Diabetic Eye Disease and American Indian and Alaska Native Populations

Findings From Focus Groups and Key Informant Interviews

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1. Executive Summary

1.1 Introduction

American Indians and Alaska Natives have the highest prevalence of diabetes in the United States, in some groups exceeding 50 percent of adults (IHS 2001). Diabetic eye disease (DED) is the leading cause of new blindness in the United States for people age 20 to 74 (CDC 1994). People with diabetes have a 25 times greater likelihood of becoming blind than do those without diabetes (CDC 1991). According to the American Academy of Ophthalmology, the American Optometric Association, and the American Diabetes Association (ADA), national best practice models indicate that people with diabetes should have diabetic eye exams every year.

The National Eye Health Education Program (NEHEP) of the National Eye Institute (NEI) began in 1989 with a congressional directive to the Institute to increase its commitment to the prevention of blindness through education programs and the encouragement of regular eye exams. The NEHEP focuses on glaucoma and DED, two conditions that often have no early warning signs, and low vision. The program's science-based message urges people to get regular dilated eye exams so that these diseases may be detected before vision loss occurs and to seek out low vision rehabilitation when appropriate. With the rising rates of diabetes and its accompanying complications among American Indians and Alaska Natives, the NEHEP has embarked for the first time on an outreach effort focused specifically on reaching these populations with DED messages.

Formative research with American Indians and Alaska Natives was conducted to gain a better understanding of the knowledge, awareness, and approaches related to DED among these populations and their communities. A new primary target audience of the national DED education program is American Indians and Alaska Natives already diagnosed with diabetes. The secondary audiences selected include those who are in a position to influence or support the health practices of individuals at risk, such as tribal leaders and providers, family members, health professionals, and community health representatives.

1.2 Methodology

The objectives of this formative research with American Indians and Alaska Natives were to learn about and measure current awareness and understanding of:

- Diabetes management and what it means for the primary audience
- The importance of eye health care
- Frequency of exams, especially related to the diagnosis of diabetes
- Benefits of early detection of eye disease
- Barriers to receiving or accessing eye health care
- Motivators for behavior change
- Communication channels.

The NEHEP research team sought feedback from a sample representation of tribes across Indian Country—those with broad geographic locations, including urban and rural settings, as well as self-governance health services systems and Indian Health Service (IHS) systems. Given this context, the NEHEP team proposed collecting data from the following five locations:

- Fort Totten, North Dakota (Spirit Lake Dakotah Nation)
- Anchorage and Village of Dillingham, Alaska (Yu'pik Eskimos, Athabascan Indians, and Aleut Natives)
- Atmore, Alabama (Poarch Creek Nation)
- Seattle, Washington (Seattle Indian Health Board, urban Indian location)
- Denver, Colorado (Diabetes Prevention in American Indian Communities Conference—representatives of Navajo, Ojibwe, Chippewa-Cree, and Pima and Maricopas [Gila River Indian Communities] Nations).

In fall 2002 and spring 2003, the NEHEP team conducted a total of eight focus groups with American Indians and Alaska Natives with diabetes (70 total participants [35 women and 35 men]) in four of the five data collection sites. Only key informant interviews were conducted in Colorado, as the setting was a conference rather than an American Indian or Alaska Native tribe or community. The NEHEP team held two focus groups at each location—one with "younger" individuals (age 20 to 39 in North Dakota; age 30 to 49 in the other three locations) and one with "older" individuals (age 40 and older in North Dakota; age 50 and older in the other three locations).

The Focus Group Moderator's Guide helped to capture an informal profile of each study site's health status, general management of diabetes, familiarity with and frequency of eye exams, awareness of vision problems associated with diabetes, and ideas for ways to reach American Indians and Alaska Natives with health promotion messages.

During the same period, the NEHEP team also conducted 58 one-on-one in-depth interviews with key informants representing all five data collection sites. Interviewees included community health representatives, community health aides, outreach coordinators, nutritionists, diabetes educators, optometrists, ophthalmologists, nurses, health educators, health care administrators, executive directors, diabetes program managers, tribal council leaders, and other community influencers.

The Key Informant Interview Guide probed for information about interviewees' community or tribe as it pertained to the community's health, diabetes-related resources and services provided, and available channels of communication. Questions in the guide also requested interviewees' ideas for messages that might resonate with American Indians and Alaska Natives.

Tables 1 and 2 (in Chapter 3: Methodology) provide a summary of the location and composition of the focus groups and key informant interviews.

1.3 Conclusions

Each site the NEHEP team visited to collect data for this formative qualitative research study has its own unique size, geographic location, language, and culture. The following themes, however, have applications across all data collection sites:

American Indians and Alaska Natives understand diabetes as seen through the experiences of elders in the community who have faced a life with the same disease; however, they have only a basic level of knowledge regarding the full implications of this disease. Most focus group participants in this study, in particular the younger ones, did *not* understand the connection between diabetes and eye-related problems (a longer-term consequence). The often incomplete messages patients receive from multiple health care providers add to their confusion. Very few focus group participants were aware of the term "diabetic eye disease (DED)." Although all interviewees were familiar with the relationship between diabetes and eye problems ("diabetic retinopathy" in particular), they had mixed levels of familiarity with the term "DED."

American Indians and Alaska Natives tend to be diagnosed with diabetes at later stages of the disease. American Indians and Alaska Natives in this study repeatedly remarked that their diabetes was discovered "by accident." As American Indians and Alaska Natives are inclined to seek medical care only when they are experiencing problems, the window of opportunity for prevention education is often lost. A prevention mindset, such as getting regular wellness checkups, is limited. Many American Indians and Alaska Natives do not consider themselves sick unless they are experiencing pain. When they are diagnosed with diabetes, consequently, most are in disbelief that they can have a disease while feeling well at the moment.

Social support from professional and personal networks is critical to the consistent and proper management of diabetes. Coworkers and significant others, particularly family members, play a key role in positively influencing a person's knowledge, attitudes, and behaviors related to diabetes and its management. Involving children in education and outreach efforts is essential as they are the youngest generation who will have to address this disease and its accompanying issues. Their engagement is inevitable, actually, given the rising rates of diabetes among young people. (Younger individuals with diabetes will have more years of disease burden and a higher probability of developing complications earlier in life [Burrows et al. 2000].)

Continuity among visits to a health care provider is a sure way to improve appointment and care compliance. An overwhelming majority of study participants noted the power of a personal connection with an individual health professional in the proper management of diabetes. Understaffing of key personnel (e.g., optometrists, ophthalmologists), high staff turnover rates, and a shortage of staff who speak the native language(s) are factors contributing to a current lack of continuity in care.

Women are the primary caretakers of family members with diabetes as well as the main seekers of care and information. Women are seen as invaluable assets to the health of American Indian and Alaska Native families and communities. However, because women are the primary caregivers, when women are the ones with diabetes, there is often a lack of caregiving assistance devoted to them. American Indian and Alaska Native women are more likely than men to be

diagnosed with diabetes; this higher prevalence may be due to women seeking health care more frequently than men rather than a result of true differences in risk (Burrows et al. 2000).

Interpersonal and personalized communication is the most effective way to reach American Indians and Alaska Natives with DED messages. As limited literacy poses a serious challenge in Indian Country, information presented as a conversation (one-on-one, group discussion, or storytelling), audibly (radio, TV), or visually (video, flipchart, TV) will be received favorably. Written materials should be avoided when possible; when used, written materials should be designed in easy-to-understand language. Celebrities are *not* necessary to appeal to this audience. Rather, soliciting help from local, trusted community members (well-known health care providers or members of the tribe, especially those individuals from the community who have diabetes themselves) will lend the most credibility to any health education program.

Messages developed for a DED education campaign need to include an explanation of the symptoms of diabetes, the need for regular treatment, and the consequences of not treating diabetes—which include DED. Participants suggested that the tone of messages needs to be straightforward, honest (not "sugar-coated"), and hopeful. Messages should also encourage taking action and being self-reliant and make the connection between proper care and the possibility of living a long, healthy life.

DED messages should be included within a broader integrated health approach. The general philosophy behind many American Indian and Alaska Native traditional health practices is to consider mind, body, and soul as interconnected and not to single out any one disease. Traditional medicine often focuses on underlying causes, conceptualized as spiritual in nature, rather than on the relief of acute symptoms (Buchwald et al. 2000). This may partly explain why the concurrent use of different health options characterizes much of the help-seeking behavior among American Indians and Alaska Natives (Buchwald et al. 2000): a *combination* of traditional and Western medicine seems to have the greatest appeal. Representatives of national organizations interviewed for this study are aware of the need to instill more cultural sensitivity, as well as address diabetes within larger lifestyle issues including diet and physical activity, in their organizations' national-level efforts.

A DED education program, national in scope, should collaborate with groups and activities already in place and should involve the whole health team. Participants expressed concern that a duplication of efforts might delegitimize any new or current program, and they would welcome a complementary approach instead. Interviewees agreed that partnering with the IHS Diabetes Program and the Tribal Leaders Diabetes Committee, as well as the ADA and the Centers for Disease Control and Prevention (among many other national, regional, and local key players), will be fundamental to a comprehensive DED communication plan. Interviewees also underscored their preference for involving the entire health care team at any specific local health facility (compared to focusing solely on diabetes educators, for example). If all members of the health care team (regardless of position level or geographic location) reinforce ADA's "Standards of Medical Care for Patients With Diabetes" (ADA 2002) to their patients, consistent messages would be delivered and confusion would diminish.

Diabetes health professionals are frustrated both with American Indian and Alaska Native patients' long phases of denial and with their own inability to encourage self-empowerment among their patients. It is very common for American Indians and Alaska Natives to "shut down" with denial, anger, and fear after receiving a diabetes diagnosis. As diabetes requires daily attention and care, these populations would benefit from the value of self-reliance and self-management. The findings also showed a "disconnect," at times, between patients feeling proactive about their health (e.g., commitment to a healthy diet and physical activity) and providers sensing apathy and lack of initiative among patients (e.g., a sense that patients expect providers "to do everything").

An infrastructure is in place for providing health care services to American Indians and Alaska Natives (such as that provided by IHS), yet more could be done to expand diabetes-related services across Indian Country. Health clinics on reservations and Federal Government funding have enabled health professionals to serve American Indians and Alaska Natives. For example, community health aides in Alaska and community health representatives in North Dakota link individuals living in rural villages with clinic or hospital resources. Tribes vary in their dependence on IHS and other funding, and many have taken steps toward increased self-sufficiency (e.g., tribes in Alaska manage their own health care delivery). In most American Indian and Alaska Native communities, diabetes programs are available but limited, especially for eye-related problems. Although many American Indians and Alaska Natives receive annual dilated eye exams, referrals to eye care professionals in health facilities *outside* the tribe are almost always necessary to facilitate this, regardless of tribe characteristics (e.g., urban or rural, large or small, history, language, culture).

The financial burden of paying for health care services and transportation impedes many American Indians and Alaska Natives from accessing adequate diabetes care, regardless of tribe location or size. Even when available, financial assistance is often incomplete. For example, coverage may include an initial eye care visit but not follow-up appointments or eyeglasses. Although many diverse tribes in Indian Country experience similar barriers to proper diabetes management, tribes in remote areas have the added disadvantage of being isolated—availability of transportation to proper health facilities becomes an even greater challenge for them.

Health messages, including those on DED, must be tailored to specific audiences and be respectful of the audience's community. Alaska Natives, for example, do not want to be lumped with American Indians. Messages, moreover, must be delivered in the language of the tribe and with local collaboration for translating the messages to be culturally and community relevant. Any new diabetes education effort must seek to collaborate with groups and activities already in place as well as invite the participation of community members in its design and implementation. American Indians and Alaska Natives must play a central participatory role in the research and care that affects their health (Roubideaux 2002).

1.4 Recommendations

All participants in this formative research study were in near unanimity in their endorsement of a national DED education program directed toward American Indian and Alaska Native people (Alaska was the only site that hesitated to provide full support because of a concern over the

possible unnecessary duplication of efforts and competition of scarce funds for multiple community needs). They also agreed on the importance of communicating the connection between diabetes and DED as well as the need for regular eye exams. All data collection sites for this study ranked diabetes high on their list of primary health issues in need of attention in their communities. They also reported a rise of individuals with diabetes in their communities, with an alarming increase of this disease among young people in particular.

The main recommendations offered by study participants are briefly summarized below:

- Communicate clearly the connection between diabetes and eye-related problems.
- Encourage the whole health care team to view health in an integrated manner when addressing diabetes (e.g., diabetes is one of many health concerns influenced by diet and physical activity).
- Promote the value of regular vision exams, even when feeling well, as a method for detecting diabetic eye disease at its early stages (e.g., when treatment is most effective).
- Promote self-reliance and self-management to those already diagnosed with diabetes.
- Involve children in outreach and education activities.
- Target women (e.g., mothers, wives, sisters, aunts, cousins), as they tend to be the family members with the most initiative for seeking health care and information.
- Get creative in strategies and tactics for enticing men to seek proper health care and information.
- Present information in a conversation, group discussion, or storytelling format when possible (written materials will not appeal to American Indians and Alaska Natives with limited literacy skills).
- Custom-tailor DED messages to individual communities.
- Invite the active participation of local community members in the design and implementation of any diabetes-related effort.
- Use testimonials from “ordinary” people in the community who have diabetes.
- Collaborate with groups, organizations, programs, and initiatives already investing time, money, and energy reaching American Indians and Alaska Natives with diabetes-related information. Complement, do not duplicate, their efforts.
- Sustain any program implemented for the long haul (i.e., make a long-term commitment).

Finally, study participants offered suggestions for appropriate communication channels, messages, and materials to consider when designing a national DED education program. Recommendations include dissemination channels and diabetes programs at schools and social gatherings and with products such as workshops, speaker's guides, posters, and a variety of multimedia products.

2. Introduction

2.1 General Background and Audience Profile

American Indians and Alaska Natives are a diverse group represented by 558 federally recognized tribes located in 35 different States (Dixon and Roubideaux 2001). Sixty-five American Indian and Alaska Native communities have not been recognized by the Federal Government but have been assigned tribal status by the States in which they are located. Several dozen communities have not been formally recognized in any fashion (Norton and Manson 1996). Moreover, each tribe has its own unique government system.

