that were studied.

Threats to statistical conclusion validity relevant to a cohort study comprise low statistical power, violations of assumptions of statistical tests, and multiple comparisons. In the present study, the actual sample size was sufficient for at least 90% power to detect a statistically significant result for repeated measures ANOVA. Assumptions for

statistical tests were assessed by appropriate tests and correction factors together with exploratory (e.g., descriptive and graphical) analysis. Multiple comparisons were used with appropriate corrections for the number of comparison and the extent to which underlying assumptions were or were not tenable. In addition, estimates were viewed from the perspective of clinical magnitude and the estimates of effect size, not just statistical significance.

Potential threats to internal validity include selection, instrumentation, testing, and attrition. In this study, the principal threat to internal validity was the lack of random assignment-to-treatment conditions. Causal inference is problematic in a cohort study due to potential biases arising from the lack of random assignment-to-treatment conditions. Participants in each of the four groups had the same offer to participate but for unknown reasons chose different levels of participation (e.g., three-day versus one-day versus not participating) or chose to begin but not complete the intervention. There is little basis for believing that those individual preferences were random or yielded an unbiased composition of groups. In addition, only cases with complete follow-up data for HbA1c and BMI over two years were included.

Instrumentation refers to a difference in how the dependent variable (HbA1c) was measured throughout the study. All of the HbA1c values were obtained via a CLIA-certified facility (including the lab and point-of-care devices), using equipment that was calibrated at least once daily using the manufacture specifications, and all were analyzed by trained medical personnel. The diagnostic HbA1c of every participant in this study was obtained from a venous sample, and most subsequent HbA1cs thereafter were obtained from a venous sample as well. However, the HbA1c's of some patients might

have had obtained from capillaries (finger-stick) at the clinic. If any of the finger-stick HbA1c's were significantly abnormal or vastly different from the patient's previous average, the patient had a verifying HbA1c obtained from a venous sample.

Testing and attrition were not major threats to the internal validity of this study. The HbA1c is an average value of a person's glucose level over a three-month period. Because the HbA1c represents an average, it is much more difficult for an individual to manipulate it compared to a spot glucose, which can change rapidly in a short period of time.

Attrition refers to participants dropping out of the study before it is completed. Because this study was designed to include only those participants who had an adequate number of data collection points, attrition was not a factor.

### **External validity**

External validity refers to the generalizability of the study results to populations or settings beyond those that were studied. Because this study took place on the Navajo Nation and the sample was limited to Navajo adults, the findings can be applied only to a similar population.

### **Qualitative Analysis and Rigor**

Phase II of this study used a descriptive research design that incorporated both quantitative and qualitative methods. The collection of both quantitative and qualitative data provides greater understanding of the issues surrounding NODEP. This study used a combination of written surveys and open-ended questions. Participants were given the opportunity to provide comments after each question and at the end of the survey. This meant the participants could elaborate on a pre-identified topic or could introduce other

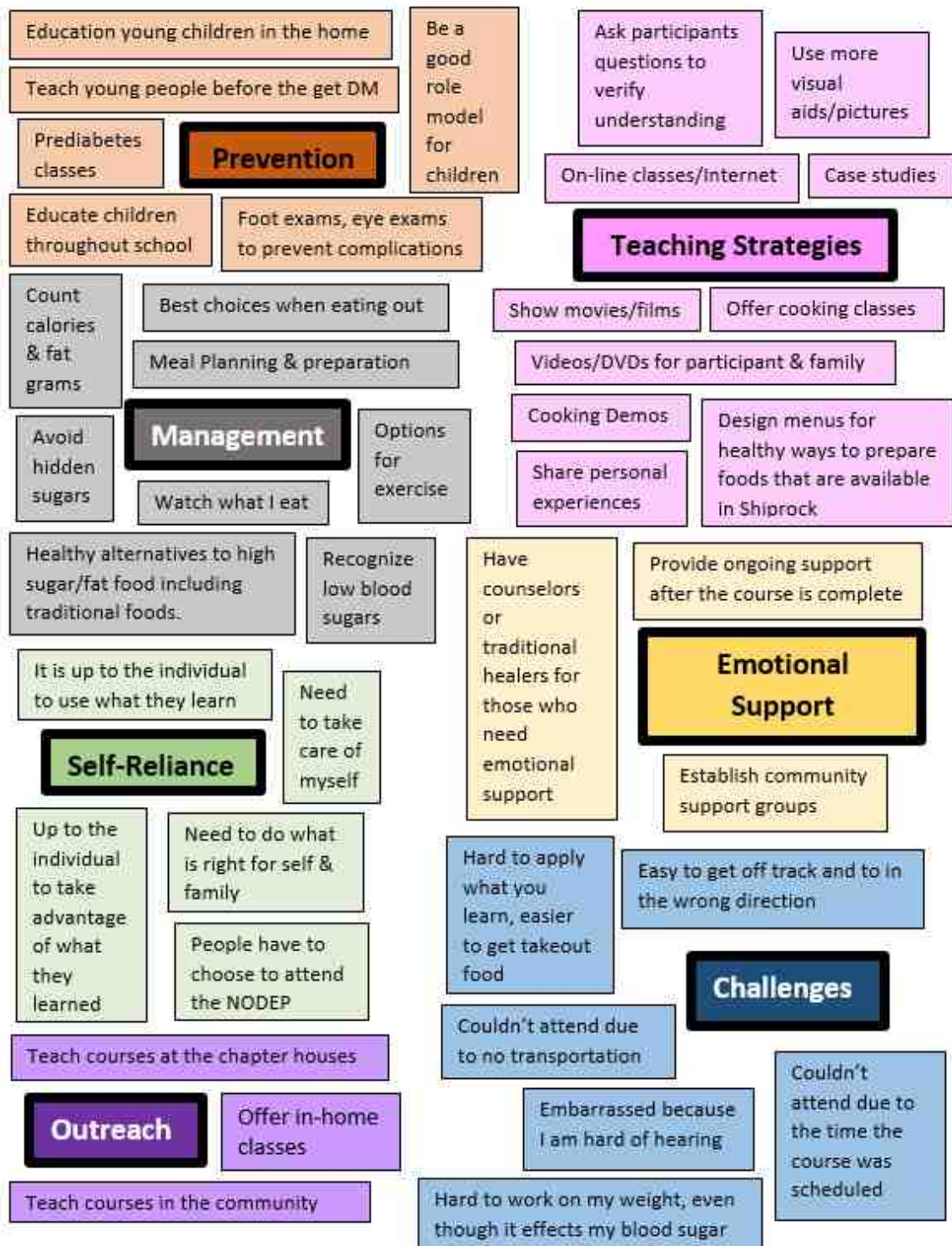
topics or concerns that were more meaningful to them. This form of inquiry was flexible and allowed the individuals' opinion and experiences to be communicated, providing more depth to the study (Creswell, 2007; Given, 2007).

As the name implies, descriptive research designs are used to describe a phenomenon or behavior as it is, without influencing it or trying to change it (Creswell, 2007; Given, 2007). Descriptive methods do not require the manipulation of variables, the predictions of outcomes, or the use of hypotheses because interventions are not being tested. One of the most common types of descriptive research designs is conducting surveys (Creswell, 2007; Given, 2007).

Thematic content analysis was used to organize the data into themes and subthemes. Using a coding matrix, data was categorized into seven primary themes. Prevention, management, variation in teaching strategies, self-reliance, outreach programs, and challenges were the major themes identified in this study (Figure 3.1). Rigor was maintained during this process by keeping the main themes unidimensional, i.e., covering only one aspect of the material. Similarly, subthemes were identified only once under the corresponding main category (Schreier, 2012).



Figure 3.1. Qualitative Data Content Analysis



## **Protection of Human Subjects**

Because this study was conducted on the Navajo Nation, it required a lengthy process for approval. First, authorization was obtained from four separate entities: (a) Shiprock Hospital Health Board (Appendix E), (b) NNMC's chief executive officer (Appendix F), (c) the Northern Agency Council (Appendix G), and, (d) the University of New Mexico's Human Research Protections Office (UNM HRPO) (Appendix H). UNM's HRPO provided expedited approval with a waiver of documentation of informed consent, the purpose of which was to assure anonymity of the participants. Additional approval was obtained from the director of the Diabetic Education Program at NNMC and from the Shiprock Chapter House (Appendix I), prior to requesting approval from the Navajo Nation Human Research Review Board (NNHRRB) (Appendix J). Following completion of all of these steps, the study was approved by the NNHRRB.

### **Confidentiality**

Multiple steps were taken to assure anonymity of both the clinical data and the survey data. In Phase I (chart review), the researcher was the only person with access to the participants' medical records and identifiable information, which was derived from the printed NODEP roster. Once the data were retrieved by chart review, each participant was assigned a study number. Not all of the participants' six HbA1c levels were obtained at exactly three-month intervals but were collected a minimum of 10 weeks apart. An Excel spreadsheet with only de-identified data was created and stored on NNMC's main server, which has restricted access that can be achieved only from within the NNMC facility.

In Phase II (survey), the researcher followed the process described previously in the procedures section of this chapter to protect the anonymity of participants. Participants were initially identified using the printed roster of people who were referred to NODEP. Participant information was logged into the password-protected, IHS iCare database, which can be accessed only via an NNMC network computer located within the facility. This database was used to identify the age, gender, and community of the participant, as well as to determine the date, time, and clinic at which the participant had a scheduled appointment. After consent of the participants was confirmed, MAs removed and destroyed the sheet with identifying information. The completed, de-identified surveys were compiled and stored in a locked office for weekly collection by the researcher over a three-month period. After all of the surveys had been collected, the data were transferred for analysis to the researcher's password-protected REDCap account stored on the UNM secure server. No identifiable participant information was removed from NNMC via laptop computer or other portable devices. The original NODEP roster was returned to program coordinator. All Phase I and Phase II data will be destroyed at the end of three years, per HRPO regulations.

### **Summary**

This study involved a two-phase (retrospective cohort and exploratory descriptive) research design. Phase I examined pre-intervention and post-intervention (NODEP) HbA1c levels of Navajo adults at six time points using one-way and repeated measures ANOVA. Phase II analyzed responses to a researcher-developed survey designed to explore barriers to participation in NODEP and the strengths and weaknesses of the program. Multiple-choice item responses were analyzed using descriptive statistics,

and open-ended responses (Fowler, 2009) were examined via thematic content analysis (Fowler, 2009). The following chapter presents the results of the study.

## **CHAPTER 4**

### **RESULTS**

The purpose of this study was to examine the effectiveness of NODEP at NNMC for Navajo adults who had been newly diagnosed with DM and were referred to the program between January 1, 2010, and December 31, 2015.