The number of American Indians and Alaska Natives is growing, according to the U.S. Census Bureau, which counted 4.3 million people who self-identified as "American Indian and Alaska Native alone or in combination with one or more other races" (U.S. Census Bureau 2003). The Director of the National Center for Health Statistics has reported that American Indian data are undercounted by 38 percent nationwide (Sondik 1999).

According to the U.S. Census Bureau, 22 percent of American Indians and Alaska Natives live on reservation and trust lands. More than half live in urban areas (Kaur 2000). Many American Indian and Alaska Native families live and work from time to time in metropolitan areas but have regular patterns of living on a reservation or in their community of origin (Parker et al. 2002; Burhansstipanov 2000). Factors prompting this sometimes-transient lifestyle include the scarcity of jobs on the reservation or in the rural, isolated community and the need to obtain services, particularly health care services, not otherwise available on the reservation or in the community (Parker et al. 2002; Burhansstipanov 2000).

The following key facts characterize the American Indian and Alaska Native population:

- The estimated median age is 24.2, compared to 32.9 for the general U.S. population and 34.4 for U.S. whites (Rhoades 1996).
- Only 9.3 percent are age 65 or older, compared to 12.4 percent for all races (U.S. Census Bureau 2001).
- Thirty-two percent live below the poverty level, compared with 13 percent for all races (IHS 1997).

- The birth rate is 74 percent greater than that of the U.S. white population (IHS 1997).
- Life expectancy at birth is 71 years, compared with 76 years for U.S. whites (IHS 1997).

American Indians and Alaska Natives have had a unique relationship with the Federal Government, one result of which was the establishment of the Indian Health Service (IHS) in 1954 (Rhoades 1996). The IHS, comprising 12 administrative units called area offices, is further divided into 150 service units, 84 of which are operated and managed by tribes. Included in the 12 area offices are 37 hospitals, 61 health centers, 4 school health centers, and 48 health stations (IHS 1997).

According to IHS, 60 percent of American Indians and Alaska Natives use services provided by the federally funded IHS; in other words, 40 percent of these populations are *not* being served by IHS (IHS 1997).

One of the most significant changes in the Indian health system has been the passage of the Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638). This act made it possible for tribes to operate their *own* health care services through tribal compacting and contracting (Roubideaux 2002). These "638 contracts" may be for planning, conducting, and administering programs that are provided by the Federal Government for the benefit of Indians (Dixon and Roubideaux 2001). To date, 279 tribes, including all tribes in Alaska, are providing their own health care rather than receiving it through IHS (IHS 2002). Tribes have entered into a compact or contract with the Federal Government for their portion of the health care money that would have been retained at the IHS level. These mechanisms allow tribes to assume control over services previously provided by the Federal Government (through IHS) and give tribes great flexibility in the use of Government funds (IHS 1997).

2.2 Diabetes

2.2.1 Definition

Diabetes, also called "diabetes mellitus," is a disorder of carbohydrate metabolism, usually occurring in genetically predisposed individuals. This disorder is characterized by inadequate production or use of insulin resulting in excessive amounts of glucose in the blood and urine, excessive thirst, weight loss, and in some cases progressive destruction of small blood vessels leading to such complications as infections and gangrene of the limbs or blindness (NIDDK 2003a).

Approximately 17 million people in the United States (6.2 percent of the population) have diabetes. An estimated 11.1 million have been diagnosed, but 5.9 million people (or one-third) are unaware that they have the disease (ADA 2003).

2.2.2 Diabetes and American Indians and Alaska Natives

Diabetes is common among American Indians and Alaska Natives and has increased substantially over the years.

Information from the IHS national outpatient database shows that between 1990 and 1997 the number of American Indians and Alaska Natives of all ages diagnosed with diabetes increased from 43,262 to 64,474 individuals. Prevalence of diagnosed diabetes increased by 29 percent. The increase in prevalence between 1990 and 1997 ranged from 16 percent in the Northern Plains region to 76 percent in the Alaska region (Burrows et al. 2000). Other researchers have also reported diabetes rates between 40 and 50 percent in some American Indian and Alaska Native communities (Lee et al. 1995; Will et al. 1997).

About 15 percent of American Indians and Alaska Natives who receive care from IHS have been diagnosed with diabetes, translating into a total of approximately 105,000 people (NIDDK 2003b).

The age-adjusted prevalence of diabetes among American Indians and Alaska Natives is almost three times that of U.S. non-Hispanic whites (CDC 1998).

Although diabetes was rarely reported among American Indians and Alaska Natives 50 years ago, it is now a major cause of morbidity (Burrows et al. 2000). Compared with all U.S. races, American Indians and Alaska Natives have higher rates of diabetes-related complications such as blindness, kidney disease, amputations, and heart disease (Parker et al. 2002; Moy and Bartman 1995).

IHS recognized the growing problem of diabetes in American Indian and Alaska Native communities in the 1970s. Subsequently, IHS implemented programs and policies to provide comprehensive services for individuals with diabetes within its system of health programs and facilities. The Indian Health Care Improvement Act of 1976 (P.L. 94-437) included specific language to create expanded health care services for diabetes. Congress established the IHS Diabetes Program in 1979 to address the growing problem of diabetes in American Indians and Alaska Natives.

In the mid-1990s, many providers in the Indian health care system expressed concern about the future of the IHS Diabetes Program as IHS continued to reorganize and downsize. The program and its services were clearly needed, but resources were declining and positions were being eliminated. The Balanced Budget Act of 1997 provided a much-needed injection of funding for new programs for the treatment and prevention of diabetes in Indian Country. The specific language of the legislation provided $30 million to IHS each year for the next 5 years ($150 million total) to establish grants for new prevention and treatment services in IHS, tribal, and urban health programs. An additional $3 million was added to the IHS budget through the U.S. Department of the Interior appropriation for diabetes grants. This was the first time since 1979 that a significant new appropriation of funds for diabetes was added to the IHS budget. It soon became clear, however, that $30 million a year was only a “drop in the bucket” in terms of the amount of resources needed to address the problem of diabetes in the Indian health system (Dixon and Roubideaux 2001). Under this legislation, the Tribal Leaders Diabetes Committee (TLDC) was formed and determined the formula for distributing funds for diabetes programs throughout Indian Country (TLDC 2001). In 2002, the Department of Health and Human Services (DHHS) announced an additional $100 million in grants to support this program (DHHS 2002).

2.3 Diabetic Eye Disease

Diabetic eye disease (DED) refers to a group of eye problems that people with diabetes may face as a complication of their diabetes (NEI 2003). All can cause severe vision loss or even blindness. DED may include the following:

- *Diabetic retinopathy (damage to the blood vessels in the retina).* Diabetic retinopathy is a leading cause of blindness in American adults. In some people with diabetic retinopathy, retinal blood vessels may swell and leak fluid. In other people, abnormal new blood vessels grow on the surface of the retina. These changes may result in vision loss or blindness. Diabetic retinopathy can be treated with laser surgery in which a strong light beam is aimed onto the retina to shrink the abnormal vessels. Laser surgery has been proven to reduce the risk of severe vision loss from diabetic retinopathy by 95 percent. However, laser surgery often cannot restore vision that has already been lost.

- *Cataract (clouding of the eye's lens).* Studies have shown that people with diabetes are twice as likely as those who do not have diabetes to develop a cataract. Also, cataracts develop at an earlier age in people with diabetes. Cataracts can usually be treated by surgery.

- *Glaucoma (increase in fluid pressure inside the eye that leads to optic nerve damage and loss of vision).* A person with diabetes is nearly twice as likely as other adults to develop glaucoma. The longer a person has had diabetes, the greater the risk of getting glaucoma. Glaucoma may be treated with medications, laser surgery, or other forms of surgery.

People with diabetes should have a dilated eye exam at least once a year. Although DED cannot be prevented totally, the risk for DED can be greatly reduced. The Diabetes Control and Complications Trial (DCCT) showed that better control of blood sugar level slows the onset and progression of retinopathy caused by diabetes and lessens the need for laser surgery for severe retinopathy (DCCT 1993). Because DED often presents no symptoms, finding DED early through annual dilated eye exams and treating it is the best way to control this disease.

Despite the lack of published statistics on American Indians and Alaska Natives and diabetic eye disease, prevalence rates of diabetic retinopathy (one of several DED complications) among Indian diabetic populations are available. Studies have reported the prevalence of diabetic retinopathy among Sioux Indians (South Dakota) with diabetes as 45 percent; 24 percent among Comanches, Kiowas, Seminoles, and Creeks (Oklahoma) with diabetes; between 24 and 49 percent among Cheyenne-Arapaho Indians (Oklahoma) with diabetes; and 18 percent among Pima Indians (Arizona) with diabetes (Berinstein et al. 1997). [1]

[1] Sioux Indians represents the federally recognized name of the tribe; however, their preference is that the tribe be referred to as Lakota.

2.4 The National Eye Institute

As one of the Federal Government's National Institutes of Health (NIH), the National Eye Institute (NEI) conducts and supports research that helps prevent and treat eye diseases and other disorders of vision.

The NEI's National Eye Health Education Program (NEHEP) began in 1989 with a congressional directive to the Institute to increase its commitment to the prevention of blindness through education programs and the encouragement of regular eye exams. Although the NEI already was involved in education and materials development, the formalized education program constituted a new role for the Institute—and at the time was only the third national education program among the Institutes at NIH. The NEHEP focuses on glaucoma and diabetic eye disease, two conditions that often have no early warning signs, and low vision. The program's science-based message urged people to get regular dilated eye exams so that these diseases may be detected before vision loss occurs and to seek out vision rehabilitation when appropriate.

With the rising rates of diabetes and its accompanying complications among American Indians and Alaska Natives, the NEHEP has embarked for the first time on an outreach effort focused specifically on reaching these populations with DED messages.

2.5 Purpose of Research

The purpose of conducting the formative qualitative research presented in this report was to capture the knowledge and awareness among American Indians and Alaska Natives of diabetic eye disease and to collect information on their current approaches for managing DED. The findings from this research will inform the NEI on ways to create an effective and appropriate communication plan for a national DED education program designed specifically for American Indians and Alaska Natives.

The objectives of this formative research with American Indians and Alaska Natives were to learn about and measure current awareness and understanding of the following:

- Diabetes management and what it means for the primary audience
- The importance of eye health care
- Frequency of exams, especially related to the diagnosis of diabetes
- Benefits of early detection of eye disease
- Barriers to receiving or accessing eye health care
- Motivators for behavior change
- Communication channels.

3. Methodology

3.1 Strengths and Limitations of Qualitative Research

Inherent to qualitative research, such as focus groups and key informant interviews, are methodological strengths as well as limitations. Qualitative research is especially powerful in providing detailed insights into a target audience's perceptions and motivations. It can capture the complexities of the thinking and behavior of a target audience far better than a quantitative survey. In focus groups, group interaction and dynamics can help elicit in-depth thought and discussion as well as brainstorming, because participants can build off one another's ideas. Key informant interviews allow interviewers to assess body language and to have participants' undivided attention (NCI 2002).

However, qualitative research can be both labor- and time-intensive. Furthermore, in focus groups, group responses do not necessarily reflect individual participants' opinions because some people may dominate the group discussion or influence others' opinions. During key informant interviews, participants may not be as forthcoming about some issues, since they do not have the anonymity they would have in a blind survey. Finally, it should be remembered that qualitative research is not intended to be representative of a larger audience; in other words, findings are not generalizable to the population but only provide insight into a small group's thoughts, feelings, and behaviors (NCI 2002).

3.2 Background: The NEHEP Work Group

On June 28, 2002, the National Eye Institute's (NEI's) National Eye Health Education Program (NEHEP) held a work group meeting in Bethesda, Maryland, with representatives from American Indian and Alaska Native communities. Traveling from different regions and tribes in the United States, participants represented national organizations as well as the NEHEP Partners. The NEHEP invited tribal leadership, members of the Tribal Leaders Diabetes Committee (TLDC), health care providers, health educators, and communicators currently working in Indian Country.

At this meeting, the NEHEP work group discussed the need for a diabetic eye disease education program specifically targeted to American Indians and Alaska Natives with diabetes. Work group members provided ideas for appropriate and effective messages to disseminate. They also identified key contacts in Indian Country who could serve as intermediaries between program staff and target populations.

Formative research with American Indians and Alaska Natives was conducted to gain a better understanding of the knowledge, awareness, and approaches related to diabetic eye disease (DED) among these populations and their communities. From the findings of this research, the work group thought it would be in a better position to develop a communication plan for a DED education program.

The work group established the DED education program's primary target audience as ***American Indians and Alaska Natives already diagnosed with diabetes***. The secondary audiences included ***people who are in a position to influence or support the health practices of individuals at risk***, such as tribal leaders and providers, family members, health professionals, and community health representatives.

The NEHEP work group members agreed to the conduction of formative research in the form of focus group sessions and one-on-one key informant interviews. Members collaborated to identify sites and hosts in each of the five sites proposed to assist with the logistics planning for the focus groups and interviews.

3.3 Description of Focus Groups and Key Informant Interviews

3.3.1 Focus Groups

In fall 2002 and winter 2003, the NEHEP team conducted a total of eight focus groups with American Indians and Alaska Natives with diabetes (70 total participants [35 women and 35 men]) in four locations: (1) Fort Totten, North Dakota; (2) Village of Dillingham, Alaska; (3) Atmore, Alabama; and (4) Seattle, Washington. The NEHEP team held two groups at each location—one with younger individuals (age 20 to 39 years in North Dakota; age 30 to 49 in the other three locations) and one with older individuals (age 40 and older in North Dakota; age 50 and older in the other three locations). (*Note*: When recruiting participants in North Dakota, the NEHEP team learned it was difficult to find a density of American Indians and Alaska Natives in their 20s with diabetes. Therefore, the age recruitment criteria for the younger group were changed from age 20-39 to age 30-49, and the criteria for the older group were changed from age 30-49 to age 50 and older. In addition, only key informant interviews were conducted in Denver, the fifth site selected for data collection, because the visit was at a conference rather than at a specific American Indian or Alaska Native tribe or community health center. Table 1 (in Chapter 3: Methodology) presents a summary of the location and composition of the focus groups.