#### **Phase I: Retrospective chart review**

##### **Demographic Characteristics**

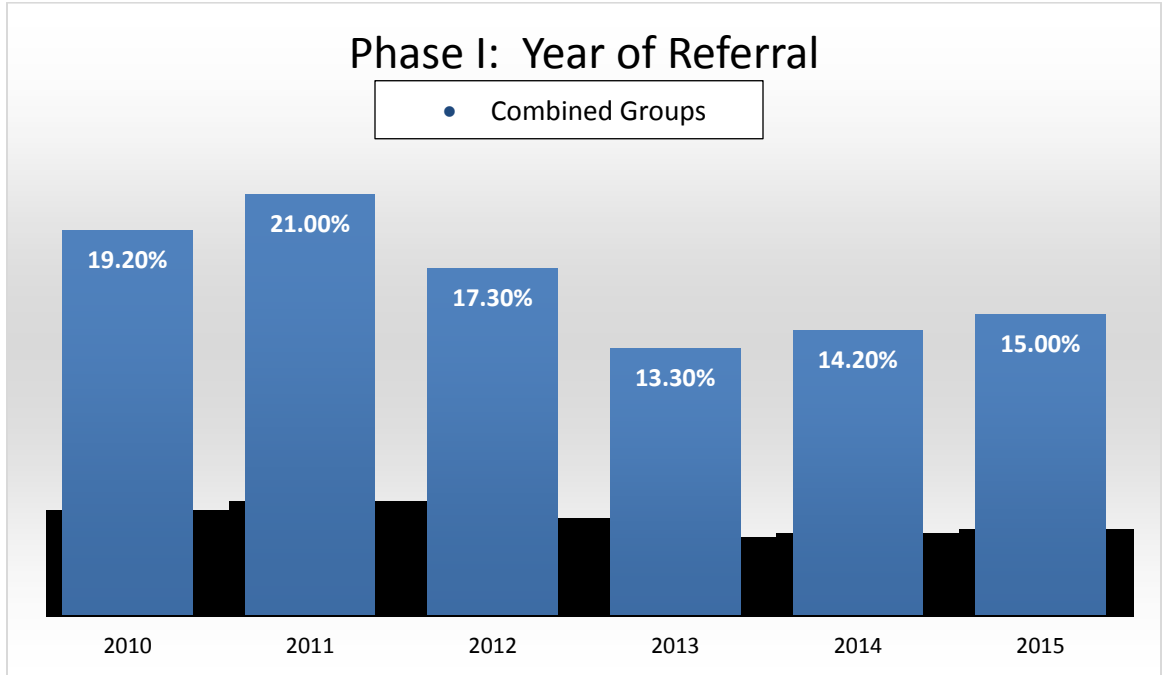
Table 4.1 provides a comparison of the demographic characteristics of the combined sample (N = 480) and each of the four sample (N = 120) groups. The combined sample had nearly equal percentages of males (50.4%) and females (49.6%). The mean age of participants was 48.7 ranging from 18-85. Participants resided in 47 communities both on and off the Navajo reservation. However, nearly half of the participants were from either Shiprock (29.5%) or Farmington (17.5%). Referrals to NODEP varied by year, with the highest number in 2011 (21%) and the fewest in 2013 (13.3%) (Figure 4.1).

Table 4.1

*Characteristics of groups in Phase I – retrospective chart review*

	<i>Combined N = 480</i>	<i>Group 1 n = 120</i>	<i>Group 2 n = 120</i>	<i>Group 3 n = 120</i>	<i>Group 4 n = 120</i>
<b>Gender</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Male	242 (50.4)	57 (47.5)	49 (49.2)	65 (54.2)	59 (49.2)
Female	238 (49.6)	63 (52.5)	61 (50.8)	55 (45.8)	61 (50.8)
<b>Age</b>					
< = 49	242 (50.4)	56 (56.7)	48 (40)	67 (55.8)	71 (59.1)
50-59	137 (28.5)	39 (32.5)	40 (33.3)	30 (25)	28 (23.3)
60-69	76 (15.8)	22 (18.3)	19 (15.8)	19 (15.8)	16 (13.3)
70+	25 (5.2)	3 (2.5)	13 (10.8)	4 (3.3)	5 (4.2)

Figure 4.1. Year of referral for combined group



Group 1 (completed the three-day course;  $n = 120$ ) consisted of slightly more females (52.5%) than males (47.5%). The mean age of participants in this group was 49, with a range of 18-73. Most of the participants in Group 1 were from Shiprock (32.5%) or Farmington (20%). Most participants from Group 1 were referred to NODEP in 2010 (19.2%), with the fewest referred in 2015 (15%).

Group 2 (one-day course;  $n = 120$ ) consisted of 59 (49.2%) males and 61 (50.8%) females. The range of age of the participants was 18-81 with a mean of 52. Most of the participants were from Shiprock (20.8%); followed by Farmington at 15.8%; Upper Fruitland (7.5%), which is a community on the Navajo Nation; and Kirtland (5.7%), which borders Upper Fruitland.

Group 3 (did not complete NODEP;  $n = 120$ ) had 65 males and 55 females. The mean age was 47 with a range from 21 to 79. Most participants in Group 3 were from Shiprock (34.2%), Farmington (16.7%), or Kirtland (11.7%).

Group 4 (did not attend;  $n = 120$ ) was almost evenly divided between males ( $N = 59$  (49.2%) and females ( $N = 61$  (50.8%)). The mean age was 47, with a range between 19 to 85. Similar to the other groups, most of the participants were from Shiprock (24.1%), Kirtland (14.1%), or Farmington (12.5%).

### **Analysis of NODEP**

#### **Research Question 1**

Is participation in either the three-day NODEP or the one-day NODEP associated with a meaningful reduction in HbA1c compared with incomplete or no participation?

For the full sample ( $N = 480$ ), on average, HbA1c was the highest at baseline and lowest at six months' follow-up. Thereafter, HbA1c values increased through 24 months of follow-up but remained substantially less than at the baseline level (Table 4.2).



Table 4.2

*Sample (N = 480) HbA1c (%) at Baseline and at 3, 6, 12, 18, and 24 month follow-ups*

HbA1c	Mean	SD	Median	25th %ile	75th %ile	Skewness	Kurtosis
Baseline	9.3	2.6	8.2	7.0	11.4	0.65	-1.02
3 months	7.8	2.1	7.0	6.3	8.9	1.26	0.68
6 months	7.5	2.1	6.7	6.1	8.2	1.67	2.17
12 months	7.7	2.1	6.9	6.2	8.5	1.47	1.45
18 months	7.9	2.3	7.1	6.3	8.7	2.26	0.95
24 months	8.0	2.2	7.1	6.3	9.4	2.24	0.37

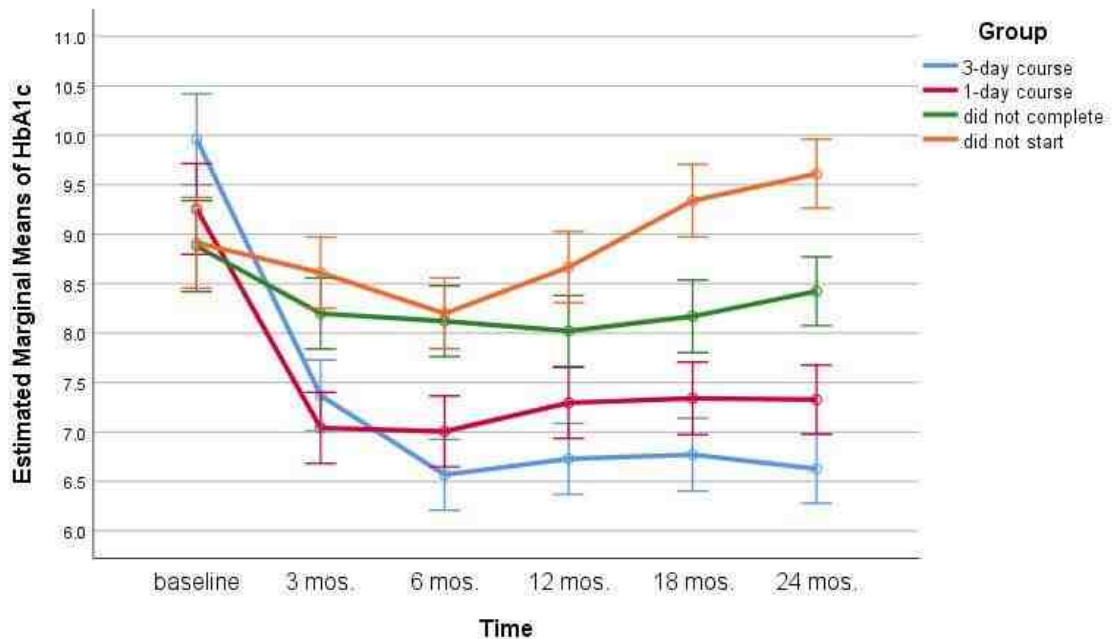
HbA1c glycosylated hemoglobin

One-way repeated measures ANOVA was used to evaluate HbA1c values of four groups over time (baseline, 3, 6, 12, 18, and 24 months) and to test for group by time interaction. The multivariate model contained one independent variable (NODEP group) and the dependent variable of HbA1c. As shown in Table 4.2, the distributions at each time point except at the baseline were positively skewed. Therefore, distributions could not be assumed to be normal at most time points. However, this was expected because the participants were chosen specifically because they had DM; therefore, outliers were far more likely to be at a higher level. In addition, ANOVA procedures are robust to deviations from normality when sample size is large and groups are equal in size (Box, 1953). An assessment of multivariate outliers identified only 13 cases (< 3%) with an extreme value (i.e., Mahalanobis distance greater than the  $\chi^2$  [df = 6] critical value at  $p <$

.001; Tabachnick & Fidell, 2007). Box's test of equality of covariance matrices was statistically significant, but that is not of concern when group sizes are equal or nearly so (Box, 1953; Tabachnick & Fidell, 2007).

Multivariate estimates for the model were significant for group by time interaction (Wilks'  $\lambda = .734$ ,  $p < .001$ , partial  $\eta^2 = .10$ ) and for main effects of time (Wilks'  $\lambda = .708$ ,  $p < .001$ , partial  $\eta^2 = .29$ ). Mauchly's test of sphericity was statistically significant, as is common with large samples; therefore, the Greenhouse-Geisser correction ( $\epsilon = .84$ ) was used for estimating within-subjects effects that were significant for group x time interaction ( $p < .001$ , partial  $\eta^2 = .09$ ) and for the main effect of time ( $p < .001$ , partial  $\eta^2 = .12$ ). The assumption of homogeneity of variances across groups was satisfied at baseline ( $p = .586$ ) but at none of the subsequent time points ( $p < .001$  at each). In order to adjust for not being able to assume homogeneity of variances, the post hoc Games-Howell tests showed that on average, the groups that did not start or did not complete NODEP had significantly higher HbA1c values over time than the groups that completed either the three-day or one-day course; there was no significant overall difference between participants who complete the three-day or the one-day course (Figure 4.2).

Figure 4.2. One-way repeated measures ANOVA for group differences in mean HbA1c at baseline and at follow-up intervals of 3, 6, 12, 18, and 24 months



Error bars display 95% confidence intervals for group means for HbA1c at baseline and follow-ups at 3, 6, 12, 18, and 24 months

Figure 4.3 shows the percentage of participants with HbA1c less than 7.5% at baseline and at each follow-up. In Group 1 (completed three-day course), only 30% of participants had HbA1c < 7.5% at the baseline. This doubled to 60% of Group 1 at three months and exceeded 85% by six months. For Group 1, the improvement over time was statistically significant; Cochran's Q (df = 5) = 172.5,  $p < .001$ . Approximately 80% of Group 1's participants maintained HbA1c < 7.5% over the remaining 18 months of the study. Among Group 2 participants (completed 1-day course), approximately 39% had HbA1c < 7.5% at baseline compared with approximately 80% at three months and six

months, and with approximately 70% from 12 through 24 months; Cochran's Q (df = 5) = 92.5,  $p < .001$ . Group 3 (did not complete) showed no significant change in the percentage with HbA1c < 7.5 over time: 49% at the baseline; 55% and 57% at three months and six months, respectively, and 53%, 55%, and 51% at 12, 18, and 24 months respectively; Cochran's Q (df = 5) = 3.2,  $p = .673$ . Group 4 (did not attend NODEP) also had a statistically significant change in the HbA1c over 24 months; however, the change after six months was in the wrong direction. More than 40% of the participants in Group 4 had an HbA1c < 7.5 at baseline and this improved to ~ 55% by six months. Unfortunately, this improvement was followed by a rapid decline over the remaining 18 months, with only 23% of participants having HbA1cs < 7.5% at 24 months; Cochran's Q (df = 5) = 52.1,  $p < .001$ .

Figure 4.3. Percentage of each group with hemoglobin A1c < 7.5% at baseline and over the 24 month follow-up.



## Research Question 2

Is participation in either the three-day NODEP or the one-day NODEP associated with a meaningful reduction in BMI compared with incomplete or no participation?

BMI was examined at three intervals: the baseline (time of referral), 12 months, and 24 months. For the sample as a whole, mean BMI was > 30.0 throughout the study (Table 4.3).

Table 4.3

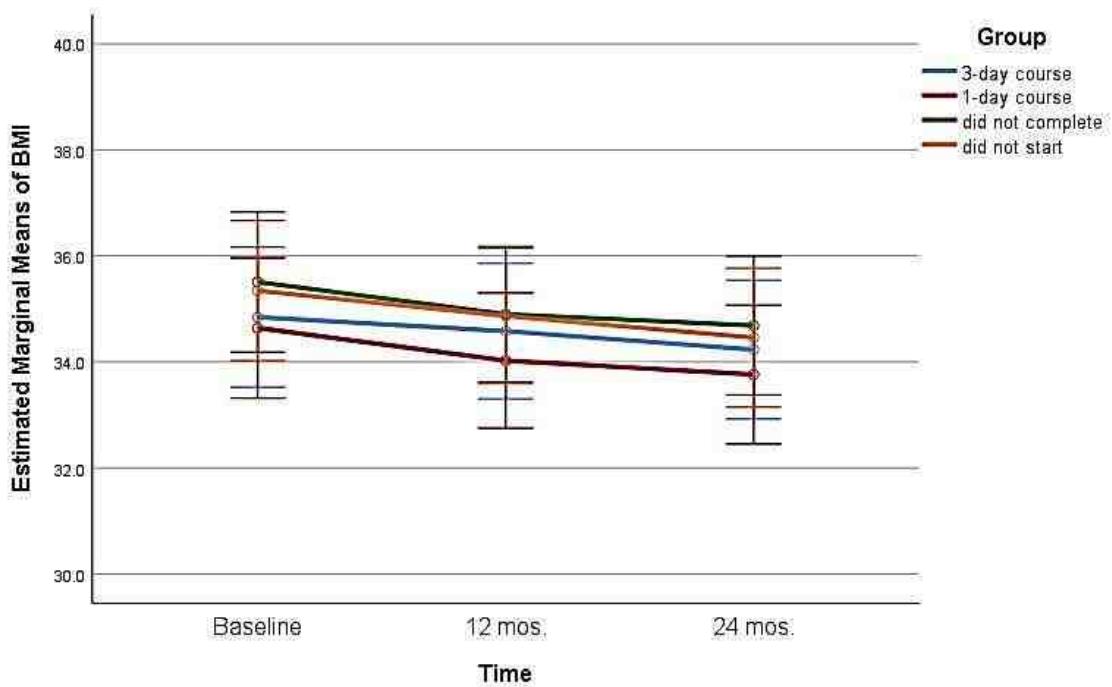
*Sample (N = 480) BMI at the baseline, and at 12 and 24 month follow-ups*

BMI	Mean	SD	Median	25th %ile	75th %ile	Skewness	Kurtosis
Baseline	35.1	7.4	34.0	30.1	38.5	1.11	2.13
12 months	34.6	7.1	33.6	29.7	38.1	1.11	2.27
24 months	34.3	7.3	33.3	29.0	38.2	1.25	2.90

One-way repeated measures ANOVA was used to evaluate BMI over time (baseline, 12 months, and 24 months) and to test for group by time interaction. The multivariate model consisted of one independent variable (NODEP) and the dependent variable of BMI. As shown in Table 4.3, the distributions at each time point were positively skewed for the entire sample. As noted previously, ANOVA is robust to departures from an assumption of normality when sample size is large and group sizes are equal. An assessment for multivariate outliers using Mahalanobis distance identified only 10 cases (< 3%) with an extreme value (i.e., greater than the  $\chi^2$  (df = 3) critical value at  $p < .001$  (Tabachnic & Fidell, 2007)). Box's test of equality of covariance matrices was not statistically significant. Multivariate estimates for the model were not significant for group by time interaction (Wilks'  $\lambda = .996$ ,  $p = .908$ , partial  $\eta^2 = .002$ ) but were statistically significant for main effects of time (Wilks'  $\lambda = .928$ ,  $p < .001$ , partial  $\eta^2 = .07$ ). Mauchly's test of sphericity was statistically significant. The Greenhouse-Geisser correction ( $\epsilon = .91$ ) was used to estimate within-subjects effects that were not statistically significant for group x time interaction ( $p = .918$ , partial  $\eta^2 = .02$ ) but were statistically

significant for main effect of time ( $p < .001$ , partial  $\eta^2 = .05$ ). The main effect of time was not clinically meaningful because the means of all four groups were between 33.0 and 36.0 at all three time points. The assumption of homogeneity of variances across groups was satisfied at all time points. Post hoc Bonferroni tests showed no overall significant pairwise difference in BMI between any of the groups at any time point (Figure 4.4).

Figure 4.4. One-way repeated measures ANOVA for group differences in BMI at the baseline and at 12, and 24 month follow-ups



BMI body mass index; error bars display 95% confidence intervals for group means

## Phase II: Survey

### Demographic Characteristics

A total of 416 surveys were prepared, and 126 (30.3%) completed surveys were returned. Some 187 surveys were prepared for participants from Groups 1 and 2 (attended and completed the three-day and one-day NODEP), and 77 completed surveys were returned (41% response rate). Of 229 surveys prepared for participants from Groups 3 and 4 (began but did not complete the three-day course and did not attend any portion of NODEP), 49 were returned (21% response rate). Participants who completed Survey A were predominantly female (58%). Participants completing Survey B were approximately equally divided by gender (Table 4.4). Differences in proportions by gender between those who completed Survey A and Survey B were not statistically significant. A majority of the Survey A participants were in the age 50-59 and age 60-69 groups (mode 50-59 years) as were a majority of the Survey B participants. However, the modal age group was 50-59 for Survey A versus younger than 50 for Survey B. Differences in proportions by age group between those who completed Survey A and Survey B were not statistically significant (Figure 4.5).

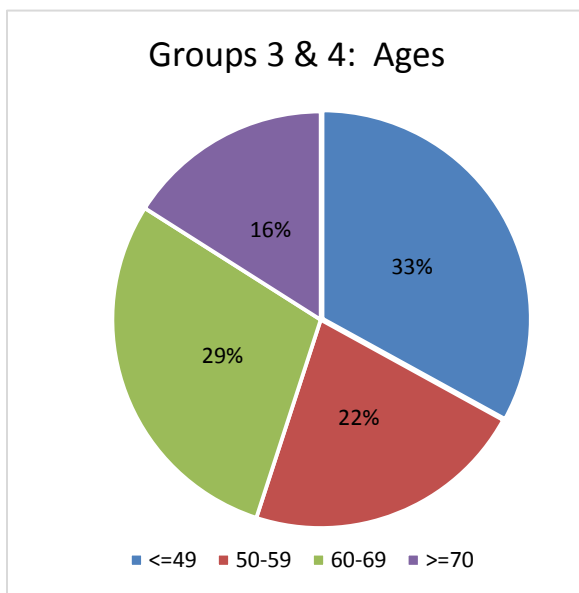
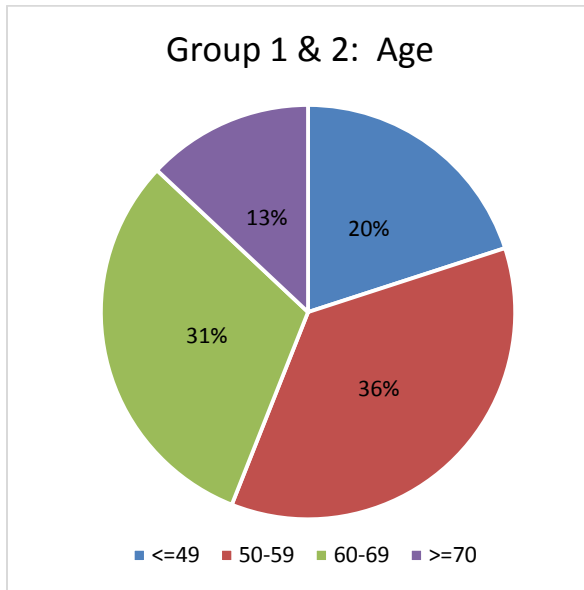


Table 4.4

*Comparison of Survey Groups 1 and 2 and Groups 3 and 4*

	Groups 1 and 2 (Survey A: $N = 77$ )			Groups 3 and 4 (Survey B: $N = 49$ )	
	$n$	%		$n$	%
<b>Gender</b>					
Male	32	41.0		24	49
Female	45	58.4		25	51
<b>Age</b>					
< = 49	15	19.5		16	32.7
50-59	28	36.4		11	22.4
60-69	24	31.2		14	28.6
70+	10	13.0		8	16.3
<b>Group</b>					
1	62	80.5	3	14	28.6
2	15	19.5	4	35	71.4

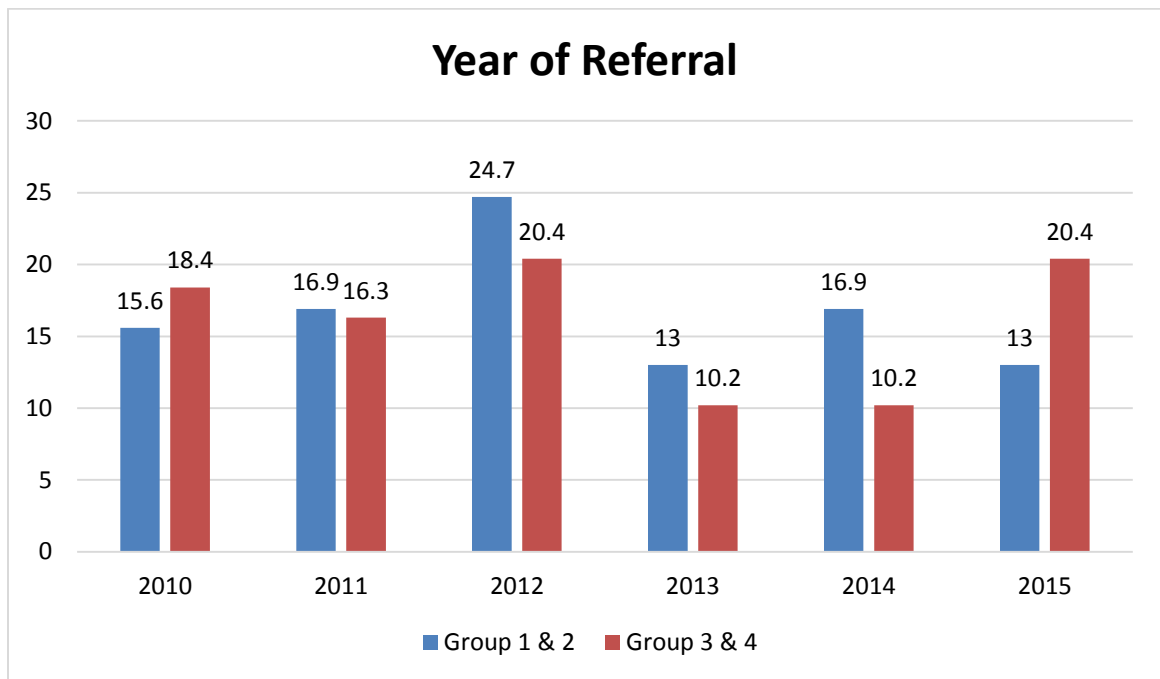
Figure 4.5. Age comparison of Survey A (Groups 1 and 2) and Survey B (Groups 3 and 4)



Most of the participants who completed Survey A had been referred to NODEP in 2012 (24.7%), with 16.9% referred in 2011 and 2014, followed by 15.6% in 2010 and

13.0% in 2013 and 2015 (Figure 4.6). This compares to participants completing Survey B, with the majority having been referred in 2012 and 2015 (20% and 20.4%, respectively). The years with the fewest referrals were 2013 and 2014 (10.2% and 10.2%, respectively) (Figure 4.6). The majority of respondents for Survey A and Survey B were from Shiprock, N.M., followed by Farmington, N.M.

*Figure 4.6.* Comparison of Survey A (Groups 1 and 2) and Survey B (Groups 3 and 4) year of referral



**Results of Survey A: Groups 1 and 2**

A substantial majority (80.5%) of participants who completed Survey A participated in the three-day course, while 19.5% completed the one-day class. In these groups, no one attended a course taught in the Navajo language alone, 50.6% attended a

course taught in both Navajo and English while the remaining 49.4% attended a course taught in English only.

### ***Research Questions 3 and 4***

Research Question 3 and 4 will be discussed collectively because together they provide a more comprehensive examination of NODEP characteristics.

Question 3: What are the strengths of NODEP as perceived by participants who attended and completed the three-day course (Group 1) and by those who attended and completed the one-day course (Group 2)?

Question 4: What are the weaknesses of NODEP as perceived by participants who attended and completed the three-day course (Group 1) and by those who attended and completed the one-day course (Group 2)?