3.3.2 Key Informant Interviews

At the same time, the NEHEP team conducted a total of 58 one-on-one interviews with key informants representing five sites: (1) Fort Totten, North Dakota; (2) Village of Dillingham and Anchorage, Alaska; (3) Atmore, Alabama; (4) Seattle, Washington; and (5) Denver, Colorado (Diabetes Prevention in American Indian Communities Conference). The team sought interviews with tribal council leaders, health care administrators and professionals, community health representatives, and other community influencers. Table 2 (in Chapter 3: Methodology) presents a summary of the location and composition of the interviews.

3.4 Site Selection Criteria

To conduct the formative research, the NEHEP research team sought feedback from a sample representation of tribes across Indian Country—those with broad geographic locations, including urban and rural settings, as well as self-governance health services systems and Indian Health

Service systems. Given this context, the NEHEP team collected data from the following five locations:

- Fort Totten, North Dakota (Spirit Lake Dakotah Nation)
- Village of Dillingham and Anchorage, Alaska (Yu'pik Eskimos, Athabascan Indians, and Aleut Natives)
- Atmore, Alabama (Poarch Creek Nation)
- Seattle, Washington (Seattle Indian Health Board, urban Indian location)
- Denver, Colorado (Diabetes Prevention in American Indian Communities Conference—representatives of Navajo, Ojibwe, Chippewa-Cree, and Gila River [Pima and Maricopas] Nations).

See appendix A for a map depicting the locations of the data collection sites.

North Dakota served as the location for testing the data collection tools. Following this visit, the NEHEP team modified the research tools according to the feedback received.

During the scheduling of focus groups and interviews, the NEHEP team developed a research protocol for communities' institutional review boards to review. Sites were guaranteed a report on their individual community as well as a compilation report summarizing the findings from all visits.

3.5 Data Collection Tools

3.5.1 Recruitment Screener

A Recruitment Screener was developed to select focus group participants for certain criteria. For example, the instrument was used to screen for two focus groups at each site (except in Colorado) with 10 participants each. Family members were excluded from participating in the same group. The "younger" group screened for American Indian and Alaska Native adults age 30 to 49 with diabetes. The "older" group screened for American Indian and Alaska Native adults age 50 or older with diabetes. Individuals were excluded from participating if they work, or had worked (or a member of their family works or had worked) at the NEI; at any State or local government agency responsible for eye care; or in the eye care industry. They were also not invited if they had participated in a focus group or other research study during the past year, had worked for an advertising agency or the media, or were running for public office.

3.5.2 Focus Group Moderator's Guide

The Focus Group Moderator's Guide was developed to capture an informal profile of each study site's health status, general management of diabetes, familiarity with and frequency of eye

exams, awareness of vision problems associated with diabetes, and ideas for ways to reach American Indians and Alaska Natives with health promotion messages.

3.5.3 Key Informant Interview Guide

The Key Informant Interview Guide was designed to probe for information about interviewees' community or tribe as it pertained to the community's health, diabetes-related resources, and available channels of communication. Questions in the guide also requested interviewees' ideas for messages that might resonate with American Indians and Alaska Natives.

See appendices B, C, and D for the Recruitment Screener, the Focus Group Moderator's Guide, and the Key Informant Interview Guide, respectively.

Table 1
Summary of Focus Groups

Data Collection Site	Spirit Lake, North Dakota	Village of Dillingham and Anchorage, Alaska	Atmore, Alabama	Seattle, Washington	Total
Date of Data Collection	October 20–22, 2002	November 18–21, 2002	February 3–4, 2003	February 26–27, 2003	
Community Represented in the Focus Groups	American Indians, Spirit Lake Reservation, Dakotah Nation, Fort Totten	Alaska Natives in the Village of Dillingham (Yu'pik Eskimos, Athabascan Indians, Aleut) (Focus groups were *not* conducted in Anchorage.)	American Indians, Poarch Creek Nation	American Indians, Seattle Indian Health Board (SIHB) health center	
"Younger" Focus Groups	n=5 (3 women, 2 men) age 20-39*	n=4 (2 women, 2 men) age 30-49	n=4 (4 women, 0 men) age 30-49 (includes one 9-year-old girl represented by her caretaker)	n=13 (6 women, 7 men) age 30-49	n=26 (15 women, 11 men)
"Older" Focus Groups	n=13 (6 women, 7 men) age 40+*	n=7 (4 women, 3 men) age 50+	n=10 (5 women, 5 men) age 50+	n=14 (5 women, 9 men) age 50+	n=44 (20 women, 24 men)

*When recruiting participants in North Dakota, the NEHEP team learned that it was difficult to find a density of American Indians and Alaska Natives with diabetes in their 20s. Therefore, the age recruitment criteria for younger groups were changed from age 20-39 to age 30-49 in subsequent groups, and the criteria were changed from age 30-49 to 50 and older for subsequent older groups.

Table 2
Summary of Key Informant Interviews

Data Collection Site	Spirit Lake, North Dakota	Village of Dillingham and Anchorage, Alaska	Atmore, Alabama	Seattle, Washington	Denver, Colorado**	Total
Key Informant Interviews	n=8	n=17	n=9	n=7	n=17	N=58
Interviewee Characteristics	Indian Health Service staff: two community health representatives, a diabetes educator, a pediatric nurse, a Head Start program staff person, a director of tribal health, a podiatrist, and a community educator	Alaska Native Medical Center and Southcentral Foundation staff in Anchorage and Kanakanak Hospital in Dillingham: two physicians, two optometrists, two ophthalmologists, two nurses, a clinical diabetes consultant, four community health aides, three diabetes outreach coordinators, and an executive director	Poarch Creek Indian Health Department staff: a physician, nurse practitioner, community health nurse, human services representative, nutritionist, senior services director, clinic director, community health representative, and a diabetes educator	Seattle Indian Health Board: the executive director, three community health nurses, a referral clerk, a nutritionist/diabetes coordinator, and a mental health therapist	Diabetes Prevention in American Indian Communities Conference participants: five health educators, four diabetes program managers, two physicians, a physical therapist, and an optometrist [Navajo, Ojibwe, Chippewa-Cree Tribe, Gila River Indian Community (Pima and Maricopas) Nations]. After the conference: a representative each from IHS, ADA, CDC-New Mexico office, and NIDDK; some of the interviewees are technical work group members of the TLDC.	

**Only key informant interviews were conducted in Denver, Colorado, because the research was conducted at a conference rather than at a specific tribe or community health center.

4. DETAILED FINDINGS FROM FOCUS GROUPS

4.1 General Overview and Health Profile of Communities

North Dakota

The National Eye Health Education Program (NEHEP) team conducted focus groups with residents of the Spirit Lake Reservation in Fort Totten, North Dakota, on October 20-22, 2002.

The Spirit Lake Dakotah Tribe—formerly the Devil's Lake Sioux Tribe—is a band of the Sisseton-Wahpeton Sioux.[2] Located near Fort Totten in northeastern North Dakota, the tribe's reservation was established in 1897 between the Devil's Lake Basin and the Cheyenne River. The tribe originated in what is now Minnesota but was displaced when settlers discovered gold there in 1862.[3]

As of the 2000 Census Report, there are 4,435 people living on the Spirit Lake Reservation and about 75 percent are American Indian. The number of American Indians living on the reservation has increased in the last few years, while the number of non-American Indians has decreased. In April 1999, the unemployment rate was 59.9 percent. The Spirit Lake Nation's economy relies heavily on the leasing of land to outside sources. The tribal and Federal governments are the tribe's biggest employers.[4] Patients with diabetic eye disease (DED) are referred to eye clinics located in Devil's Lake (15 miles away) or Grand Forks (100 miles away). Focus group participants reported their need to travel to Devil's Lake for medications and health care specialists not available on the reservation.

Focus group participants referred to the Indian Health Service (IHS) clinic as the "primary point of service for everyone." Focus group participants easily named the two staff members in the clinic's diabetes program by their first names, demonstrating their familiarity with the clinic and program.

Alaska

The NEHEP team conducted focus groups with Alaskan residents of the Village of Dillingham on November 19, 2002. The NEHEP team collected information mostly from Yu'pik Eskimos, Athabascan Indians, and Aleut Natives.

Alaska is a geographically large State, encompassing about 586,112 square miles, about two-thirds the size of the United States east of the Mississippi River. The indigenous population of Alaska numbered 103,688 in 1998 (Schraer et al. 2001). Alaska is home to 237 tribes,

[2] Sisseton-Wahpeton Sioux represents the federally recognized name of the tribe; however, their preference is that the tribe be referred to as Dakotah.
[3] FEMA.gov. Region VII: Spirit Lake Tribe of North Dakota. www.fema.gov/regions/viii/tribal/spiritlakebg.shtm. Accessed on May 7, 2003.
[4] United States Census. 2002. http://www.ndsu.nodak.edu/sdc/data/demographics/profileDP1/reservations/spiritlake.pdf. Accessed on May 8, 2003.

constituting approximately 40 percent of the 558 federally recognized tribes. The largest grouping of Alaska Natives is Eskimo, followed by American Indian (e.g., Tlingit-Haida, Alaska Athabascan) and Aleut (Dixon and Roubideaux 2001).

By the time Alaska became the 49th State of the United States in 1959, the U.S. Government was aware of the social, cultural, and economic failures of the reservation system. Thus, a new system was created for Alaska Natives, including the creation of 12 Alaska Native corporations rather than reservations (Burhansstipanov 2000).

The Alaska Native Medical Center (ANMC), a large primary and tertiary center in Anchorage, provides health care services for the entire State of Alaska including the Anchorage service area and 57 outlying villages. Together with ANMC, the Southcentral Foundation provides comprehensive health services, from prevention and family health to medical travel and community health aide training.

A study among Native residents of southwestern Alaska in 1987 showed that during a 25-year period the prevalence of diabetes in people older than age 40 increased from 1.7 percent to 4.7 percent among Yu'pik Eskimos and from 1.8 percent to 10.0 percent among Athabascan Indians (Murphy et al. 1992). Data from the Statewide Alaska Native Tribal Diabetes Registry show an 80-percent or higher increase in diabetes prevalence among Alaska Natives from 1985 through 1999, with the highest increase observed among Eskimos (compared to other ethnic groups). According to State registry research, this increase can be attributed to changes in diet and lifestyle, with less physical activity and more high-calorie, store-bought food as the main culprits (Murphy et al. 1992).

Data from the Alaska Native diabetes registry for 1998 indicated that 1,666 Alaska Native residents have diabetes. The prevalence varied widely by region and ethnic group, from 12.8 per 1,000 in the Yukon-Kuskokwim (primarily Yu'pik Eskimo) to 76.4 per 1,000 on Annette Island in southeastern Alaska (Tsimshian) (Schraer et al. 2001). Nearly half of Alaska Natives with diabetes live in villages that have no direct access to physician-staffed health care facilities. Most of these patients are served primarily in village clinics staffed by community health aides and have access to larger facilities only by small aircraft (Schraer et al. 2001).

Alaska has a mix of village governments, tribal governments, village corporations, regional Native profit-making and non-profit-making corporations. In general, it is the regional Native non-profit corporations that provide health care to Alaska Native people (Dixon and Roubideaux 2001).

Alabama

The NEHEP team conducted focus groups with residents of Poarch Creek Nation in Atmore, Alabama, on February 3-4, 2003.

The Poarch Creek Indian Health Department has received Federal grants from the IHS and the 1997 Balanced Budget Act Special Diabetes Program for Indians. This legislation provided $150 million for diabetes funding for American Indians and Alaska Natives (TLDC 2001).

Recently, Poarch Creek also received a food and nutrition grant from the U.S. Department of Agriculture.

The Poarch Band of Creek Indians is a segment of the original Creek Nation that avoided removal and has lived together for more than 150 years. Today, there are approximately 2,200 members of the Poarch Band of Creek Indians; more than 1,500 live in the vicinity of Poarch, Alabama (8 miles northwest of Atmore, Alabama, in rural Escambia County, and 57 miles east of Mobile, Alabama). Officially recognized in 1985, Poarch Creek is the only federally recognized tribe in the State of Alabama.

Washington

The NEHEP team conducted focus groups with American Indian residents of Seattle, Washington, on February 26-27, 2003.

More than 150 tribes reside in the Seattle metropolitan area. The Seattle Indian Health Board (SIHB), a multiservice community health center, has served Puget Sound, Washington, since 1970. SIHB programs are State-licensed and nationally accredited by the Joint Commission on the Accreditation of Healthcare Organizations. According to one interviewee in Washington, "SIHB is the largest urban Indian clinic according to employee numbers and budget."

SIHB provides direct-care services on a sliding-fee basis and accepts many public and private insurance plans. SIHB receives additional funding from public and private sources including Federal, State, and local government agencies. The clinic is a federally qualified health center for Medicaid and Medicare services.

Although SIHB is not an IHS facility, it contracts with IHS under Title V of the Indian Health Care Improvement Act (P.L. 94-437). The IHS Urban Indian Health Program supports contracts and grants for 34 urban health programs funded by Title V. SIHB provides services ranging from school-based and homeless outreach to adult outpatient treatment for chemical dependency.

SIHB serves patients primarily from King County but also from five counties surrounding the Seattle metropolitan area. During the summer, many transient patients from Alaska, Montana, and North Dakota also visit SIHB. Although SIHB serves all populations (about 5,000 patients a year), two-thirds are of American Indian and Alaska Native descent.

Focus group participants in Washington, especially in the younger group, shared that many people they know go to the SIHB health center for most of their health care needs. Participants cited a broad array of services, the Native staff, and the availability of appointments as reasons for SIHB's appeal.

4.2 Main Health Issues Affecting Communities

In all groups, participants mentioned diabetes as one of the leading health problems affecting their community. Alcoholism, substance abuse, accidents (due to alcoholism), and poor sanitation were also mentioned as top concerns. Among some participants, especially in

Alabama, diabetes was the number one concern; however, generally it was not as much of a concern as alcoholism. A number of participants also mentioned obesity or poor eating habits as an important health concern. Older participants were more likely than their younger counterparts to also list cancer, heart disease, and high blood pressure.