One section of questions on Survey A (Appendix A) focused on NODEP course content (most useful to least helpful), while a second section inquired about other program features (most helpful [strengths] and weaknesses). For these questions, participants could select more than one response (Table 4.5).

Table 4.5

*Survey A: Most and least useful or helpful course content and program features*

Aspect of Course / Program	Most useful / helpful <i>n</i> (%)	Least helpful / program weaknesses <i>n</i> (%)
<u>Course Content</u>	<u>Most useful</u>	<u>Least helpful</u>
Understanding what diabetes is	70 (90.9)	1 (1.3)
How what I eat affects my blood sugar	66 (85.7)	3 (3.9)
How exercise helps control my blood sugar	61 (79.2)	5 (6.5)
How my weight affects my blood sugar	59 (76.6)	4 (5.2)
Understanding the medications I take	56 (72.7)	7 (9.1)
How I can monitor my blood sugar using glucometer	54 (70.1)	3 (3.9)
<u>Program features</u>	<u>Most helpful</u>	<u>Program weaknesses</u>
Location: That it was held at NNMC	8 (62.3)	6 (7.8)
Schedule: That it was held during the week	40 (51.9)	6 (7.8)
Content: The things that were taught	41 (53.2)	2 (2.6)
That my family could attend with me	25 (32.5)	N/A
It was taught with Navajo culture in mind	27 (35.1)	4 (5.2)
Teachers were well informed about the content	45 (58.4)	1 (1.3)
That I received a primary care provider	N/A	2 (2.6)

### ***Research Question 5***

What are the barriers to attending NODEP as perceived by participants who attended and completed the three-day course (Group 1), those who attended the one-day course (Group 2), those who began the traditional three-day course but did not complete it (Group 3), and those who did not attend any portion of NODEP (Group 4)?

Potential barriers to attending or completing NODEP were calculated in percentages, and study participants could select more than one response. Responses from participants in Groups 1 and 2 (n = 77) are shown in Table 4.6, and responses from participants in Groups 3 and 4 (n = 49) are discussed in the following section.

Table 4.6

*Survey A: Things that would have made it easier to attend and participate*

<i>It would have been easier for me to attend if the course</i>	<i>n (%)</i>
Was taught in the evenings	12 (15.6)
Was taught on the weekend	13 (16.9)
Was taught in my community	19 (24.7)
Had childcare available	0 (0.0)
Was taught in a better way	6 (7.8)

One survey question asked participants how often they used the information they learned from the program (Figure 4.7), and another asked if they would recommend the program to a friend or family member (Figure 4.8).

Figure 4.7.

Since completing the diabetes class(es), I use the information I learned (n = 77)

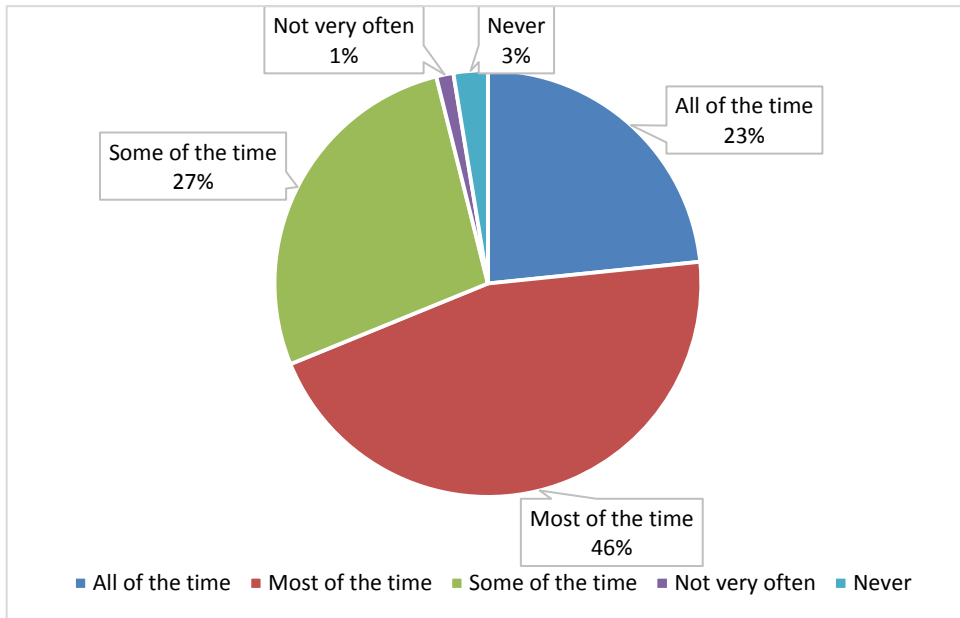
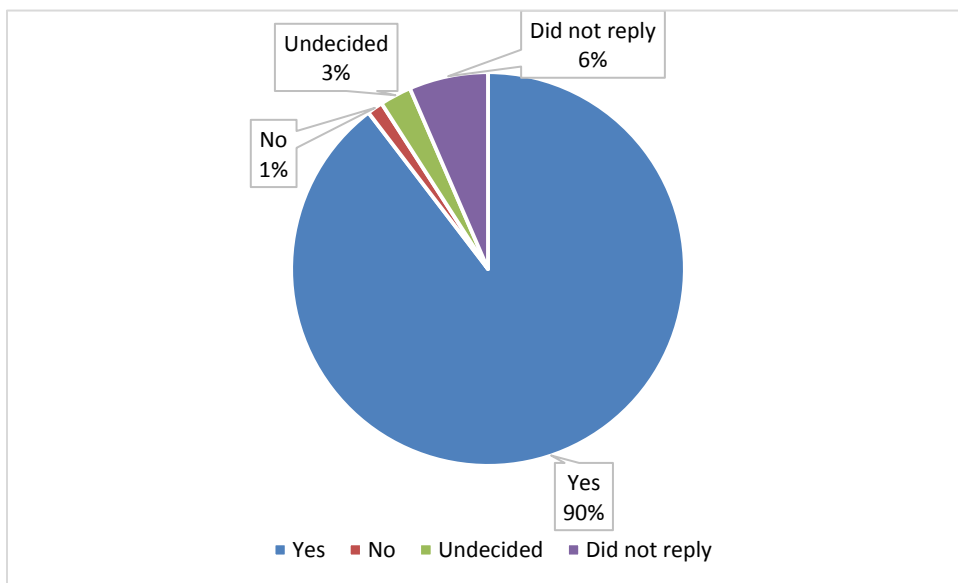


Figure 4.8. Would you recommend NODEP to friends and family? (n = 77)



### **Results of Survey B: Groups 3 and 4**

Separate sections of Survey B ( $n = 49$ ) with slightly different wording were addressed by those who began but did not complete classes (Group 3;  $n = 14$ , 28.6%) and from those who did not attend any portion of NODEP; Group 4;  $n = 35$ , 71.4%). Tables 4.7 and 4.8 compare responses to these questions by the two groups; for both groups in both tables, multiple responses were permitted. The most frequently endorsed reasons for not attending differed between Groups 3 and 4 (Table 4.7). In contrast, the two most helpful alterations identified by each group were similar (teaching in local communities and during evening hours; Table 4.8).



Table 4.7

*Reasons for not attending all (Group 3) or for not attending any (Group 4) NODEP classes*

Reason given	Group 3*		Group 4†	
	<i>n</i>	%	<i>n</i>	%
I did not have transportation	6	42.9	6	17.1
I had other obligations	5	35.7	9	25.7
I could not take time off work	2	14.3	8	22.9
I did not like the class	2	14.3	N/A	N/A
I wasn't learning anything new about diabetes / already knew about diabetes	1	7.1	3	8.6
Other (comment only)	2	14.3	12	34.3

\*Group 3: "I did not attend all of the classes held by the NODEP because. . ."

†Group 4: "I did not attend any of the NODEP classes because..."

Table 4.8

*I would have attended if. . .*

Reason given	Group 3*		Group 4†	
	(n = 14)		(n = 35)	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
They were taught in my community	5	35.0	9	25.7
They were taught in the evening	3	21.4	7	20.0
They were taught on the weekend	2	14.3	4	11.4
The classes were taught in a better way	2	14.3	N/A	N/A
Would not have attended more / any, no matter what	2	14.3	7	20.0
Childcare was available	0	0.0	2	5.7

\*Group 3: "I would have attended more of the classes if. . ."

†Group 4: "I would have attended the NODEP if. . ."

### Qualitative Results

Each of the survey questions was followed by an area for the participants to add comments or clarifications (Appendixes K, L, M, N). Many of the participants' comments in these sections repeated or emphasized an answer option, such as, "It would be better if taught in my community" or "No changes are needed. I liked the classes as they are."

However, the final question on both surveys was open-ended and solicited additional comments or suggestions (Appendixes K, L, M, N). The information obtained from this section was insightful and can be seen in detail in Appendix K for Group 1, Appendix L for Group 2, Appendix M for Group 3, and Appendix N for Group 4. These

comments were categorized into seven themes: prevention, management, teaching strategies, self-reliance, outreach programs, and challenges (Figure 3.1).

The most common theme among the participants of both surveys was self-reliance. Participants verbalized that “DM education is a tool” that the individual must decide whether to use or not. Participants identified challenges in implementing skills they learned. Participants said it is more convenient and time saving to pick up fast food instead of preparing meals at home. One participant said he was very motivated to eat health foods initially, but then he lost focus and said it has been difficult to go back to the healthier habits. However, this brings up another theme that was identified by participants from both surveys, which was the need for support. Participants who completed NODEP felt that on-going support in the form of community support groups or attending refresher classes would help them maintain healthier lifestyles after the completion of NODEP. Additionally, some participants voiced the need for counselors or traditional healers to help with the stress and/or denial of the initial diagnosis, as well as with emotional support over time, as DM is a chronic disease.

A number of participants who completed Survey A (completed one-day or three-day course) said that it was important to have more education focused on prevention for the younger members of the tribe. Participants believed that if healthy lifestyles (avoiding fast food, portion control, diet heavy in vegetable and lean meats, exercising, and maintaining healthier weights) were initiated for young children in the home and continued throughout their years in school, then problems with DM would decrease and Navajo communities would be healthier over time.

Suggestions for the improvement of teaching strategies included using more visual aids in the form of pictures, movies, and DVDs. Participants felt the increased use of visual aids would help those who did not read well. Other methods of teaching, such as using more case studies, sharing personal experiences, and having cooking demonstrations, were also identified as methods that would improve NODEP classes.

Participants who completed Survey B (did not complete the three-day course or did not attend) said they did research and learned about DM on their own. This group said they knew what to do to control DM and that NODEP would not be beneficial to them. Others said that the course would have been helpful and that had it been held in their community, they would more likely have attended.

### **Summary**

The overall results of this study were positive. Results from Phase I demonstrated a significant difference in HbA1c values based on the level of attendance in NODEP in a pattern suggestive of a dose-effect relationship with the degree of change in HbA1c and the percentages with HbA1c < 7.5% clearly superior in the three-day and one-day courses compared with either not completing the course or not participating at all. Because changes in BMI were neither statistically significant nor clinically meaningful, a change in weight cannot account for the changes in HbA1c, which makes it likely that the effects of the program were mainly behavioral or lifestyle changes.

The majority of the Phase II survey respondents found that participation in the course had helped them to better control their DM. The most common response with regard to improvement of the program was to provide NODEP across a broader range of

communities. Chapter 5 provides additional discussion of the results and provides recommendations for implementing the findings.

## **CHAPTER 5**

### **DISCUSSION**

This two-phase study provided a comprehensive evaluation of NODEP, a diabetes self-management education program tailored to the learning philosophy and cultural needs of Navajo adults with new-onset T2DM. Phase I retrospectively examined the HbA1c values and BMI of four groups of patients referred to NODEP over a 24 month period. The participants completed either a three-day program; a one-day version of the program; started but did not complete either program or never began participating in NODEP. In Phase II, surveys were administered to consented participants from the four groups who were still receiving care at NNMC in order to help identify the strengths and weaknesses of NODEP, as well as its barriers to attendance.

#### **Diabetes Education**

Diabetes is a chronic disease that requires a person to make daily decisions to ensure appropriate self-management. Therefore, providing patient education is a cornerstone of effective management of DM in order to improve health outcomes.