- "Diabetes comes in at number three or number four in the community." (North Dakota, age 40+)
- "Cancer, diabetes, and heart attack. That is my three." (Alabama, age 50+)
- "I'll bet you one of [the top health problems] is liquor.…Everybody that I grew up with, particularly the men, all became alcoholics." (Washington, age 50+)
- "Along with alcohol, I think eating habits…a lot of things that are related to the illnesses come from… the food that we eat." (Washington, age 50+)
- "Diabetes doesn't have that major concern. It is like a slow working disease, so it is not really presented to the public." (Washington, age 30 to 49)

4.3 Perceptions of Personal Health and Health Care Habits

Although not all participants were asked to describe their health status, the portrait that developed across the focus groups was one of a fairly ill population. Especially in the older groups, participants were suffering from a multitude of health problems, including vision problems, heart disease, cancer, and substance abuse.

- "I feel like I'm falling apart." (Alabama, age 30 to 49)
- "[My health status is] good and bad. Once I gave up booze and lost my teeth, now my eyes are going bad, [so] I want to go back to booze." (North Dakota, age 40+)
- "Well, my health started failing me a couple or three years ago, but I have had high blood pressure and I treated it I guess for 20-something years." (Alabama, age 50+)

In general, most participants seemed to be regularly accessing medical care, but a few younger participants indicated they were not getting regular care. Many participants admitted that before being diagnosed with diabetes they were not seeking regular health checkups, rather going only when they were acutely ill; this often led to a delayed diagnosis of diabetes.

- "[I go to the doctor] only when I have problems." (North Dakota, age 20 to 39)

4.4 Diabetes-related Health of Communities

4.4.1 Knowledge of Diabetes and DED

Overall, the focus group participants had a high level of knowledge about diabetes but a more limited awareness and understanding of diabetic eye disease. Knowledge of diabetes risks and symptoms tended to be stronger among the older participants. Some of this knowledge came through their own experiences.

- "[Diabetes is] when the pancreas quits shooting out the regular insulin." (Alaska, age 50+)
- "[Diabetes comes from] eating rich food, fatty foods, salt, ice cream." (Alaska, age 50+)
- "I thought diabetes was for elders [before I was diagnosed]." (Alabama, age 30 to 49)

A few participants had heard of DED specifically, and many were aware of the connection between diabetes and eye disease. However, some were not aware of such a connection. Older participants tended to be more aware of the risk of eye disease among people with diabetes, perhaps because more of them suffer from vision problems. A few participants began to understand the connection between diabetes and their eye problems as the discussion continued in the groups.

- "I can't understand how diabetes affects the eyes." (Alaska, age 50+)
- "When my sugar level goes down, my right eye gets spots." (Alaska, age 50+)
- "I didn't know what glaucoma was. I have heard about it, but I never realized what it was." (Washington, age 50+)
- "Everything just gets blurred and swimmy. So I don't know if that is the diabetes or blood pressure problems." (Alabama, age 50+)

4.4.2 Diagnosis of Diabetes

Many participants indicated that they were not diagnosed with diabetes until they were already suffering from symptoms. A few reported that they discovered that they had diabetes while they were seeking care for other health problems. A number also confessed that they avoided being diagnosed even though they were suffering from symptoms that they knew could be diabetes.

- "I had real blurred vision, and that is when I came to see the doctor the next day.…They told me I was a diabetic." (Washington, age 50+)
- "I had diabetes since I was probably 24. We didn't go to the doctor that much, and I [had] spells and got sick before I was diagnosed. It affected me because I had one leg amputated. The quicker you find out about it, the better off." (Alabama, age 50+)

- "I was always thirsty, wanting to drink all the time. [My wife's] father was a diabetic, and [my wife] was the one that told me, 'you need to go get checked for diabetes.' " (Alabama, 50+)

- "Because of all this sickness that I was having [related to cancer], I was never diagnosed with diabetes, I mean I was never told.…Then a specialist over here…he checked and went back on my chart and…said, 'You have been a diabetic since '94.' " (Alabama, age 50+)

- "I am one for not wanting to know if I had it or not because I already suspect it myself that I had it since 2000." (Washington, age 50+)

4.4.3 General Management of Diabetes

Most participants claimed that they managed their diabetes primarily by modifying their diets and/or exercising. Many also indicated that they took medication.

- "I watch my diet and stay away from sweets." (North Dakota, age 20 to 39)

- "I went through my kitchen when I found out I was diabetic, and I started getting rid of some stuff that I didn't need, like a lot of cornbread and biscuits and that kind of stuff." (Alabama, age 50+)

- "I try to keep the diet and everything, I know it has to be done . . . the thing is to start doing those things that you are supposed to be doing and they always have to be practiced daily and put into real life. It is the only thing that is going to get you healthier and make you live longer." (Washington, age 30 to 49)

- "[I am] on the meds too…they put an extra one on me about eight months ago. It is a pink pill. I don't even know what that is for." (Washington, age 30 to 49)

Younger participants were slightly more likely than older participants to also mention trying to get more exercise.

- "I stay active." (North Dakota, age 20 to 39)

- "Since [accepting my diagnosis] I have lost a lot of weight, and I am exercising." (Washington, age 50+)

- "Exercise, you know, is a big thing...but that has to be practiced, too...you have to put that in your daily living." (Washington, age 30 to 49)

But there were a number of participants who admitted that they did not always properly manage their diabetes.

- "I'm supposed to have regular checkups, but I get frustrated. I think I'm doing good but it's not helping." (North Dakota, age 20 to 39)

- "I have always liked to exercise and try to do things for my health. But I have been a drug addict and an alcoholic, and that makes you sway from a lot of the things that you should be doing in your life." (Washington, age 30 to 49)

- "I think we all cheat a bit. I do." (Alabama, age 50+)

Many participants stated that the involvement of their families, significant others, and friends was critical to helping them manage their diabetes. In a couple of sites, younger participants were less likely to have the social support that older participants had. Several participants across all groups mentioned that they had family members with diabetes who provided information and support. Women appear to be especially important in supporting diabetes care, and some mentioned that they are concerned for their family now that they themselves have diabetes.

- "It's just me and my husband. A couple of times I've looked funny with wrong sugar levels, and he'll ask if he needs to check my blood sugar level. He is scared to death of it and is learning." (Alabama, age 30 to 49)

- "If it weren't for my team approach with my office workers, I don't know what I would have done. They help remind me to check my blood sugar and when to eat." (Alabama, age 30 to 49)

- "Sometimes I don't have the courage to [check my sugar levels] so I had to teach my kids to do it." (North Dakota, age 20 to 39)

- "It is like I am the go-getter of my whole family and taking care of everybody all the time. And why me? Who is going to take care of them when I am gone?" (Washington, age 50+)

Some participants, especially those in Washington, mentioned the importance of being proactive and self-reliant regarding their diabetes management, particularly when family members live in different geographic areas.

- "I have to stop and take the information, use what I can, if it is going to help me be better. But the whole thing is taking responsibility of your own life." (Washington, age 50+)

- "Diabetes is our illness. It is not the doctor's, it is not the nurse's, it is not the receptionist's. We have to take the responsibility to learn as much as we can about it, if we want to be healthier." (Washington, age 50+)

4.4.4 Eye Exams

While most participants were aware of the general importance of getting a yearly eye exam and knew the type of doctor to visit for such exams, it varied by location whether most participants

had had an eye exam in the past year. Participants in North Dakota were far less likely to have had a recent eye exam than participants in the other locations. Almost every participant in Alaska claimed that they attended at least yearly eye exams.

- "When it concerns my teeth and my eyes, I'm pretty good about it." (Alaska, age 30 to 49)

- "I didn't even know that [you were supposed to get regular eye exams]." (Washington, age 50+)

Across groups there was a mix of understanding as to why people with diabetes should seek regular eye exams. Many were told about the connection between diabetes and eye disease when they were diagnosed. However, some indicated that they discovered the connection between diabetes and eye disease by chance. No matter how long they have known about the connection, it seems some participants did not clearly understand how diabetes could affect their vision and why they should get regular eye exams.

- "For me, a hospital staff person that I know knew about diabetes. When she overheard me talk about my vision problems, she told me to get checked." (Alaska, age 30 to 49)

- "I can't understand how diabetes affects the eyes." (Alaska, age 50+)

- "I'd like more information about it because I don't understand when it happens, if retinopathy does happen, I don't understand what the medical people can do to improve my situation. I don't understand what it is, do you start seeing blood or what?" (Alaska, age 30 to 49)

- "No doctor ever told me that [people with diabetes may have serious problems with their eyes]." (Alaska, age 50+)

- "When I was diagnosed…[my doctor] told me, all he said to me is, 'There is no sugar in your eyes.' What does that mean?" (Alabama, age 50+)

It appeared that participants who received timely referrals and reminders from their doctors or clinic staff were more likely to be getting regular exams. Not having a relationship with one particular specialist may be a deterrent. Several younger participants mentioned that they appreciated seeing the same health professional at each visit.

- "[I] just go when I get a notice from the clinic." (North Dakota, age 20 to 39)

- "The first year I got an exam through here, and the following year I got another one, and [the doctor] called me back in six months… he just wanted me to have regular eye exams." (Washington, age 50+)

- "I try to see the same doctor consistently." (Alaska, age 30 to 49)

4.4.5 Use of Traditional Health Practices

Very few participants mentioned using traditional medicines as part of their diabetes management. Those who did indicated that traditional practices did not play a large role in their diabetes treatment, but rather were used to treat general symptoms of not feeling well. Older participants mentioned traditional practices more often than younger ones. Based on the interviews with local health providers and diabetes program staff, participants may have been somewhat reluctant to discuss their use of traditional practices.

- "As far as herbs go, I have taken some.…In my culture, you have to believe what you are taking is going to help you. You take it to your heart and mind." (Washington, age 50+)

- "I think that is the same way we should do it for our cultural herbs and medication that we use. It is in the person's mind and culture." (Washington, age 50+)

- "I think that what a lot of us lost is our spirituality, because Indians have always been spiritual type people. If you will get hold of your spirituality and listen to your body, it will tell you when something is wrong and when something is right." (Alabama, age 50+)

4.4.6 Barriers to Proper Diabetes Management

Most participants mentioned the psychological barriers to proper diabetes treatment. These participants were especially likely to mention denial and fear being barriers to early treatment: denial of their symptoms and the need to seek treatment, and fear of a diagnosis of diabetes. Many participants noted that they had seen someone they know die of diabetes; this fact sometimes worked as a barrier to early diagnosis and treatment (the fear of it) and sometimes as a motivator.

- "I said, 'It is not going to happen to me. It is not going to be me.' But yeah, it came down to me. It is me now." (Alabama, age 50+)

- "Denial is the thing, and a lot of people will stay in denial because they don't want to realize they have it." (Alabama, age 50+)

- "I wouldn't tell the truth to my family." (Alabama, age 50+)

- "I am more afraid of the diabetes than when I was diagnosed with cancer. Diabetes scares me to death." (Alabama, age 50+)

- "I have seen people die from [diabetes] that were close to me….I saw mom go through it for 45 years. She kept a good diet and everything. But still, she lost her eyes and her toes no matter how much she dieted." (Washington, age 30 to 49)

Once they accepted their diagnosis, some participants said they still have trouble treating it properly because it can be "overwhelming" and symptoms can be easy to ignore.

- "[My reason for not managing my diabetes] is just downright laziness. I forget, too. I don't know, I am like, I will do it later.…You think if you lose all this weight and get [yourself] into condition, maybe it will go away. It doesn't go away. It is still there." (Washington, age 30 to 49)

- "I am supposed to take six pills and two shots…but I don't.…You just don't continue it, and you can't verbalize why.…All this stuff that happens to you because of one simple diabetes is just so overwhelming.…It is denial, it is fear, it is depression, it is laziness, it is not knowing, it is all kinds of things." (Washington, age 30 to 49)

- "Diabetes is such a silent thing that it is doing damage and you don't know it." (Alabama, age 50+)

Across all groups some participants mentioned cost—of proper food, eyeglasses, complete health coverage, and travel—as an issue affecting their ability to manage their diabetes properly.

- "Here we are so spread out, and it is hard for people to get to a clinic even here." (Washington, age 50+)

- "It costs too much money to fly to Anchorage [for specialty care]." (Alaska, age 50+)

- "Devil's Lake [Hospital] is inconvenient—if you don't have insurance you can't get medical care." (North Dakota, age 40+)

4.4.7 Sources of Diabetes-related Health Information

Local clinics and hospitals are the primary sources for diabetes information for these focus group participants. Only a few participants mentioned other sources, including "outside" specialists, *Diabetes Forecast* (the health and wellness magazine of the American Diabetes Association), and other publications from bookstores or libraries. Although not stated explicitly, it was apparent that some patients got information from friends and family with diabetes.

Many participants stressed the importance of their personal relationship with local health staff in managing their diabetes. Many relied on staff members to notify them of their appointments and educate them about their disease.

- "I appreciate having Lois (diabetes program coordinator in the Village of Dillingham) here and available because she makes things consistent for me because when I see a physician, I never see the same person. Lois is the only continuity I have." (Alaska, age 50+)

- "I always like to gather the information from Dawn (a diabetes educator). She always has little pamphlets for me to read when I come to the clinic." (Washington, age 30 to 49)

Perhaps because of the reliance on personal communication for information, many older participants (especially in Washington) felt that they were getting incomplete information.

- "I was getting information, but not the whole thing. See, I didn't get the whole thing from the doctor nor did the nurse handle my situation like it should have been." (Washington, age 50+)

- "We have to ask questions, because a lot of times they [doctors and nurses] get busy." (Washington, age 50+)

- "I mean, they discuss everything with us, but they don't have time to take each thing, I guess." (Alabama, age 50+)

4.5 Effective Methods of Outreach to People at Risk for DED

Across all groups interpersonal outreach was mentioned as the most effective method of reaching people at risk for DED. Workshops, one-on-one counseling, support groups, social gatherings, and appointment reminders were mentioned as being particularly effective for the participants.