Although this is the first study to examine diabetes education in Navajo adults, research has shown that diabetes education programs are beneficial in reducing the HbA1c of participants. In various studies, which did not focus on ethnicity nor race, participants with DM who attended DM education programs were able to decrease their HbA1c by as much as 1% (Duncan et al., 2009; Siminerio, Ruppert, Huber, & Toledo, 2014; Steinsbedd et al., 2012; Tshiananga et al., 2012). Therefore, the ADA (2018) strongly encourages all individuals with diabetes to receive education at the time of diagnosis and as needed thereafter.

The goals of NODEP are to provide diabetes self-management education and diabetes self-management support. Diabetes self-management education enables the individual to manage diabetes by providing knowledge to patients and family members and helping patients to develop the necessary skills and overall ability to self-manage DM (Powers et al., 2015). In addition, diabetes self-management support helps to provide the support that an individual or caregiver might need to sustain the skills and behaviors necessary to manage diabetes on an on-going basis (Powers et al., 2015). At NNMC, any patient with DM, a caregiver, or family member can meet with diabetic educators on a walk-in basis to obtain continued education or support as needed.

As with any education program, however, the needs of the individual participants are diverse. This diversity requires NODEP educators to have to adjust to the needs of the participant from class to class or even from topic to topic. This constant adjustment to balance the needs of the participants based on health and cultural beliefs, medical history, current knowledge, emotional concerns, family support, financial status, and health literacy is one way NODEP aims to help the individual find stability and wellness (hózhó).

### **The Navajo Philosophy of Learning and NODEP**

The Navajo philosophy of learning, which was the framework for this study, is built on the traditional teachings that are based on the four directions and the concept of hózhó; seeking, obtaining, and maintaining harmony, wellness, and balance. Benally (1986) developed this philosophy based on the traditional beliefs of the Navajo, which are flexible enough to adapt to a changing world. This flexibility is one of the strengths of the philosophy. The Navajo philosophy of learning is adaptable to formal and informal

educational situations, both within the health system itself and within the community. It also meets the needs of the individual Navajo learner, because it is applicable within a range of traditional beliefs.

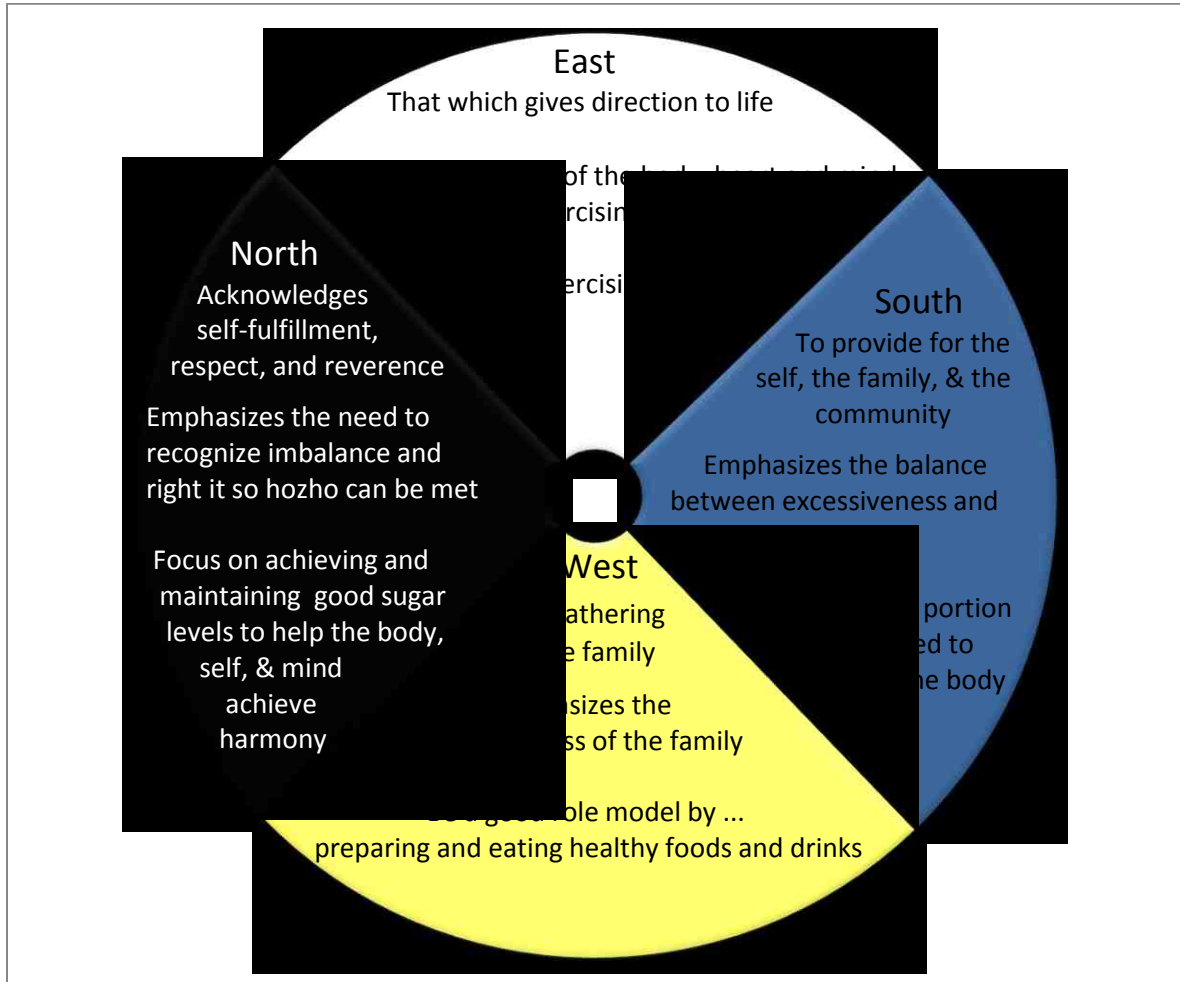
The teaching from the four directions are fundamental in Navajo culture and have been incorporated into NODEP in a manner intended to help the individual focus on specific goals at specific times. Each of the four directions focuses on an area (topic) that the individual must master to meet the goal and to achieve balance. Though the areas of education are divided into specific directions, each direction aims to help the person reach and maintain hózhó. Similarly, the NODEP is divided into separate topics—diet, exercise, medications, and others. Each of these topics might seem to stand alone at first glance; however, they are related and interwoven so they can help the person achieve and maintain the goal of wellness.

The Navajo philosophy of learning incorporates areas of learning and knowledge, based on the traditional teaching of the four directions in order to help a person obtain and/or maintain hózhó (balance, wellness, harmony). To be in hózhó, all aspects of an individual's being must be in balance and working together harmoniously. If at any time the individual with DM loses focus, she or he can use the traditional teachings from the four directions and NODEP to help restore balance and harmony.



Figure 5.1.

*Example of teaching from the four directions incorporated into the NODEP*



### **The Effectiveness of NODEP Based on HbA1c in Four Groups over Time**

Phase I results support the effectiveness of either the three-day course or the one-day course with respect to clinically meaningful change in HbA1c compared to those who began but did not complete the program or those who did not attend any portion of it. All four groups had a clinically meaningful decrease in improvement in mean HbA1c

at the six-month mark of at least 0.5%. An initial improvement following diagnosis is often referred to as a honeymoon phase and can be a result of multiple factors, especially the initiation of medication of glucose control (Avanzini, 2006) and the willingness of the individual to change with the diagnosis before becoming less diligent in maintaining healthy habits over time (Brown & Bussell, 2011).

Participants who attended and completed either version of NODEP at NNMC had significantly improved HbA1cs over the 24 month period. Participants who attended the three-day course had a clinically meaningful improvement in HbA1c (from a mean of 10.0% at the time of referral to 7.4% at three-months and < 7.0% at the 6, 12, 18 and 24 month follow-ups), as did those who completed the one-day course (from a mean of 9.3% at the time of referral to 7.0% at the three-month follow-up and  $\leq$  7.3% at the 6, 12, 18, and 24 month follow-ups). In contrast, mean HbA1c for those who did not complete or who never started the program was never lower than 8.0% at any time point. Moreover, between the three-month follow-up and the 24 month follow-up, the percentage of patients in each group with an HbA1c lower than 7.5% was much higher in those who completed either version of the program compared with those who did not complete it or who never started it. In both magnitude and duration of HbA1c change, these outcomes surpassed those reported in previous studies (Duncan et al., 2009; Siminerio et al., 2014; Steinsbedd et al., 2102; Tshiananga et al., 2012). A decrease of this magnitude in HbA1c, if sustainable over a longer duration than the two-year follow-up in this study, could reduce or delay the onset of diabetes-related macrovascular and microvascular complications (Stratton et al., 2000) and diabetes-related hospital admissions and readmissions (Healy et al., 2013; Duncan et al., 2011).

There was no meaningful change in BMI in any of the groups over the 24 month period. BMI was examined at three time points: the baseline, 12 months, and 24 months post-referral. The BMI from the highest point at any time interval (35.5) and lowest point at any time interval (33.7) was a difference of only 1.8. In addition, mean BMI in all four groups was in the obese range at all time points. Assuming that the height of an adult participant in the study is relatively stable over a two-year interval, it is unlikely that any of the groups had meaningful change in weight, on average. Therefore, it is apparent that the effects of the program on HbA1c are not due to a change in a participant's weight.

One characteristic of Group 4's participants that might explain their lack of attendance in NODEP is that this group, on average, was younger than members of the other groups, with the majority of participants (59%) 49 or younger. Traditionally, people of this age are employed, which means that classes held during the day and during the week might be inconvenient for them. Survey results supported this observation, because participants from Group 4 indicated that they preferred to have classes taught during evenings or weekends. Another suggestion was to provide the classes on CD, DVD, or online so that people can fit them into their schedule.

Group 2 had the highest percentage (11%) of participants aged 70 and older. Participants in Group 2 attended the one-day course; a possible explanation for this finding is that these elders might have chosen the one-day course for convenience (unable to drive themselves) or comfort (uncomfortable in group settings). A participant who completed Survey B (did not complete or did not attend NODEP) said he did not attend because he was hard of hearing and that embarrassed him; attending an individualized,

one-on-one course might have helped him feel more comfortable with the education process and improve his health outcome.

Despite the observation that BMI was basically unchanged over the 24 months of this study, 77% of participants who responded to Survey A (completed the one-day or the three-day program) identified information about how weight affects DM as being one of the most helpful area taught in NODEP. However, respondents from Survey A and Survey B stated they *knew* what needed to be done to improve their health, but that actually doing it (exercise, eating right) was far more challenging.

Despite the wide range in age (18-81 years), the interaction of age with HbA1c was not statistically significant and did not alter the effect size for the interaction of group and HbA1c. Although the interaction between HbA1c and gender was statistically significant ( $p = .01$ ), the effect size for the interaction was negligible (partial eta-square  $<.01$ ) and did not alter the effect size for the interaction of group and HbA1c.

### **Phase II: Survey**

The surveys provided greater insight into the usefulness and accessibility of NODEP than was possible by chart review alone. More than 90% of the participants who completed NODEP said that learning about DM (what it is and what it does to the body) was the most helpful information obtained from the program, while only 1% believed this was the least helpful information presented.

The second-most helpful element involved identifying how different foods break down to affect the glucose levels in the body. Participants said this enabled them to identify “hidden sugars” more appropriately, improving overall DM control. Several participants also said that learning to read food labels and how to count calories and fat

grams had been very helpful in managing their DM day to day. One participant noted that some traditional foods, such as frybread, should be replaced with healthier alternatives such as homemade tortillas (5 fat grams, 180 carbohydrates). This participant said that she intended to serve more tortillas to her family instead of frybread and that she would take tortillas to celebratory and community events.

According to most of the participants, the least helpful instruction was related to the medications they were taking (9%). It is possible that because medications had already been discussed with them in depth by their medical provider and pharmacist, they already were familiar with their medications by the time they attended NODEP.

The majority of participants (62%) who completed Survey A (completed one-day or three-day program) identified that the location of the program (at NNMC) was convenient for them. However, those who answered Survey A, Question 7 (completed one-day or three-day), Survey B, Section B, Question 2 (began but did not complete) and Survey B, Section C, Question 2 (did not attend) said the biggest difficulty to attending NODEP was the location and believed it would have been easier for them to attend NODEP had it been taught in their community (24.7%, 10.2%, 18.4%, respectively).