- "A support group or something, have times that you could come in and talk about what is going on, have somebody there to answer some questions." (Alabama, age 50+)

- "[Use] health aides in villages." (Alaska, age 50+)

- "People listen to health care [staff]." (North Dakota, age 40+)

- "I wish they had more diabetes meetings like this, like talking circles where we can come, have them more often where we can sit and talk like this about diabetes and what it does to us and our children." (Washington, age 30 to 49)

Many participants also suggested using local radio, television, and videos as effective ways to disseminate information.

- "Radio is the best way, TV." (Alaska, age 30 to 49)

- "The video idea or something [is] the easiest way for the person to receive it, that is obvious. This gentleman doesn't like to read…there's all kind of literature available, but sitting down and reading, if you have something that is a visual, it is another [way of getting information]." (Washington, age 50+)

Social gatherings—powwows, church events, bingo nights, etc.—were also mentioned as places that people could pick up information or hear a speaker. They also suggested using local speakers and leaders to talk to young people as a method of prevention.

- "I think the ideas about putting out information are very good, like in public places and places we go to, powwows and social events, and dinners and things like that." (Washington, age 50+)

- "Have kids pass out information at powwows." (North Dakota, age 40+)

- "I would just love to…listen to somebody that has experienced it, to tell me what happened and how they took care of it." (Alabama, age 50+)

- "I think we should start teaching our children at a young age about this disease." (Washington, age 30 to 49)

4.6 Potential Types of Messages

When asked what people with diabetes need to know to prevent DED, most participants suggested general diabetes prevention and treatment messages. Participants across all groups felt that an educational program on DED needed to include an explanation of the symptoms of diabetes, the need for regular treatment, and the consequences of not treating diabetes—which include DED.

- "People have to learn to change eating habits." (North Dakota, age 20 to 39)

- "Number one [message] would be to monitor your blood sugar and get an eye exam." (Alaska, age 30 to 55)

- "I think the basic thing [to tell people to motivate them to get their eyes checked] would be [about] potential blindness." (Alabama, age 50+)

- "Why can't we have a booklet that would cover major aspects of what to look for in diabetes?" (Alabama, age 50+)

Some participants also felt that messages should encourage a sense of hope and self-reliance.

- "To me, also, the thing that really helped me as a diabetic was finding out not all the bad things that can happen, but how you can arrest that process. Just what losing a little bit of weight does for you. What having a little bit of exercise does for you. What getting a vision check once a year does for you versus just letting it go." (Washington, age 50+)

- "Tell me this can happen, this can go wrong, and what I am supposed to be looking for. Then give me the support to be able to take care of myself and to understand." (Washington, age 30 to 49)
- "[A message should say] don't live in denial, and take responsibility for your disease." (Washington, age 50+)

Many participants across all groups felt it was important to provide prevention messages to children.

- "Do interventions with kids and educate them." (North Dakota, age 40+)

- "Younger ones don't see how important their eyes are when they are diabetic." (Washington, age 30 to 49)

4.6.1 Tone of Messages

Participants suggested the tone of any message should be simple and straightforward. It should include a sense of hope but should be blatant in describing what can happen when diabetes goes untreated. A few participants also mentioned that a message should incorporate the traditional spirituality with which many American Indians view their health.

- "They should break it down…where they will understand, simple language like you were saying." (Washington, age 30 to 49)

- "You know how that smoking commercial is that in-your-face information?…Where they just blatantly right out…tell you how it is, give you statistics and so forth?…If [diabetes-related diseases were] presented at a statistical level, people would wake up." (Washington, age 30 to 49)

- "Show the worst side of it. Not just if someone loses their leg." (Alabama, age 50+)

- "I think to present the serious side of diabetes would have been way, way more important to me than the cute little coating, 'Well you are going to get it [if you keep eating that way].' " (Washington, age 30 to 49)

- "If we were taught on that [spiritual] level, like listen to your body, listen to what you are hearing when something goes wrong in your body [it could be effective]." (Alabama, age 50+)

5. Detailed Findings From Interviews

5.1 General Overview and Services Profile

North Dakota

The National Eye Health Education Program (NEHEP) team conducted interviews with representatives of the Spirit Lake Reservation in Fort Totten, North Dakota, on October 20-22, 2002.

From the interviews in North Dakota, the NEHEP team learned that although the Indian Health Service clinic sponsors a diabetes program, patients with diabetic eye disease (DED) are referred to eye clinics located in Devil's Lake (15 miles away) or Grand Forks (100 miles away). Interviewees also mentioned that a mobile van, coordinated by the Early Childhood Tracking Program, visits the school (grades K through 12) on the Spirit Lake Reservation to provide vision screening. According to the interviewees in North Dakota, the population on Spirit Lake Reservation is young.

During the interviews in North Dakota, the NEHEP team learned that about 30 Indian Health Service (IHS) staff members are available at the reservation's clinic and pharmacy, including two full-time doctors, a nurse practitioner, a dentist, and a psychiatrist. An ophthalmologist visits the reservation once a month. The general sense is that services are convenient and efforts have been made to minimize barriers, such as providing transportation assistance.

Alaska

The NEHEP team conducted interviews with representatives of both the Village of Dillingham and Anchorage on November 18-21, 2002.

The Alaska Native Medical Center (ANMC) has received Federal grants from IHS and the 1997 Balanced Budget Act Special Diabetes Program for Indians. This funding has enabled ANMC to manage a dedicated diabetes program and provide community health support for diabetes in each village or tribe in Alaska. This Federal-level effort also supports the Community Health Aide Program that enables rural villages to link basic health care needs with physician-staffed resources in Anchorage. As one Anchorage interviewee commented:

- "Without funding, there would not be a program. It would be back to 1997 where ANMC only goes to eight sites doing a consultation with primary care interventions. Now we are doing more consultation work and educating providers. We do one or two in-services a year on prescriptions, cardiovascular risk factors for providers, and we do a lot in the field."

In the Village of Dillingham, 375 employees work at Kanakanak Hospital. Referrals are made to the ANMC in Anchorage, as necessary. Kanakanak Hospital (Bristol Bay Area Health Corporation) covers 34 village clinics, spanning 44,000 square miles.

The NEHEP team collected information mostly about Yu'pik Eskimos, Athabascan Indians, and Aleut Natives. Interviewees in the Village of Dillingham remarked on the characteristics that distinguish their communities from others:

- "I have lived in three villages, and Yu'pik people are more traditional. Their language, lifestyle, subsistence, berry picking, and arts and crafts are more traditional. The Athabascans and Aleuts are more Westernized. There is no Aleut language, less handicrafts. There is better fishing now and more exposure to many non-Natives."

Alabama

The NEHEP team conducted interviews with representatives of Poarch Creek Nation in Atmore, Alabama, on February 3-4, 2003.

Interviewees said the Poarch Creek tribe is facing the problem of sustainability with decreasing interest among its younger population, as evidenced by a recent low election turnout. In addition, the tribe's sense of a unique culture is limited because of the absence of a still-spoken tribal language or traditions and an overlap between perceived tribal culture and religious practices:

- "English is the primary language. There is a resurgence of some wanting to use the [tribal] language—a small number. There is more an issue of people not able to read or write."

- "Most of the tribe is active in churches [Episcopalian, Pentecostal, Baptist, and Catholic]. Some of the charismatic religious practices overlap with what may be perceived as cultural. For example, some women do not cut their hair or only wear dresses which are prescribed by their church and not the tribe."

The tribe has been able to maintain a fairly cohesive spirit over time despite the aforementioned realities. Interviewees commented on the following attributes that distinguish Poarch Creek Nation from other tribes:

- "There are strong grassroots and energy and commitment of the people."

- "Poarch Creek is not liberal with blood quantum. Here you have to have one-quarter or greater."

The Poarch Creek health clinic in Alabama has been operating as a self-compacted system for 14 years; in other words, its management is independent of IHS. The clinic provides a wide range of services spanning from immunizations to dental care to five counties in Alabama and Florida:

- "A lot of people don't live on tribal land. The tribal land is not contiguous, as one-third might live in one area and another two-thirds in another area. Whether people use the health services or not, they all use the nutrition and pharmacy services."

Currently, the Poarch Creek clinic employs a physician, a nurse practitioner, two nurses, a licensed practical nurse (with a vacancy for another), a pharmacist, a dentist with two dental assistants, and a lab technician. Other professionals, including a psychologist, endocrinologist, nephrologist, and podiatrist, are employed on a contract basis; they provide services once a month or are scheduled when needed.

Although health care providers at the Poarch Creek clinic have years of experience in health care, they have only served at the clinic for 1 to 2 years, with one staff member working intermittently for 6 years. During the NEHEP team visit, the clinic welcomed its newly assigned dentist as well. The clinic relies on health care providers assigned from the Public Health Service Corps. One interviewee mentioned that with the constant change in staff, patients are vulnerable to mixed messages depending on the style and background of the current health care provider serving at the clinic.

Washington

The NEHEP team conducted interviews with representatives of the Seattle Indian Health Board (SIHB) on February 26-27, 2003.

The SIHB employs four doctors, six residents in the family residency program for Indian health, four nurse practitioners, four physician assistants, two mental health professionals, and two dentists, many of whom have been at SIHB for at least 10 years.

As noted, although SIHB serves all populations (about 5,000 patients a year), two-thirds are of American Indian and Alaska Native descent. Several interviewees' comments indicated area residents are attracted to the SIHB health center because the clinic is sensitive to the diversity of cultures.

- "The clinic is physically located next to Chinatown in Seattle and though there is a clinic located within Chinatown, the people come here because they think we are nice."

- "It is an open-door policy here regardless of what tribe you are from. Anyone can come, and the clinic is flexible."

Colorado Conference

The NEHEP team interviewed participants of the Diabetes Prevention in American Indian Communities Conference held in Denver on December 10-13, 2002. Focus groups were not conducted at this site.

The Diabetes Prevention in American Indian Communities Conference: Turning Hope Into Reality was held at the Adams Mark Hotel in Denver. More than 800 people attended. The

conference was hosted by the Tribal Leaders Diabetes Committee and supported by the National Institute of Diabetes and Digestive and Kidney Diseases, the IHS Diabetes Program, the American Diabetes Association (ADA), the Association of American Indian Physicians, University of Oklahoma, and Nike, Inc. The conference provided an opportunity for workshops, poster and exhibit sessions, plenary sessions, and a powwow.

Interviewees representing national organizations (e.g., IHS, ADA, Centers for Disease Control and Prevention [CDC]) that have worked in Indian Country for 11 to 23 years, providing strategic planning, training and technical assistance, clinical services, and public health prevention education, related their respective national-level diabetes programs. These national-level representatives described both the assets within Indian communities, such as family and community orientations, and their challenges, including a high incidence of poverty.

Health care staff from several health centers in Colorado were also interviewed. Health centers of the Navajo, Mille Lacs Band of Ojibwe, and Rocky Boy Reservations provide screenings, physical therapy, and prenatal care, among other services. Staffs at these health centers remain small, and only one health care professional specializing in diabetes works at each clinic.

Rocky Boy and Gila River Indian Community Reservations manage their own tribal health care services. [5]

Health educators from the Navajo Nation serve as liaisons between the community and health providers. Not only do they conduct home visits in their own language, health educators also are involved in walking clubs, exercise programs with schoolchildren, traditional medicine, food demonstrations, and health screenings for blood pressure, blood glucose, cholesterol, and body mass index. Health educators provide an invaluable service as they travel long distances on unpaved roads to visit families lacking telephones, running water, and electricity.

5.2 Main Health Issues Affecting Communities

As with the focus group participants, the participants in the key informant interviews indicated that diabetes is an important health issue—if not the number one health issue—facing American Indians and Alaska Natives. Other health care concerns mentioned by many of the interviewees were cardiovascular disease, cancer, obesity, depression, substance abuse, and accidents related to substance abuse. Most interviewees were aware that diabetes is more prevalent among American Indians and Alaska Natives than many other races.

- "Nine out of ten elders have diabetes." (Alabama)
- "Seventy to 75 percent of my patients at the clinic are diabetic. Half of all adults over age 30 have diabetes. We have the highest rate of diabetes in the world." (Colorado conference)

[5] The Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638) made it possible for tribes to operate their own health care services through tribal compacting and contracting (Roubideaux 2002).

- "Diabetes ranks as one of the top health problems in Indian Country. Other problems include heart disease, cancer, high blood pressure, and accidents and injuries. In Indian Country diabetes is near the top. In the southwest diabetes is at the top." (Colorado conference)

- "Alaska Natives have the lowest prevalence in Indian Country (3 percent), but have the highest increasing prevalence (sic) in Indian Country. We are on the tidal wave of diabetes. There is a lot of obesity, and diabetes is right behind. We are 20 years behind where they are [in the rest of the United States] now, but if we don't do something now, we will be developing dialysis centers." (Alaska)

A couple of participants mentioned that, in general, a major health problem for these patients is lack of easily accessible specialty care.

- "The lack of specialty care [is a big problem]. We are managing a lot of disease that is complex and should be handled at a higher level [of service at a large hospital]." (Washington)

5.3 Perceptions of Health Care Habits

Several themes emerged from the interviews related to the health care habits of American Indians and Alaska Natives. Many described the traditional, holistic philosophy their patients have toward their health. Some interviewees also described a resistance to seeing health professionals unless patients have acute symptoms, which results in delayed diagnoses for many people with diabetes. Finally, almost all interviewees described the numerous and significant barriers preventing American Indians and Alaska Natives from obtaining adequate health care.

Across most geographical locations, interviewees described similar traditional attitudes toward health. In general, health is seen as a relationship among mind, body, spirit, and environment. This means that for many American Indians and Alaska Natives, illness must be treated spiritually and emotionally, as well as physically. However, in Alabama, interviewees indicated that there was little evidence (or at least discussion) of traditional medicine practices among the Poarch Creek Indians.

- "The integration of the spiritual, mental, emotional, and physical health is an inherent trait among Indian people." (Colorado conference)

- "It is important to remember that traditional medicine is practiced differently than Western medicine. Traditional medicine takes in to account the concepts of balance of mind, body, and spirit." (Colorado conference)

Some interviewees also mentioned that their patients are reluctant to seek Western medical care unless they have an acute symptom, and even then they may put off seeking care because they do not want to find out they are ill.

- "Indian people have a tendency to think they are healthy if they are not ill. If their function is not affected, they are OK." (Colorado conference)

Many of the interviewees described the barriers that prevent American Indians and Alaska Natives from obtaining the level of health care they need. The primary barriers are cost and lack of transportation. However, perhaps just as significant are the prevailing attitudes toward health—the lack of a prevention mindset and a fear of finding out one is ill. These may be especially important in hindering early detection of diabetes.

- "[Use of health care services] is based on coverage. They won't pay out of pocket." (Washington)

- "There is a fatalistic attitude, and a lot simply do not care. There is no essence of prevention." (Alabama)

5.4 Interviewees' Knowledge of DED

While diabetes knowledge was very high among almost all the participants in the interviews, knowledge (and even awareness) of DED was mixed. In some locations, few of the non-health professional participants had heard of DED and were only slightly knowledgeable of other eye complications (retinopathy, glaucoma, etc.) related to diabetes. A number of interviewees reported that they did not see many people suffering from eye diseases, but many health professionals reported seeing a lot of eye disease related to diabetes. In all locations (with the exception of Anchorage), providing regular eye care was difficult. Most interviewees reported having limited access to optometrists (who also provide dilated eye exams) and having to refer patients to off-site clinics to see ophthalmologists.

- "I am a diabetes educator. I understand the basics of diabetic eye disease, the use of laser treatments, the risks of blindness, etc." (Colorado conference)

- "I am a physician, so I know some about diabetic eye disease. American Indians have a much higher rate of complications—of which eye disease is one of the complications. Diabetic retinopathy is very common….I would say that it is two or three times more common among American Indians and Alaska Natives." (Colorado conference)

- "Most tribal health facilities have access to trained optometrists who have expanded their scope of practice to complete dilated eye exams." (Colorado conference)

- "…Overall, the IHS or tribal programs pay through contract health funding for ophthalmologist or specialized eye care." (Colorado conference)

5.5 Perceptions of Patients' Knowledge, Attitudes, and Practices Related to Diabetes

5.5.1 Diagnosis of Diabetes

Almost all interviewees felt that diabetes was a significant health problem facing their American Indian and Alaska Native patients. Many reported that the prevalence of diabetes is growing among these populations, but that too often cases are being detected relatively late. These participants discussed the attitudinal and infrastructure barriers that prevent patients from receiving an early diagnosis of diabetes. As discussed earlier, these barriers are primarily a lack of a prevention mindset and cost. Echoing the focus group participants, many interviewees mentioned that their patients are being diagnosed "by accident" when they come to a doctor for a specific symptom or when they visit for a routine check-up or screening.

- "They often visit the doctor for other reasons, and they find out they have diabetes through a routine health exam….Others find out because they have symptoms or they have family members that have diabetes." (Colorado conference)

5.5.2 Management of Diabetes and DED

Once diagnosed, most participants felt that accessing a clinic for routine diabetes care was relatively convenient for patients. However, they pointed out that there were still many barriers to American Indians and Alaska Natives receiving adequate treatment for diabetes. These barriers included cost issues related to coverage for health care services—often exams are covered but follow-up visits are not. Transportation issues related to costs and accessibility for elders are also problems. Participants also felt an inability to generate personal empowerment deterred patients from seeking routine care.

- "Funding is terrible. There is a wait list for [prescriptions]." (Washington)
- "Elders with no family support cannot use the bus." (Washington)
- "Need to have one-stop-shopping concepts versus five appointments." (Colorado conference)
- "The biggest issues are transportation, lack of resources, and lack of coordination of appointments." (Colorado conference)
- "Some are in denial after they are diagnosed. Some seek care and some don't—it varies. Most are sad and upset." (Colorado conference)
- "The main problem is getting people to take initiative with care." (Alaska)
- "People don't understand why they need to see a doctor or what is really happening to them." (Alaska)

- "If we tell someone they need a test that would cost five cents, they would not get the test. Their attitude is if it's not important to Poarch Creek to pay for me, then I don't care." (Alabama)

A few interview participants suggested that a lack of adequate communication between providers and patients served as a barrier to proper diabetes care for some patients. The providers sometimes have trouble getting accurate information from the patients. And a few interviewees pointed out that because of the high turnover of health staff in many clinics, patients sometimes get mixed messages about treatment from providers depending on the style and background of the current health care provider serving in the clinic.

- "We have to struggle to get details [during a patient exam]. Providers really have to probe, and it gets frustrating [because the patient] does not provide any response or a response that is 'I don't know.' " (Alabama)

- "We have to explain to them what diabetes is and why it is so important that they take care of it. But it is hard to explain certain things to them because we do not have Navajo words for them." (Colorado conference)

A few interviewees indicated that one barrier to appropriate eye care among patients may be their confusion over the difference between seeing an optometrist regularly for eye glasses and getting a regular dilated eye exam to diagnose eye diseases.

- "Most seek care to get glasses. There is a major disconnect between getting eyeglasses versus getting a dilated eye exam. People do not understand the difference and the need for dilated eye exams." (Colorado conference)

5.5.3 Involving Families

Interviewees noted that family involvement in the management of diabetes varies. Some patients rely on a good deal of family support. It was noted that often the wife of a male patient plays a significant role in his care. Also, some patients have a family history of diabetes and get support and information from those family members with diabetes. However, interviewees also mentioned that some people with diabetes hide their disease from family members because they feel ashamed or fear being stigmatized. And some patients do not live near family and, therefore, do not get the support they might need.

- "Kids bring parents to the doctors. That's what I see." (Washington)

- "If a male is diagnosed, the woman helps more. If a woman is diagnosed, she does more on her own." (Alabama)

- "In the elderly, yes, we see family involvement if they have family close by. Some don't have family ties close by. Some have no support." (Washington)

- "Some families are uncomfortable with diabetes. For some having diabetes is a stigma. Many do not want their family members to know… because they feel they have not done the right things, and they may feel ashamed for their family to know." (Colorado conference)

5.5.4 Using Traditional Medicine

Across all locations, most interviewees knew of American Indians and Alaska Natives who used traditional medicines. However, fewer were aware of these medicines being used to specifically treat diabetes. A number of interviewees pointed out that, when traditional medicines such as herbs, sweats, or stomp dances are used, they are more for the management of general illness or stress than for the treatment of a specific disease such as diabetes. One site, the Seattle Indian Health Board, employs a traditional counselor to help patients access traditional medicine if they are interested. A number of participants felt that it was important to be able to support patients who wanted to combine traditional and Western medicines to provide an integrated approach to treatment. A few interviewees pointed out that since diabetes is not a traditional disease, it does not have a traditional solution.

- "Traditional medicine is used to help them cope with the stress of illness. Traditional medicine is used more to take care of the coping versus the management of diabetes." (Colorado conference)

- "There is an emotional side to the disease and at least [traditional medicine] brings comfort. We have a traditional counselor, and he works with healing and uses healthful language." (Colorado conference)

- "If they use [traditional medicines for diabetes], they don't share it [with health professionals]." (Alabama)

5.5.5 Sources of Diabetes-related Health Information

All the key informants indicated that American Indian and Alaska Native patients primarily received their diabetes information directly from their health care providers—doctors, nurses, diabetes counselors, and health educators—at local clinics and hospitals. Participants also described support groups, peer-to-peer education, and health fairs as common methods of disseminating information. The amount of diabetes education materials available to patients varied across sites. Some interviewees noted that they had little information on eye diseases, and several noted that there was a need for culturally appropriate materials. Diabetes education materials come from a variety of sources including the ADA, CDC, IHS, National Institutes of Health (NIH), and universities.

- "[Patients get information] from the IHS or tribal health clinics, providers, community health representatives, health fairs, etc. Sources include booklets, videos, posters, magazines, the ADA Web site, the NIH-Diabetes Institute, the NDEP [National Diabetes Education Program]." (Colorado conference)

- "We are overwhelmed with materials. We create our own with our grant money. We also have support groups, but people don't show up." (Alabama)

- "People have access to basic information. Dissemination is possible, but we need more culturally-appropriate basic information." (Colorado conference)

5.6 Effective Methods of Outreach to People at Risk for DED

The key informants had a lot of suggestions for ways to reach people with diabetes with eye health messages. Almost all participants suggested that one-on-one communication is the most effective for this audience; many noted that using peers or local tribal leaders with diabetes as educators would be especially effective. Many participants also suggested using social gatherings such as powwows, health fairs, church events, and bingo halls as venues for diabetes education. A few also suggested diabetes workshops. Several forms of mass media were also suggested, although their effectiveness may vary from site to site. Some participants suggested local newspapers as a good channel, while others pointed out that many American Indians and Alaska Natives do not like to or cannot read. Others suggested local television or radio outlets; however, in larger markets there may not be a channel that primarily reaches this target audience. A number of participants also suggested reaching out to children who could then provide information to their parents. Most participants felt that videos that could be aired in a variety of settings (at home, in doctor's offices, etc.) would be useful. Newsletters and direct mailings (with simple language and large typefaces) were also recommended. A few participants suggested that the most effective way to reach American Indians and Alaska Natives with diabetes is to use a comprehensive approach to education.

- "[Communication] needs to be personal or you will get a poor response." (Washington)

- "Conduct workshops with a diabetes specialist to answer questions and invite the families to attend." (North Dakota)

- "Use personal stories such as [those] in 'Health for Native Life.' " (Colorado conference)

- "Going through kids to get to parents [is effective]." (Alabama)

- "Posters and other visuals work effectively in Alaska." (Alaska)

- "Everyone likes videos. I did a survey with the health aides and video was the number one choice for working with patients." (Alaska)

- "I would recommend that a comprehensive approach be utilized. For example, start with the health care provider instruction to the patient…reinforce the provider's message with a diabetes team approach… and provide general education in communities about what constitutes good diabetes care." (Colorado conference)

5.7 Potential Types of Messages

Overall, the interview participants felt that there were three aspects to developing an effective DED education message. First, the message should explain in plain language the causes, consequences, and treatments associated with DED and, specifically, *why* they should get a regular eye exam. Second, the message needs to encourage self-reliance and empowerment. And third, the message needs to be straightforward, simple, positive, and culturally sensitive.

Interviewees reported that their patients' most commonly asked questions related to the basics of the causes, risks, and treatments related to diabetes, and they suggested that patients do not understand the relationship between diabetes and eye disease. Several interviewees felt that patients need to know why they should get routine eye exams and that getting an exam for eyeglasses is not the same as a dilated eye exam. Several participants also suggested that a message needs to provide coping skills and help patients feel a sense of empowerment to control the complications of their disease. Almost all interviewees stressed the importance of providing simple, positive, and culturally appropriate messages. These participants did not think that "scare tactics" would be effective. A few participants stated that they had not yet found the message that would captivate and effectively communicate diabetes complications to this population.

- "They need to understand the concepts of prevention of complications. They need to know why they are being told to have their eyes checked and to get an eye exam." (Colorado conference)

- "I don't know if a lot of our patients understand the relation between diabetes and eyes." (Alabama).

- "The most important thing is that patients have to understand the purpose of getting an eye exam. It is not enough to just tell them to get an eye exam. The messages should be conveyed as a positive message. [Conveying] the idea that it is possible to save and preserve their vision is important." (Colorado conference)

- "We really like to give the Native population tools for being self-reliant. The Native population has low self-esteem. Giving them tools to build their self-esteem gives them personal control and incentive." (Washington)

- "[An effective message] used an elder with a younger person for the visuals. It is important to always use ties to tradition." (Alaska)

- "Use local people, someone people trust. Native stuff works better here. [Use anatomical graphics] for Alaskans! Make it Yu'pik!" (Alaska)

- "Messages need to be positive. Don't use scare tactics." (Colorado conference)

- "We haven't found the hot buttons yet [for reaching this audience]." (Alabama)

A few examples of messages that participants thought would be effective included:

- "If your vision is getting blurry, get to a doctor in a hurry." (Alaska)
- "Eat your traditional foods, do traditional activities. Pick berries." (Alaska)
- "To save your vision, we need to get your eye exam." (Colorado conference)
- "Vision for a lifetime." (Colorado conference)

5.8 Program Development Issues

Most interviewees stressed that the National Eye Institute (NEI) should develop a DED program that can be effectively integrated into existing diabetes education programs. The two most important characteristics required of such a program are *flexibility* and *sustainabilit*y. Almost all interviewees felt that a DED education program was needed for American Indians and Alaska Natives (although participants in Alaska were less enthusiastic than in other locations). But many participants were concerned that a program would not be effective if it could not be easily integrated into current efforts, and a few suggested that the NEI should provide a template that could be tailored to local situations. A number of participants also indicated that they would want assurance that the program would be supported by the NEI over the long term.

- "You need to work with existing diabetes education (IHS) programs. It needs to be integrated with the existing efforts. There isn't dedicated information on the eyes." (Washington)

- "Be sensitive of limited resources." (Alabama)

- "Approach through the diabetic team. Don't just go through the diabetes contact." (Alabama)

- "NEI needs to work with community participants to help design, implement, and evaluate with the community. Don't bring an already designed program, [rather] work with the community to develop and tailor. Provide a template." (Colorado conference)

- "How is NEI planning to sustain the program? They need to make a commitment for a prolonged period. If it's just doing a short-term campaign, don't do it. We still have bits and pieces of other programs that we are still trying to sustain and incorporate." (Washington)

- "We have turned down programs that were short term. If the government can't maintain or sustain, or if there is a Robert Wood Johnson grant that could follow up, then maybe. …If the NEI wants to do a media campaign, what happens next? Will there be something to follow the campaign?…NEI needs to be in partnership with existing private/non-profit groups with leadership to create sustainability." (Washington)

- "Don't do it. There are better ways to spend the money." (Alaska)

6. DISCUSSION

6.1 Recurring Themes From Findings

Each site the National Eye Health Education Program (NEHEP) team visited to collect data for this formative qualitative research study has its own unique size, geographic location, language, and culture. The following themes, however, have application across all data collection sites.