Though it would be possible for the three-day NODEP course to be taught in various communities throughout the Navajo Nation, it might not be feasible because some of the topics are taught by experts in that field (dietitians, pharmacists) who have difficulty getting away from the facility. However, because the one-day course can be taught by one or two educators, and because its participants had statistically and clinically significant improvement in HbA1c values, the one-day course could reasonably be taught

in the community. This would further assist community members who did not have transportation and would be more convenient for those who are employed.

Participants who completed either course identified other strengths of the program to be the staff, which were well informed about content (58%) and reiterated that the contents of the course were very beneficial to them (53%). Thirty-five percent of respondents believed it was valuable that the course was taught with the Navajo culture in mind, while only 5% said this was not helpful for them.

When reflecting on the significance of culture to the participants, it should be recognized that culture means different things to different people. Although virtually all of the participants in NODEP were Navajo this does not mean that each person embraces Navajo traditional philosophy and practice. Each person has a variety of family influences and personal experiences that defines what culture means to them. Based on these contacts and influences, the individual will determine their cultural identity and practices (Pawa, 2003). Further, an individual's perception of culture might change over time as they are exposed to different experiences (Pawa, 2003). When considered in this light, it is understandable that some participants would not consider cultural influences as having an impact on the way they were taught to manage DM.

Another insight that was shared in the survey data included that influence of individual choice. For example, while some participants found diabetic education to be beneficial and helpful, they also recognized that the individual must be the one who chooses to use the information they were taught. One participant acknowledged that it was much easier to pick up meals at the drive-through on her way home from work. However, after taking the NODEP class, she better understands the need to take care of

herself, and be able to care for her family: “I have to do the hard thing [eating healthy, taking medications, exercising] because it is the right thing for my family.”

This sense of choice and responsibility further extended to the care of children. Several participants said that children needed to be brought up eating healthy foods heavy in fresh fruits and vegetables, no sugary drinks, and limited processed or fast food. Similarly, another participant said that nutrition education and diabetes prevention needed to be taught to the younger generations so they can live healthier lives and pass on healthy habits for the next generation.

### **Limitations of the Study**

This study had several limitations. Because only Navajo adults who received medical care at NNMC were included, it must be pointed out that the results are not necessarily generalizable to all Navajos, to other American Indian populations, or to non-native populations.

Second, self-selection bias should also be considered when interpreting the results of this survey. Participants were obtained from a population of Navajo adults who were diagnosed and referred to NODEP between January 1, 2010, and December 31, 2015. From this cohort, participants were divided into one of four groups, depending on their level of participation in NODEP. Ultimately, each participant chose which group they were in by participating in and completing either the three-day course, the one-day course, beginning but not completing the three-day course, or not attending NODEP at all. Given that the HbA1c data are retrospective and included only patients with complete data at all time points, the effects of the course are potentially confounded by factors such as a motivation or expectancies. In addition, the survey responses illustrate that being

sufficiently clear of other obligations affected who could complete various version of the course. Nevertheless, given the magnitude and duration of effects on HbA1c seen in Groups 1 and 2 compared with Groups 3 and 4, and especially the appearance of a dose-effect relationship, seems unlikely to be due entirely to sampling bias and confounding.

### **Implication for Future Research**

There are many opportunities for future research that would focus on DM and its related co-morbidities in the Navajo people. As this study focused on the Shiprock Service Unit only, a study evaluating the effectiveness of diabetic education programs across the entire Navajo Nation is an obvious next step.

Findings from Phase II of this study have identified potential means to improve health outcomes in Navajo people by improving access to DM education classes, such as holding DM education classes in the communities. If the diabetic education program at NNMC acts on this suggestion, a study to evaluate the effectiveness of community-based NODEP classes would be telling.

Further, an evaluation of NODEP with more focus on the Navajo cultural would provide greater insight to the program's overall balance. An investigation to determine if NODEP fosters hózhó among the participants would support the programs goal to meet the needs of all participants, at all levels.

This study provided an in-depth evaluation of NODEP at NNMC. Though NODEP was developed specifically for the Navajo people in the northern area of the Navajo Nation, it can be used a framework for other Navajo area service units. The key teaching elements included in NODEP are the same core as many diabetic education programs; however, this information was taken and adapted based on the traditional



philosophy of the Navajo people. Using the example set forward by NODEP at NNMC, similar adaptations could be made for other American Indian populations, building on their traditional philosophy framework.

### **Summary**

The proportion of adults diagnosed with DM is significantly higher among AI/AN populations than in the general U.S. population. Further, people of the Navajo Nation have a higher burden of DM compared with at least some other AI/AN groups. This study provided an in-depth evaluation of a program—NODEP—designed to provide culturally congruent diabetes education to a large group of Navajo people receiving services at a large IHS facility.

The Navajo philosophy of learning was used as a framework for the study. This philosophy was fundamental to the content of NODEP because it incorporates areas of learning that are based on the traditional values and ideals represented in the four directions, the goal of which is to obtain and maintain hózhó.

The study findings were remarkable in that the participants who attended NODEP's one-day and three-day courses had sustained, statistically significant, and clinically meaningful reductions in HbA1c (2% and 3%, respectively maintained over 24 months with approximately 80% and 70% respectively attaining and maintaining HbA1c levels lower than 7.5%).

Survey data was also compelling. Participants indicated that the most beneficial information offered in the courses included “what DM is” (91%) and “how different foods influence blood glucose levels” (86%), with the least helpful information being a review of the medications they used (9%). Participants from both survey groups said that

having the program taught in their communities would have allowed easier access and that more people could have attended. Given the significant impact on HbA1c levels of completion of NODEP courses, it would be prudent to try to present NODEP in the community settings.

Traditionally, Navajo elders knew the importance of living healthy lives, promoting well-being through exercise, planning for success, re-evaluating and setting new goals, and that the support of family and community are essential for maintaining direction and focus. While these teachings are steeped in tradition, they also remain essential to the Navajo people, particularly in light of the effect that modernization, conveniences, and technologies will continue to have on current and future generations.

## Appendix A

### New Onset Diabetic Program Survey - Groups 1 & 2

Date of Scheduled Visit: \_\_\_\_\_

Clinic: \_\_\_\_\_

Number: \_\_\_\_\_

**You are being asked to fill out this survey because you were identified as being someone who was diagnosed with diabetes between 2010 and 2015 and attend the New Onset Diabetes Education Program at Northern Navajo Medical Center.**

**The purpose of this survey is to try to identify the strengths and possible improvements of the New Onset Diabetic Education Program so that it may better serve the needs of the Navajo People.**

**Your opinion is important; however, you are under no obligation to complete this survey.**

**The survey results will be discussed with the Shiprock health board and diabetic education staff with recommendations for improving the diabetes education classes and making them easier to attend. These groups will not know who participated in the survey and your name and personal information will not be used when the survey results are shared.**

**Thank you for taking the time to complete this survey. Your participation will help improve diabetes education for future patients.**

Age: \_\_\_\_\_

Male  Female

I was diagnosed with diabetes in 2010 2011 2012 2013 2014 2015

1) What Community are you from? \_\_\_\_\_

*For the following questions, please circle the appropriate answer*

2) I attended the... three-day course 1-day course

3) The course I attended was taught in...

Navajo English Both

*For the following questions, please circle all of the answers that apply*

**4) The content of the course I found to be the most useful includes:**

Understanding what diabetes is

How what I eat affects my blood sugars

How exercise helps control my blood sugars

How my weight affects my blood sugars

Understanding the medications I take

How I can monitor my blood sugars by using my glucometer

Other:

\_\_\_\_\_  
\_\_\_\_\_

5) Please circle all of the answers that apply.

**The content of the course that I found least helpful includes:**

Understanding what diabetes is

How what I eat affects by blood sugars

How exercise helps control my blood sugars

How my weight affects my blood sugars

Understanding the medications I take

How I can monitor my blood sugars by using my glucometer

Other:

\_\_\_\_\_  
\_\_\_\_\_

6) Please circle all of the answers that apply.

**I found the most helpful part(s) of the program to be...**

Location: That it was held at Northern Navajo Medical Center

Schedule: That it was held during the week

Content: The things were taught in the class

That my family could attend with me

It was taught with Navajo culture in mind

Teachers were well informed about their content

That I was assigned a primary provider after completion of the course

Other:

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7) Please circle all of the answers that apply.

**In my opinion, the weakness(es) of the program include:**

Location: That it was held at Northern Navajo Medical Center

Schedule: That it was held during the week

Content: What they taught in the class was not helpful

The class did not understand Navajo culture

Teachers were not knowledgeable about the content

Being assigned a primary provider after completion of the course was not helpful

I like the program like it is; no improvement needed

Other:

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8) Please circle all of the answers that apply:

**It would have been easier for me if the course**

Was taught in the evenings

Was taught on the weekend

Was taught in my community

Had childcare available

Was taught in a better way

Other:

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*Circle the most appropriate answer*

9) **Since completing the diabetes class (es), I use the information I learned**

All the time      Most of the time      Sometimes      Not very often      Never

10) Would you recommend this program to friends and family?

Yes      No      Undecided

11) Is there anything else that would make the diabetes education classes better or easier for members of the community to attend?

If you have any questions regarding this survey, please contact Denise Bartley, NP-C, PhD candidate, and contact person at NNMC for this study: 505-368-7022

Thank you for taking the time to complete this survey.

## Appendix B

### New Onset Diabetic Program Survey - Groups 3 & 4

Date of Scheduled Visit: \_\_\_\_\_

Clinic: \_\_\_\_\_

Number: \_\_\_\_\_

**You are being asked to fill out this survey because you were identified as being someone who was diagnosed with diabetes between 2010 and 2015 and were referred to attend the New Onset Diabetes Education Program at Northern Navajo Medical Center. Individuals receiving this survey either attended one or more classes but did not complete the course or did not attend any of the educational classes.**

**The purpose of this survey is to try to identify ways to improve access to the diabetic education program. A PhD candidate from the University of New Mexico with full approval from the Shiprock Chapter House, Northern Navajo Agency Counsel, Shiprock Health Board, NNMC CEO, the UNM IRB and the Navajo Nation IRB is conducting this study.**

**Your opinion is important to; however, you are under no obligation to complete this survey.**

**The survey results will be discussed with the Shiprock health board and diabetic education staff with recommendations for improving the diabetes education classes and making them easier to attend. These groups will not know who participated in the survey and your name and personal information will not be used when the survey results are shared.**

**Thank you for taking the time to complete this survey. Your participation will help improve diabetes education for future patients.**

**SECTION A:**

Age: \_\_\_\_\_

Male

Female

What community are you from? \_\_\_\_\_

*Please circle the most appropriate answer*

I was diagnosed with diabetes in      2010      2011      2012      2013      2014      2015

If you **attended one or more** of the New Onset Diabetes Education Classes please continue to **SECTION B**

If you **did not attend any** of the New Onset Diabetic Education classes please go to **SECTION C**

**SECTION B (ATTENDED ONE OR MORE CLASS)**

1) I did not attend all of the classes held by the New Onset Diabetic Education Program because...

*Please circle answer(s) that apply*

I did not have transportation

I could not take time off of work

I wasn't learning anything new about diabetes

I had other obligations

I didn't like the class

Other:

---

---

2) I would have attended more of the classed if...

*Please circle the answer(s) that apply*

They were taught in the evenings

They were taught on the weekend

They were taught in my community

Childcare was available

The classes were taught in a better way

No matter what, I would not have attended more of the classes

Other:

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---



3) Is there anything else that would make the diabetes education classes better or easier for members of the community to attend?

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**SECTION C (DID NOT ATTEND ANY OF THE CLASSES)**

1) I did not attend any of the classes because...

*Please circle the answer(s) that apply*

I did not have transportation

I could not take time off of work

I had other obligations

I already knew about diabetes

Other:

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2) I would have attended the diabetic education classes if...

*Please circle the answer(s) that apply*

They were taught in the evenings

They were taught on the weekend

They were taught in my community

They offered childcare

No matter what, I would not have attended the diabetic education classes

Other:

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---

3) Is there anything else that you think would make the diabetes education classes better or easier for members of the community to attend?