6.1.1 Knowledge of Diabetes and DED

American Indians and Alaska Natives understand diabetes as seen through the experiences of elders in the community who have faced a life with the same disease. However, they have only a basic level of knowledge regarding the full implications of this disease. Most focus group participants in this study, in particular the younger ones, did *not* understand the connection between diabetes and eye-related problems (a longer-term consequence). The often incomplete messages patients receive from multiple health care providers add to their confusion. Very few focus group participants were aware of the term "diabetic eye disease (DED)." Although all interviewees were familiar with the relationship between diabetes and eye problems (diabetic retinopathy in particular), they had mixed levels of familiarity with the term "DED."

6.1.2 Diagnosis and Management of Diabetes

American Indians and Alaska Natives tend to be diagnosed with diabetes at later stages of the disease. American Indians and Alaska Natives in this study repeatedly remarked that their diabetes was discovered "by accident." As American Indians and Alaska Natives are inclined to seek medical care only when they are experiencing problems, the window of opportunity for prevention education is often lost. A prevention mindset, such as getting regular wellness checkups, is limited. Many American Indians and Alaska Natives do not consider themselves sick unless they are experiencing pain. When they are diagnosed with diabetes, consequently, most are in disbelief that they can have a disease while feeling well at the moment.

Social support from professional and personal networks is critical to the consistent and proper management of diabetes. Coworkers and significant others, particularly family members, play a key role in positively influencing a person's knowledge, attitudes, and behaviors related to diabetes and its management. Involving *children* in education and outreach efforts is essential as they are the youngest generation who will have to address this disease and its accompanying issues. Their engagement is inevitable, actually, given the rising rates of diabetes among young people. Younger individuals with diabetes will have more years of disease burden and a higher probability of developing complications earlier in life (Burrows et al. 2000).

Continuity among visits to a health care provider is a sure way to improve appointment and care compliance. An overwhelming majority of study participants noted the power of a personal connection with an individual health professional in the proper management of diabetes. Understaffing of key personnel (e.g., optometrists, ophthalmologists), high staff turnover rates,

and a shortage of staff that speak the Native language are factors contributing to a current lack of continuity in care.

Women are the primary caretakers of family members with diabetes as well as the main seekers of care and information. Women are seen as invaluable assets to the health of American Indian and Alaska Native families and communities. However, because women are the primary caregivers, when women are the ones with diabetes, there is often a lack of caregiving assistance devoted to them. American Indian and Alaska Native women are more likely than men to be diagnosed with diabetes; this higher prevalence may be due to women seeking health care more frequently than men rather than a result of true differences in risk (Burrows et al. 2000).

6.1.3 Effective Channels and Messages

Interpersonal and personalized communication is the most effective way to reach American Indians and Alaska Natives with DED messages. As limited literacy poses a serious challenge in Indian Country, information presented as a conversation (one-on-one, group discussion, or storytelling), audibly (radio, TV), or visually (video, flipchart, TV) will be received favorably. Written materials should be avoided when possible. When used, written materials should be designed in easy-to-understand language. Celebrities are *not* necessary to appeal to this audience. Rather, soliciting help from local, trusted community members (well-known health care providers or members of the tribe, especially those individuals from the community who have diabetes themselves) will lend the most credibility to any health education program.

Messages developed for a DED education campaign need to include an explanation of the symptoms of diabetes, the need for regular treatment, and the consequences of not treating diabetes—which include DED. Participants suggested that the tone of messages needs to be straightforward, honest (not "sugar-coated"), and hopeful. Messages should also encourage taking action and being self-reliant, and make the connection between proper care and the possibility of living a long, healthy life.

DED messages should be included within a broader integrated health approach. The general philosophy behind many American Indian and Alaska Native traditional health practices is to consider mind, body, and soul as interconnected and not to single out any one disease. Traditional medicine often focuses on underlying causes, conceptualized as spiritual in nature, rather than on the relief of acute symptoms (Buchwald et al. 2000). This may partly explain why the concurrent use of different health options characterizes much of the help-seeking behavior among American Indians and Alaska Natives (Buchwald et al. 2000): A *combination* of traditional and Western medicine seems to have the greatest appeal. Representatives of national organizations interviewed for this study are aware of the need to instill more cultural sensitivity, as well as address diabetes within larger lifestyle issues including diet and physical activity, in their organizations' national-level efforts.

A DED education program, national in scope, should collaborate with groups and activities already in place and should involve the whole health team. Participants expressed concern that a duplication of efforts might delegitimize any new or current program, and they would welcome a complementary approach instead. Interviewees agreed that partnering with the Indian Health

Service (his) Diabetes Program and the Tribal Leaders Diabetes Committee, as well as the American Diabetes Association (ADA) and the Centers for Disease Control and Prevention (among many other national, regional, and local key players), will be fundamental to a comprehensive DED communication plan. Interviewees also underscored their preference for involving the entire health care team at any specific local health facility (compared to focusing solely on diabetes educators, for example). If all members of the health care team (regardless of position level or geographic location) reinforce ADA's "Standards of Medical Care for Patients With Diabetes" (ADA 2003) to their patients, consistent messages would be delivered and confusion would diminish.

6.1.4 Patient vs. Provider Perspectives

Diabetes health professionals are frustrated both with American Indian and Alaska Native patients' long phases of denial and with their own inability to encourage self-empowerment among their patients. It is very common for American Indians and Alaska Natives to "shut down" with denial, anger, and fear after receiving a diabetes diagnosis. As diabetes requires daily attention and care, these populations would benefit from the value of self-reliance and self-management. The findings also showed a "disconnect," at times, between patients feeling proactive about their health (e.g., commitment to a healthy diet and physical activity) and providers sensing apathy and lack of initiative among patients (e.g., a sense that patients expect providers "to do everything").

6.1.5 Infrastructure Issues

An infrastructure is in place for providing health care services to American Indians and Alaska Natives (such as that provided by IHS), yet more could be done to expand diabetes-related services across Indian Country. Health clinics on reservations and Federal Government funding have enabled health professionals to serve American Indians and Alaska Natives. For example, community health aides in Alaska and community health representatives in North Dakota link individuals living in rural villages with clinic or hospital resources. Tribes vary in their dependence on IHS and other funding, and many have taken steps toward increased self-sufficiency (e.g., tribes in Alaska manage their own health care delivery). In most American Indian and Alaska Native communities, diabetes programs are available but limited, especially for eye-related problems. Although many American Indians and Alaska Natives receive annual dilated eye exams, referrals to eye care professionals in health facilities *outside* the tribe are almost always necessary to facilitate this, regardless of tribe characteristics (e.g., urban or rural, large or small, history, language, or culture).

The financial burden of paying for health care services and transportation impedes many American Indians and Alaska Natives from accessing adequate diabetes care, regardless of tribe location or size. Even when available, financial assistance is often incomplete. For example, coverage may include an initial eye care visit but not follow-up appointments or eyeglasses. Although many diverse tribes in Indian Country experience similar barriers to proper diabetes management, tribes in remote areas have the added disadvantage of being isolated—availability of transportation to proper health facilities becomes an even greater challenge for them.

6.1.6 Tailoring Messages

Any health education program, including those on DED, must be individually tailored to a specific audience and be respectful of the audience's community. For example:

- Alaska Natives do not want to be lumped with American Indians residing in the "lower 48."

- Although a major concern, diabetes did not rank as the *leading* health issue in certain geographic areas.

- Although Poarch Creek Nation in Alabama does not have a unique language or history, many of the Poarch Band of Creek Indians are very active in churches (e.g., Episcopalian, Pentecostal, Baptist, Catholic) and rely on the Bible for guidance. Placing health and DED messages in church bulletins would therefore be especially appropriate for this community. Although airing public service announcements on television and radio might be a successful way for reaching community members in some geographic areas, it would *not* be effective in Poarch Creek because there are too many overlapping channels and competing markets in this geographic area (between Mobile, Alabama, and Pensacola, Florida).

- Staff turnover at clinics serving American Indians and Alaska Natives may be affected by the size of the tribe or community. For example, Poarch Creek Nation in Alabama is relatively small, compared to the Seattle Indian Health Board (SIHB) in Washington and the Spirit Lake Reservation in North Dakota. The health clinic at Poarch Creek relies on rotating IHS physicians and health care providers, whereas health professionals in the larger communities (e.g., SIHB) have served longer periods of time (more than 10 years) and tend to be from the community themselves.

- Messages should be locally translated and delivered in the language of the tribe, whether it is Yu'pik or Navajo (especially as there is no equivalent term for "diabetes" in some tribal languages).

- American Indians and Alaska Natives must play a central participatory role in the research and care that affects their health (Roubideaux 2002). It is therefore important that any new diabetes education effort invite the active participation of local community members in its design and implementation.

6.2 Logistics of Methodology: Lessons Learned

6.2.1 Collaborating With American Indian and Alaska Native Communities

Historically, the relationship between researchers and tribes has resulted in numerous conflicts and abuses. The NEHEP team is honored to have been invited to visit a few of these American Indian and Alaska Native communities and to learn from their experiences.

The NEHEP team respects the importance of obtaining permission from American Indian and Alaska Native tribal leaders to conduct research in their tribes. The team learned to factor in ample time for the preparation and review of a protocol package for tribes' institutional review boards.

The National Eye Institute wanted this to be a reciprocal process and is sharing the findings both for each individual site and for all sites combined. Site coordinators at each site have already received their individual community's report and will receive the summary compilation report. The NEHEP team also learned to be sensitive about the timing for scheduling site visits. For example, fall and winter may not be the most appropriate seasons in which to conduct qualitative research of this sort given that tribal elections occur during those months in some years (a time when a community's attention needs to be focused on local politics).

In addition, the NEHEP team learned the importance of working with a liaison to the community to ease the communication and logistical planning for the site. The NEHEP work group members with pre-established relationships with American Indian and Alaska Native communities served the indispensable role of liaison between members of the target audience and the NEHEP team. Relationships with site logistic coordinators and local diabetes education programs that are connected with American Indian and Alaska Native communities were also invaluable to the data collection process: They rendered crucial assistance and guidance in effectively navigating the process. Without these key collaborating partners, this formative research study would not have been possible.

6.2.2 Pretesting

The NEHEP pretested the data collection instruments—Recruitment Screener, Focus Group Moderator's Guide, and Key Informant Interview Guide (presented in appendices B, C, and D, respectively)—as well as the proposed research methodology and its management, at Spirit Lake Reservation, North Dakota.

The NEHEP team gained insights on ways to modify the research tools (e.g., eliminating redundancy in questions, simplifying the language, reducing the length of discussion from an anticipated 2 hours to 60 to 90 minutes, and learning that interviews take about 30 to 40 minutes, depending on the openness of the interviewee). These factors were helpful in scheduling future focus groups and interviews, in addition to managing expectations.

6.2.3 Recruitment Logistics and Management of Focus Groups

A moderator of the same ethnic background as the participants or a local research company helped improve the comfort level and candidness of participants in commenting during the focus group discussion sessions.

During the first focus groups conducted in North Dakota, the NEHEP team found it challenging to recruit American Indians and Alaska Natives in their 20s (specifically for the younger group with participants age 20 to 39), as the incidence of diabetes in American Indians and Alaska Natives under age 30 in any one particular geographic area is relatively low. Therefore,

recruitment criteria for the focus groups was modified to include American Indians and Alaska Natives age 30 to 49 in the "younger" group and those age 50 and older in the "older" group. This recruitment strategy was applied to focus groups conducted in the Village of Dillingham, Alaska, Alabama, and Washington State. (Focus groups were not conducted in Colorado.)

Over-recruitment is customary to ensure adequate participation in focus groups. However, when all invited participants arrived for a focus group, such as for the older group in North Dakota, all participants were included for the sake of cultural consideration. Also, some participants traveled long distances to attend a focus group, so it was only fair to include all recruited participants. The NEHEP team found it could manage discussions among the relatively larger groups as well as they could facilitate the smaller ones.

The NEHEP team tried to avoid recruiting married couples to participate in the same focus group, as wives may follow the traditional gender-role custom of waiting for husbands to speak first. Site logistics coordinators need to keep this in mind when screening for appropriate participants. When separating married couples is not possible, moderators can take the approach of speaking with each spouse separately before the focus group begins to probe for independent comments.

For the focus groups the NEHEP conducted for this particular study, recruiting an equal number of women as men provided for a balance of gender-based perspectives. Of relevance, when recruiting from small, close-knit communities, such as from Poarch Creek Nation in Alabama, recruiting from the same family may be inevitable.

7. COMMUNICATION PLAN: RECOMMENDATIONS

Participants in this study—both from the focus groups and interviews—were in near unanimity in their endorsement of a national diabetic eye disease (DED) education program directed toward American Indians and Alaska Natives. (Alaska was the only site that hesitated in providing full support because of a concern for the possible unnecessary duplication of efforts and competition of scarce funds for multiple community needs). Participants also agreed on the importance of communicating the connection between diabetes and DED, and the need for regular eye exams. All data collection sites for this study ranked diabetes high on their list of primary health issues in need of attention in their communities. They also reported rising numbers of individuals with diabetes in their communities, with an alarming increase in this disease among young people in particular.

The main recommendations offered by study participants for an effective national DED education program are briefly summarized below:

- Communicate clearly the connection between diabetes and eye-related problems.

- Encourage the whole health care team to view health in an integrated manner when addressing diabetes (e.g., diabetes is one of many health concerns influenced by diet and physical activity).
- Promote the value of regular vision exams, even when feeling well, as a method for detecting diabetic eye disease in its early stages (e.g., when treatment is most effective).
- Promote self-reliance and self-management to those already diagnosed with diabetes.
- Involve children in outreach and education activities.
- Target women (e.g., mothers, wives, sisters, aunts, cousins), as they tend to be the family members with the most initiative for seeking health care and information.
- Get creative in strategies and tactics for enticing men to seek proper health care and information.
- Present information in a conversation, group discussion, or storytelling format when possible (written materials will not appeal to American Indians and Alaska Natives with limited literacy skills).
- Custom-tailor DED messages to individual communities.
- Invite the active participation of local community members in the design and implementation of any diabetes-related effort.
- Use testimonials from "ordinary" people in the community who have diabetes.
- Collaborate with groups, organizations, programs, and initiatives already investing time, money, and energy reaching American Indians and Alaska Natives with diabetes-related information. Complement, do not duplicate, their efforts.
- Sustain any program implemented for the long haul (i.e., make a long-term commitment).