If you have any questions regarding this survey, please contact Denise Bartley, NP-C, PhD candidate, and contact person at NNMC for this study: 505-368-7022

**Thank you for taking the time to complete this survey**

## Appendix C

### Informed Consent Letter University of New Mexico Health Sciences Center

#### Evaluation of the New Onset Diabetes Education Program for Navajo Adults at Northern Navajo Medical Center

Denise Bartley, NP-C and PhD candidate from the University Of New Mexico, Department Of Nursing, is conducting a study. The purpose of the study is to evaluate the effectiveness of the New Onset Diabetes Education Program at Northern Navajo Medical Center. You are being asked to participate in this study because you were referred to participant in this diabetic education program sometime between January 2010 and December 2015.

Your participation will involve completing a written survey. The survey should take about 5 minutes to complete. Your involvement in the study is voluntary, and you may choose not to participate. There are no names or identifying information associated with this survey. The survey includes questions such as what you liked/disliked about the program and tries to identify ways to better meet the needs of the Navajo community. You can refuse to answer any of the questions at any time. There are no known risks in this study, but some individuals may experience discomfort when answering questions. All completed surveys will be kept for one year in a secure location at NNMC then destroyed.

The findings from this project will provide information to help determine if attendance in the New Onset Diabetes Education Program helps people manage their diabetes better than those who did not receive the education and, if needed, to try to identify ways to adjust the program to meet the needs of the community, such as offering the classes at sites within the communities or at different times. If published, results will be presented in summary form only.

If you have any questions about this research project, please feel free to contact

1) Beverly Becenti-Pigman, Board Chair  
Navajo IRB Office  
Navajo Division of Health  
PO Box 1390, Window Rock, AZ 86515  
Phone: 928-871-6929, Fax: 928-871-6650

2) Denise Bartley, NP-C, PhD Candidate  
Investigator  
Northern Navajo Medical Center  
P.O. Box 160, Shiprock, NM 87420  
Phone: 505-368-7392, Fax: 505-368-7011

UNM HSC IRB Office  
HSSB 226  
University of New Mexico  
Albuquerque, NM, 87131  
Phone: (505) 272-1129

Dr. K. Cox, UNM College of Nursing  
Investigator  
MSC09; University of New Mexico  
Albuquerque, NM, 87131  
Phone: (505) 272-8050

By returning this survey, you will be agreeing to participate in the above described research study. Thank you for your consideration.

Sincerely,  
Denise Bartley, NP-C  
PhD Candidate UNM, College of Nursing  
HRRC: 17 192

Date of Scheduled Visit \_\_\_\_\_, Clinic \_\_\_\_\_, Chart # \_\_\_\_\_

## **Appendix D**

### **Scripted Dialogue for Introduction of Survey**

Good Morning Mr. Doe, you were diagnosed with diabetes in 2011 and at that time you were invited to attend the New Onset Diabetic Education classes. Those who were invited to attend the class are being asked to complete this survey in order to help identify strengths and limitations of the program, as well as potential barriers that may have prevented people from attending the course. You are being asked to provide your opinions but are not required to do so if you do not wish to, I'll be available if you have any questions. You can leave the survey (completed or not) in the collection box by the exit.

## Appendix E



### SHIPROCK AGENCY SERVICE UNIT HEALTH BOARD

#### Northern Navajo Medical Center

Hwy 491 North - P.O. Box 160 - Shiprock, NM 87420

OFFICE: (505) 368-6005 - FAX: 505-368-626

### Resolution of the Shiprock Agency Service Unit Health Board to the Navajo Nation Research Review Board and the University of New Mexico IRB to Support and Approve the "Evaluating the effectiveness of the new onset diabetic program: A mixed method study"

#### WHEREAS:

1. The Shiprock Agency Service Unit Health Board represent the collective interests of the Native American people in their respective community as well as the entire Shiprock Service Unit (SRSU); and
2. The Shiprock Agency Service Unit Health Board ensure that the community is informed of the SRSU healthcare services and that the concerns of the community regarding healthcare issues and expectations are promoted and advocated through a mutual relationship with Indian Health Service; and
3. The Shiprock Agency Service Unit Health Board support clinical research that enable researchers to conduct research, analysis, and interpret the findings to improve human health and welfare of all people who reside within the Service Unit, and;
4. The Effectiveness of Diabetic Education study represents a step toward better identification and management of diabetes among Diné – Navajo; and
5. The Northern Navajo Agency Council fully supports and is committed to the study to evaluate the effectiveness of the new onset diabetic education program for Navajo people at NNMCC. The study will also seek input from community members via interviews and discussions to help identify ways to enhance the education program to better meet the needs of the Diné – Navajo. Providing native people with better education concerning the prevention and management of diabetes will lead to improved quality of life for those living on the Navajo Nation

#### NOW, THEREFORE BE IT RESOLVED THAT

1. Shiprock Agency Service Unit Health Board reviewed the study, recognized the need to improve the new onset diabetic education program and passed resolution to support the study;
2. The Shiprock Agency Service Unit Health Board encourages its approval by the Navajo Nation Human Research Review Board and the University of New Mexico IRB, subject to satisfaction of all applicable rules and regulations of the Navajo Nation related to the conduct of health studies among the Navajo people.
3. Please find attached Exhibit A, Abstract of Study

**CERTIFICATION**

We certify that the foregoing Resolution was duly considered by the Shiprock Agency Service Unit Health Board at a duly called Meeting in Shiprock, New Mexico, at which a quorum was present and that same was passed by a vote of 10 in favor, 00 opposed, and 01 abstained, this 4<sup>th</sup> day of August, 2015.

Main Motion by: Lovena Lee

Seconded by: Rannita Henderson

A handwritten signature in black ink, appearing to read "David John", written over a horizontal line.

David John, President  
Shiprock Agency Service Unit Health Board

## Appendix F



DEPARTMENT OF HEALTH & HUMAN SERVICES



INDIAN HEALTH SERVICE

Northern Navajo Medical Center  
P.O. Box 160, Shiprock, NM 87420  
Voice (505) 368-6005  
Fax: (505) 368-6265

July 28, 2016

Denise Bartley, NP-C  
Northern Navajo Medical Center  
PO Box 160  
Shiprock, New Mexico 87420

Dear Ms. Bartley:

The research project you presented to the Shiprock Agency Service Unit Health Board (SASUHB) on August 4, 2015 is designed to evaluate the effectiveness of a new diabetic education program at Northern Navajo Medical Center (NNMC). The new diabetes program is an innovative approach to improve health outcomes for Navajo patients with diabetes. The program provides education to patients that have been recently diagnosed with diabetes and waiting assignment of a provider.

I understand the study is being conducted to educate our patients' on their diabetes care. Our service unit community population is most at risk to develop the disease and need this type of knowledge and education.

In support of your proposed research among the population of the Shiprock Service Unit (SRSU), the SASUHB approved a Supporting Resolution titled, *Evaluating the Effectiveness of the New Onset Diabetic Program* on August 4, 2015. As Chief Executive Officer of SRSU, I support this study so it can be used to improve health outcomes for the Navajo people with diabetes.

We look forward to learning about the results of your study. We very much appreciate your research designed to improve the overall health of our community members.

Sincerely,

Fannessa Comer  
Chief Executive Officer

## Appendix G



# NORTHERN NAVAJO AGENCY COUNCIL RESOLUTION

NNAC-11-121915A

**Resolution of the Northern Navajo Agency Council to The Navajo Nation Institutional Review Board:**

**SUPPORTING THE REQUEST BY DENISE BARTLEY, NP-C TO CONDUCT THE PROPOSED STUDY, "EFFECTIVENESS OF DIABETIC EDUCATION FOR NEWLY DIAGNOSED NAVAJO ADULTS"**

**WHEREAS:**

1. The Northern Navajo Agency Council is a recognized political subdivision of the Navajo Nation and has the authority to advocate and make appropriate recommendations on behalf of the 20 Northern Navajo Agency chapters to the Navajo Nation Government, Federal, State, and local entities for appropriate action; and
2. The Northern Navajo Agency Council promotes various activities that improve quality of life for the Diné – Navajo. The duration of the proposed study is up to 60 months and will include systematic review of medical records to confirm diagnosis and obtain glucose levels at the time of diagnosis and at regular intervals post diagnosis. The target population will involve Navajo adults; and
3. The Northern Navajo Agency Council is committed to supporting projects oriented towards improving the health of people living on the Navajo Nation-Northern Navajo Agency to the Navajo Nation Institutional Review Board (IRB).

**NOW, THEREFORE BE IT RESOLVED THAT:**

1. The Effectiveness of Diabetic Education study represents a step toward better identification and management of diabetes among Diné – Navajo.
2. We welcome Denise Bartley NP-C to return to discuss the project once it has started so that we are aware of the progress of the study. We are pleased that Denise Bartley, NP-C will also return when the study is completed so that we are aware of the results and conclusion, and so that we can have input into future projects.
3. The Northern Navajo Agency Council fully supports and is committed to the study to evaluate the effectiveness of the new onset diabetic education program for Navajo people at NNMC. The study will also seek input from community members via survey, interviews and/or discussions to help identify ways to enhance the education program to better meet the needs of the Diné – Navajo. Providing native people with better education concerning the prevention and management of diabetes will lead to improved quality of life for those living on the Navajo Nation-Northern Navajo Agency.

## Appendix H



Human Research Review Committee  
Human Research Protections Office

June 16, 2017 REVISED September 7, 2017

Kim Cox, Principal Investigator  
Denise Bartley, Co-Investigator  
UNM College of Nursing  
1650 University Blvd. NE, MSC07 4280  
1 University of New Mexico  
Albuquerque, NM 87131  
505-272-0850  
KJCox@salud.unm.edu

Dear Kim Cox and Denise Bartley:

On 6/15/2017, the HRRC reviewed the following submission:

Type of Review: Initial Study  
Title of Study: Evaluation of the New-Onset Diabetes Education Program for Navajo Adults  
Investigator: Kim Cox  
Study ID: 17-192  
Submission ID: 17-192  
IND, IDE, or HDE: None

Submission Summary: Initial Study  
Documents Approved: • Investigator Protocol v052617.pdf  
• Data Use questionnaire .pdf  
• NODEP Surveys.pdf  
• Consent Cover Letter.pdf

Review Category: EXPEDITED: CATEGORIES (7)(b) Social science methods and (5) Data, documents, records, or specimens.

Determinations/Waivers: Waived the requirement to obtain a signed Consent form.  
Signature waived; requires written statement about research.  
HIPAA Authorization Addendum waived.

Submission Approval Date: 6/15/2017  
Approval End Date: 6/14/2018  
Effective Date: 6/15/2017

The HRRC approved the study from 6/15/2017 to 6/14/2018 inclusive. If modifications were required to secure approval, the effective date will be later than the approval date. The "Effective Date" 6/15/2017 is the date the HRRC approved your modifications and, in all cases, represents the date study activities may begin.



Before 6/14/2018 or within 45 days of study closure, whichever is earlier, you are required to submit a continuing review. You may submit a continuing review by navigating to the active study and clicking the "Create Modification / CR" button.

Please use the consent documents that were approved and stamped by the HRRC. The stamped and approved consents are available for your retrieval in the "Documents" tab of the parent study.

This determination applies only to the activities described in this submission and does not apply should you make any changes to these documents. If changes are being considered and there are questions about whether HRRC review is needed, please submit a study modification to the HRRC for a determination. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

In conducting this study, you are required to follow the Investigator Manual dated April 1, 2015 (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,

A handwritten signature in black ink, appearing to read "Thomas F. Byrd, MD". The signature is written in a cursive style with a large initial 'T'.

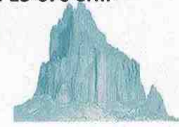
Thomas F. Byrd, MD  
*HRRC Chair*

# Appendix I

07-12-15-070-SHIP



## RESOLUTION OF THE SHIPROCK CHAPTER SHIPROCK, NAVAJO NATION



### SUPPORTING A PROPOSED STUDY ON THE GLUCOSE LEVELS OF DINÉ DIABETIC PATIENTS AND RECOMMENDING SAME TO THE NAVAJO NATION INSTITUTIONAL REVIEW BOARD

#### WHEREAS:

1. The Shiprock Chapter of the Navajo Nation acts on this resolution pursuant to the authority conferred to the Chapter through Navajo Nation Code Title 26, Chapter 1. Section B. Purpose, which states, "Through adoption of this Act, the Navajo Nation Council delegates to Chapters governmental authority with respect to local matters consistent with Navajo Law, including custom and tradition and further the inclusivity provided by the Diné Fundamental Law, in that "it is entirely appropriate for the government itself to openly observe these fundamental laws;" and
2. The Shiprock Chapter is requested to support a study that will include systematic review of medical records to confirm diagnosis and obtain glucose levels at the time of diagnosis and at regular intervals post diagnosis. The study will improve the quality of life for the Diné adults target population, and
3. The Shiprock Chapter is committed to supporting projects oriented towards improving the health of people living on the Navajo Nation-Northern Navajo Agency to the Navajo Nation Institutional Review Board (IRB). The duration of the proposed study is up to 60 months.

#### NOW, THEREFORE, BE IT RESOLVED THAT:

1. The Effectiveness of Diabetic Education study represents a step toward better identification and management of diabetes among Diné, and
2. The Shiprock Chapter requests that Ms. Denise Bartley return to discuss the project once it has started to inform us of the progress of the study and again to return when the study is completed so that the community is aware of the results and conclusion and to have knowledgeable input into future study projects, and
3. The Shiprock Chapter supports the study to evaluate the effectiveness of the new onset diabetic education program for Diné people at NNMC. The study will also seek input from community members via interviews and discussions to help identify ways to enhance the education program to better meet the health needs of diabetic Diné. This will provide the Diné with better education concerning the prevention and management of diabetes and will lead to improved quality of life for the Diné.

Motioned by: Wallace Ben

Seconded by: Marian John

#### CERTIFICATION

We hereby certify that the foregoing resolution was presented and considered at a duly called Chapter meeting at which a quorum was present and that the same was approved by a vote of 35 in favor, 0 opposed and 0 abstentions on this 29<sup>th</sup> day of July 2015.

Duane H. Yazzie  
Duane H. Yazzie, President

Tommie Yazzie  
Tommie Yazzie, Vice President

J. Kaiyah Begay  
J. Kaiyah Begay, Secretary/Treasurer

Tom Chee  
Tom Chee, Council Delegate

## Appendix J

### Navajo Nation Human Research Review Board Approval

December 01, 2017

Denise Bartley, FNP  
UNM - College of Nursing  
474 Road 6100  
Kirtland, New Mexico 87417

Dear Ms. Bartley,

This is to advise you that the **Study #NNR-17.280T: "Evaluation of the New Onset Diabetes Education Program for Navajo adults at Northern Navajo Medical Center"** has been presented to the Navajo Nation Human Research Review Board (NNHRRB) on **August 15, 2017**, and the following action taken subject to the conditions and explanation provided below.

Reasons:	New Title
Description:	Request Review and Approval of New Study.
<b>NNHRRB Action:</b>	<b><u>Accepted and Approved</u></b>

The Navajo Nation Human Research Review Board has added a very important additional contingency regarding failure to comply with NNHRRB rules, regulations, and submittal of reports which could result in sanctions being placed against your project. This could also affect your funding source and the principal investigator. Under Part Five: Certification, please note paragraph five wherein it states: *"I agree not to proceed in the research until the problems have been resolved or the Navajo Nation Human Research Review Board has reviewed and approved the changes."* Therefore, it is very important to submit quarterly and annual reports on time and if continuation is warranted submit a letter of request sixty (60) days prior to the expiration date.

The following are requirements that apply to all research studies:

1. The Navajo Nation retains ownership of all data obtained within its territorial boundaries. The Principal Investigator shall submit to the NNHRRB a plan and timeline on how and when the data/statistics will be turned over to the Navajo Nation;
2. Only the approved informed consent document(s) will be used in the study;
3. Any proposed future changes to the protocol or the consent form(s) must again be submitted to the Board for review and approval prior to implementation of the proposed change;
4. If the results of the study will be published or used for oral presentations at professional conferences, the proposed publication, abstract and/or presentation materials must be submitted to the Navajo Research Program for Board review and prior approval;
5. Upon Board approval, three (3) copies of the final publication must be submitted to the Navajo Research Program;
6. All manuscripts must be submitted to the Navajo Research Program for Board Review and prior approval;
7. The Principal Investigator must submit a dissemination plan on how the results of the study and how these results will be reported back to the Navajo Nation;

8. The Principal Investigator must share specifically how these results will generally benefit or improve the health of the Navajo people. This can be completed by:
  - a. Conducting an educational in-service for the community people and health care providers on the Navajo Nation and present the findings. Provide documentation of these in-services presented.
  - b. Developing educational materials for use by the health care providers and the community people and providing the training on how to use the materials; and
  - c. Presenting and sharing the results of the study at a research conference sponsored by the Navajo Nation for its health care providers and the Navajo people.
9. The Principal Investigator is expected to submit documentation on **8a**, b, & c;
10. The Principal Investigator must submit quarterly and annual reports as scheduled.

Please begin using your Study Protocol Number **NNR-17.280** on all correspondences. If you have any questions on this subject, please call the Navajo Research Program at (928) 871-6929.

Sincerely Yours,

Beverly Becenti-Pigman, Chairperson  
Navajo Nation Human Research Review Board

cc: #NNR-17.280 file

## Appendix K

### Qualitative Data: Survey A, Group 1 (Completed 3-day course)

Record ID	Content of the course that was most helpful	Content of the course that was least helpful	Strengths of the NODEP	Weaknesses of the NODEP	Challenges in being able to attend the NODEP	Additional comments
102b		None, all was very important!		No complaints – was fine the way it was		I was satisfied with the way the course was taught
103a						It would be nice if you served snacks
105b						(During the sessions) ask participants questions and make them provide the answer to make sure they are understanding the information
106b	Learning how to count the number of fat grams and calories in foods	The course was very helpful		It was a distance for me to travel to NNMC		Have outreach programs in different communities
107b	All content was helpful		Program is good	None		Was helpful to all ages
108b	All the topics were helpful		The course was very informative and good			I would definitely recommend this course to family and friends

109b			Loved the studies			Helpful if videos were given to participants or family members
110b	Calorie intake, meal preparation and how to make the best choices when eating out	Need coaching and support. Internet was not available		Potential future problems like body temperature, foot care, skin conditions need addressed		Should have access to websites and computers available.  The class was taught by very healthy people, it is hard for them to see my struggles.  Should offer follow-up classes for on-going evaluation/education.  Good recommendations for accessing swimming pools, exercise equipment and the weight room.
112b			Need to walk everyday			Would like home classes
113b						It would be nice if young people were taught about diabetes before they get it  NODEP staff is doing a great job!
114b				Better to have classes taught in		

				the chapter houses or in the evening		
115b						Everything was great
116b						The class was good, just applying it is hard, with working, getting off late, it's just easier to get takeout food. But I know I have to do the hard thing because it is the right thing my family.
117b						The program was great, but it is up to the individual to make it work.
118b	Good to be able to find hidden sugars in foods.					More cooking classes or healthier alternatives to traditional foods. I will serve more tortillas and less frybread to family and community functions.
119b				Nothing needs changed		It was a great class to attend. It's been a while but a refresher would be nice. Thank you!
124b	It was all very helpful!			I was satisfied with the course the way it is		It is up to the individual to make sure they attend these courses and use the information. It is important because it pertains to their overall health!

125a	This is a great program, in our busy world it is easy to relax on each one of these (topics) and you start going in the wrong direction again			There is always room for improvement, but my biggest problem is not taking advantage and using the information after I have been there	No problems with the way the program is set up. I made the time to be there	There are no problems or concerns with the course. It is up to the individual to see what is being offered and to commit to living longer and having better health
126b		None, all were helpful	All good		It might be helpful if the course was taught on weekends (sometimes) to help people who work.	If the young are taught to eat right now, they will pass it on to their children. Children should be given more fresh foods like fruits and vegetables. Should not be served sodas or boxed foods.
129b		None, all was good	All were good	None, all were good		
130b	I am fine with where, when and how the course was taught					Show movies and films on what diabetes can do to the body
131b				More information on ways to prepare foods that are available here (in Shiprock)		Young children must be taught good eating habits beginning in the home. No sugary drinks and prepare meals for them at home.



133b			I think the class was thorough. I areas have definitely helped me			
137a	I need to work on my weight because it has an effect on my blood sugar		I brought my daughter with me.	More pictures in the presentations.	Transportation was an issue	
138a				I would have liked to have more of the class taught in Navajo		
141a						The course is good the way it is, no improvement is needed
142a		None, I found all the information to be helpful				
144a	The more I can take care of myself the more I can live and take care of others				Maybe weekend classes for people who work	People have to attend on their own. Teachers are there for you, you need to ask questions. Thank you for being there for me!
147a					I would prefer morning classes.	
148a	All were helpful					

149a					Would be convenient if taught on the weekends	
151a	I didn't used to use my glucometer					
156a						I would like the class taught in my community and maybe have community support groups.
159b	None, all categories were very insightful to my discovery of DM			I liked that I was assigned a primary provider, but he died soon after being assigned to me and I was not assigned another one for over a year	The course time and place was convenient for me	The course was very helpful, it meet my needs.  How to prevent diabetes should be taught to children when they are young and continue through school. Would help prevent DM in the future.
161b		None, everything was helpful in understanding diabetes		All very helpful and informative . No weaknesses		People should not eat fast food.
176a						All was very informative and helpful.

## Appendix L

### Qualitative Data: Survey A, Group 2 (Completed the 1-day NODEP course)

Record ID	Content of the course that was most helpful	Content of the course that was least helpful	Strengths of the NODEP	Weaknesses of the NODEP	Challenges in being able to attend the NODEP	Additional comments
160b						Use more visual aids for those who don't understand or read well  I noticed some people did not understand
165a	How low blood sugars affect us					
166a				I noticed that older people did not fully understand one of the lady teachers, she was talking too fast	Take the classes to the chapter houses	Have classes about pre-diabetes
167b						
170b	To watch what I eat					
172b	Calorie counting and identifying the types of foods to avoid					

173b		Nothing, I thought the class was very helpful				
174a						Need more information in Navajo

## Appendix M

### Qualitative Data: Survey B, Group 3 (Began the 3-day NODEP course, but did not complete it)

Record ID	Barriers to attending all of the NODEP	I would have attended more classes if...	Additional Comments
203b			What I attended was helpful, I could not take more time off of work
236a	Inconvenient time scheduled		Embarrassed because I am hard of hearing
237b		Morning is better for me	
239b			I didn't want to take anymore classes
241b	Transportation is an issue	Classes were taught in my community	I liked the class I took
242b	Didn't know about additional classes, was in denial at the time	Work schedule varies, so can't say when I could attend	I know what I need to do but it is hard.
243b			<p>I would have liked the one day class instead of the series</p> <p>Share more personal experiences</p> <p>Conduct on-line classes for those who have internet access and can work at their own pace for self-learning</p> <p>Include a therapist for those that feel they need emotional guidance with the new about the diabetes diagnosis</p> <p>Add certificates to show completion</p>
245b	I didn't know about the other classes	It would be great if the classes were in my community	Cooking classes would be a fun way to learn
248b		Classes were taught in my community in the evenings	

## Appendix N

### Qualitative Data: Survey B, Group 4 (Did not attend any portion of NODEP)

Record ID	Barriers to attending the NODEP	I would have attended classes if...	Additional Comments
216a			I attended classes at San Juan Regional Medical Center
220b		Definitely on weekends, when it is convenient	
221b			I do my own nutrition research. I know you are doing a great job
222a	I didn't want to go!  I did my own research		Have classes at the time of appointments or regularly checkups. That way it's all in one visit.
223b	Was not aware of classes		
225b	I had just moved back to the area and was too busy at the time		
226b	It's the same old thing		
228a	I would not go to classes, but home visits would be okay		
229a	I wasn't told about the classes		
230a	I did not get a letter to go to class		
231a		They were in my community	
232b	They say I have diabetes, but I don't		
234b	I had no transportation		
235b	I take care of a family member who goes to medical and mental health appointments		I've been reading up on it at home, trying to eat right

	constantly, this comes first		
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