7.1 Dissemination Channels

Several basic outlets were referenced as fundamental to consider in a national DED education program:

- "Real" role models (e.g., trusted local spokesperson who has diabetes; do *not* use a celebrity)
- Diabetes programs and individuals already working on these efforts (hiring and training community members)

- Reservation health clinics (engaging the entire health care team)
- Nearest hospital (engaging the entire health care team)
- Schools
- Local radio stations (e.g., PSAs) (not an effective channel in Alabama)
- Television (e.g., PSAs) (not an effective channel in Alabama)
- Short videos
- Small group discussions
- Social gatherings (e.g., powwows, bingo halls, community center activities)
- Word of mouth
- Storytelling
- Mobile van
- Workshops (e.g., question-and-answer sessions)
- Health fairs
- Cooking classes
- Local newspapers
- Tribal newsletters
- Bulletins distributed at houses of worship
- Direct mail (e.g., appointment reminders, letters)
- Posters
- Flipcharts
- Billboards
- Flyers
- Internet

- Speaker's guide with adaptable talking points
- Simple printed materials with many visuals (e.g., easy-to-understand pamphlets) should be used only when necessary. (Note: Aleut and Navajo are not written languages, and there are no terms in these languages for "diabetes.")

7.2 Messages

Again, participants in this study provided their suggestions regarding information and the tone of messages on DED that would resonate *across* Indian Country.

7.2.1 Information to Deliver

- Ways to prevent diabetes and its complications
- Symptoms of diabetes and its complications
- Logic in treating diabetes in a regular manner (e.g., reason behind the importance of annual "well" eye exams)
- Consequences of improper diabetes management (e.g., blindness)
- Tips for self-management
- Rates of diabetes among American Indians and Alaska Natives compared to other populations and why this disease is becoming more common, given its history as a "white man's disease."

7.2.2 Tone

- Hopeful (e.g., prevention of complications is possible; reference to support systems available such as coworkers, classmates, church community, social or civic groups, and family members)
- Encouraging (e.g., of self-reliance)
- Straightforward (to the point)
- Strong (hard-hitting)
- Positive yet realistic
- Truthful (do not "sugar-coat"; emphasize serious consequences of improper diabetes management)
- Simple (avoid bombarding people with too much data)

- Culturally sensitive (i.e., sincere effort to personalize messages to a specific tribe or community [Alaska Natives are not American Indians]; reference to tradition [e.g., berry picking, fishing, healing ceremony]; use Native tribe language)

- Focused on family, especially children and grandchildren

- Fun and humorous when possible.

7.3 Health Education Materials

As a result of this formative research, actual health education materials may be developed to disseminate DED messages to the national program's primary and secondary audiences. These program materials would undergo an extensive design and evaluation process, where cultural appropriateness, sensitivity, and representation would be considered. Materials would be pretested with members of the target audience.

Below is a sampling of potential products that may be produced for the purposes of "getting the word out" about the importance of regular eye exams to American Indians and Alaska Natives:

- PSAs (television, radio)
- Short videos (to be played in health center waiting areas and schools)
- Posters (for health facilities)
- Flipcharts (for health professionals to use with patients)
- Billboards (in primary audiences' communities)
- Flyers (for direct mailings or distributed at social gatherings)
- Talking points or a speaker's guide for workshops or small group meetings.

7.4 Next Steps

Findings from the formative qualitative research reported in this document generated a multitude of issues—some larger in scope than others—with which American Indians and Alaska Natives with diabetes must contend. For example, a lack of comprehensive health insurance coverage and a shortage of funding for diabetes programs were cited as major roadblocks to adequate care for DED. Although important to address, such broad and systemic problems are beyond the scope of a communication plan whose primary purpose is to propose steps for effectively disseminating DED messages that will resonate with these populations. The National Eye Health Education Program (NEHEP) Research Team will be addressing those issues that are within the scope of a communication plan. In this plan, the NEHEP team will outline those health materials (e.g., video, flipchart) that meet the preferences of the target audiences (e.g., many visuals, culturally sensitive), as well as identify appropriate channels or venues (e.g., radio, church, other gatherings). The communication plan will also make a special point to choose communication

materials and channels that uniquely suit particular American Indian and Alaska Native communities.

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APPENDICES

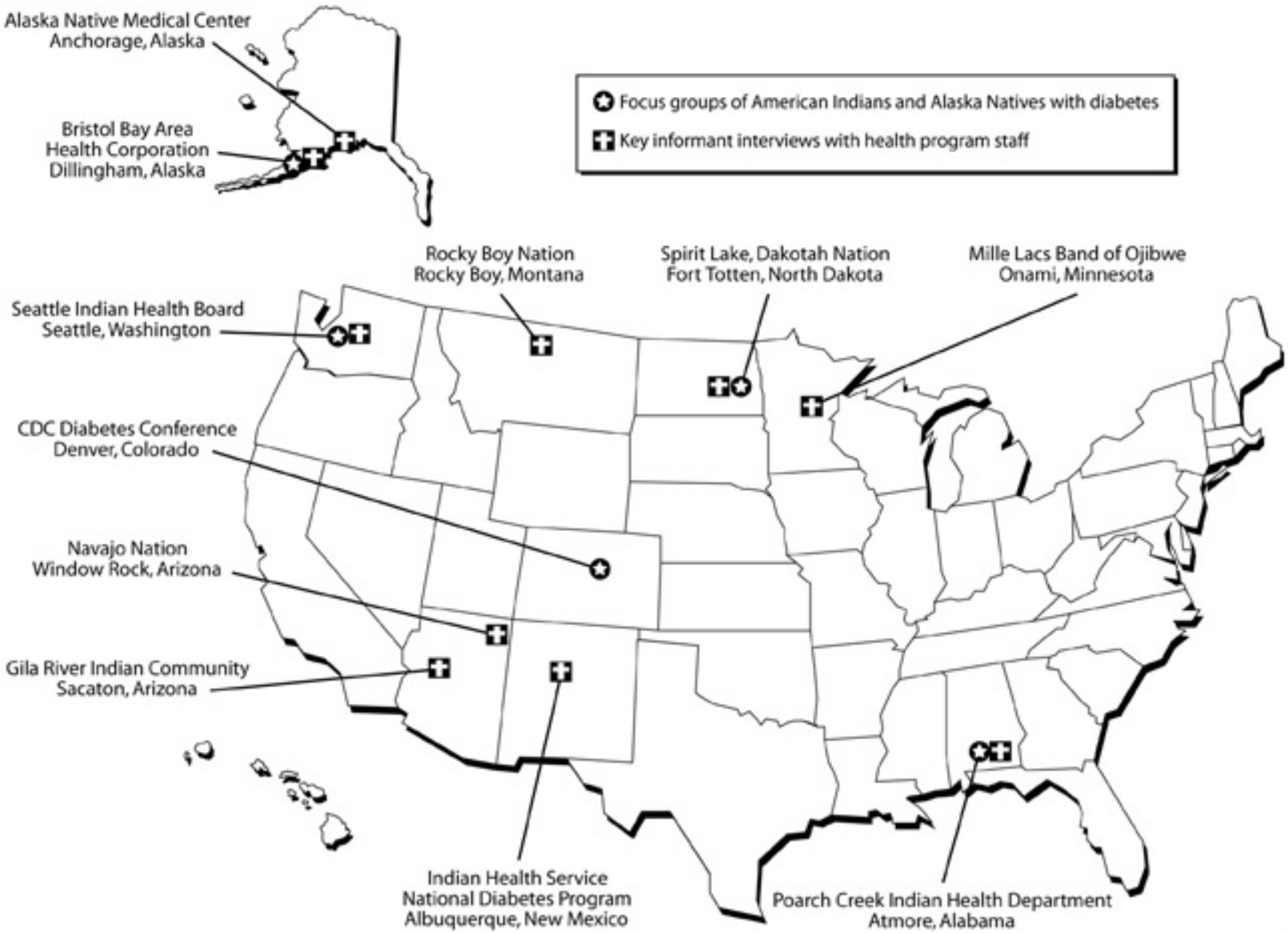
Appendix A. Map of Data Collection Sites

Appendix B. Recruitment Screener

Appendix C. Focus Group Moderator's Guide

Appendix D. Key Informant Interview Guide

Appendix A: Map of Data Collection Sites



Appendix B:

Recruitment Screener
Diabetic Eye Disease Outreach Program
Focus Group Screening Guidelines

A series of focus groups are taking place in several American Indian and Alaska Native communities. The focus groups are discussions that will last approximately 2 hours. Participants will be asked for their opinions and reactions to a series of questions about their understanding of diabetes management and eye-health-related issues. Each participant will receive a stipend at the end of the session. Refreshments will be provided.

Before any set of questions are asked, please assure the respondent that these questions will only be used in the process of selection for a series of upcoming focus groups in the community of _____ and that the purpose is to talk about diabetes and how it can affect the eyes.

Let the respondent know that we must screen for certain criteria as we select participants to be part of this test group. Also, assure the respondent that the information will not be used in any other manner.

The screening process should not last more than 4 to 5 minutes.

Screening Objectives

- ***Two focus groups will be conducted.***
- ***Each group should have 12 participants.***
- ***Each group should have a proportionate number of male and female participants.***
- ***Family members may not participate in the same group.***

Group 1:
Participants should be American Indian or Alaska Native adults with diagnosed diabetes age 30 to 49.

Group 2:
Participants should be American Indian or Alaska Native adults with diagnosed diabetes age 50 and older.

I. Exclusions from Participation for Both Groups:
(Note: There are several types of exclusions from participation that must be imposed for all participants.)

- *Do you work, or have you worked, or has a member of your family ever worked at the National Eye Institute or any State or local government agency responsible for eye care? (If yes, the person must be excluded from participating in the focus group process.)*

- *Do you work, or have you worked, or has a member of your family ever worked in the eye care industry (e.g., Lens Crafters, For Eyes, etc.)? (If yes, the person must be excluded from participating in the focus group process.)*

- *Have you participated in a focus group or other research study during the past year, excluding participation in a telephone survey? (If yes, the person must be excluded from participating in the focus group process.)*

- *Do you work for an advertising agency or the media? (If yes, the person must be excluded from participating in the focus group process.)*

- *Are you or a member of your family running for public office? (If yes, the person must be excluded from participating in the focus group process.)*

II. Logistics and Other Considerations

Transportation *will be provided for the participants as needed.*

Time Commitment*. The focus groups will be 2 hours each.*

Confidentiality*. While information on participants will be collected, the identities will be kept confidential.*

Payment*. All participants will be reimbursed for their time and effort. Each participant will be compensated for participation at the end of the session.*

Food*. Nutritious refreshments and snacks will be provided at each focus group session.*

III. Schedule (TBD)

The schedule for the focus groups is as follows:

Group 1: Participants with diabetes age 30 to 49.

Date/Time _____

Place: _____

Group 2: Participants with diabetes age 50 and older.

Date/Time _____

Place: _____

Appendix C:

Focus Group Moderator's Guide
American Indian and Alaska Native Focus Groups
National Eye Institute
2002

2-Hour Focus Group

I. Explanation and Self-Introductions

A. Introduction

1. Welcome. Thank you all for coming. My name is _____, and I work for a health communications company. Your presence and participation today are important.

B. Purpose

1. What we're doing here today is called a focus group. It's a discussion to find out your opinions—like a survey but with broad, general questions. We invited you here today to get your reactions to a series of questions about your understanding of taking care of your diabetes, health problems associated with diabetes (such as eye health complications), and how diabetes affects your overall health.

C. Procedure

1. I'm interested in all your ideas, comments, and suggestions. There are no right or wrong answers—only your opinions. Also, you do not have to agree with each other. In fact, if you agree or disagree with something that is said, please let us know.

2. Feel free to speak to one another. You do not need to speak directly to me. However, please try to talk one at a time.

3. I want you to know that I am not an expert on the topics we'll discuss today. I did not develop any of the questions, so please comment honestly. You won't hurt my feelings. I'm here to listen to your ideas and comments and to keep the discussion moving so we finish on time.

4. One of my responsibilities is to write a report about what I hear from this group and others. I've asked that the group be audiotaped because I need to use the tapes to remember what was said. But I'm not interested in who says what. Our discussion today is strictly confidential. Do I have your permission to tape this group, now that you understand the purposes for doing this? Thank you.

5. Before we get started, I'd like everyone to introduce themselves briefly to the group. Please tell us a little bit about yourself—your first name only, how long you've lived in this area, and one thing you like to do in your spare time.

II. Profile and General Health Status of Participants

[Begin audio-recording.]

1. What are the top three health issues affecting your community? (Note: Ask each participant to respond.)

2. How would you describe your general health status?

3. Do you have any other health problems besides diabetes?

4. How often do you seek medical care?

5. Where do you go for medical care? (**Probe** for use of Indian Health Service only, Medicaid, Medicare, and private insurance.)

6. What are your reasons for not seeking care?

7. Have you seen a physician in the last year?

8. Do you use anything from your culture to manage your diabetes?

9. Where do you usually get information about health in general? Where do you usually get information about diabetes?

10. Where do you get the medication you might be taking? (**Probe:** Can you get your medication on the reservation or do you need to leave the reservation? Are there any

issues with paying for medication off the reservation? Do you have Medicare? Does leaving the reservation make it harder to pick up prescriptions?)

11. Where you do go to pick up your medications? Does that site provide brochures? (i.e., at the pharmacy?) Have you asked your pharmacist/druggist for information?

III. Diabetes General Management

1. What was your age at the time your diabetes was diagnosed? How many years have you had diabetes? (**Probe** for emotional reactions, coping strategies, and timeframe for adjustment process.)

2. How do you manage your diabetes? What do you do to manage your diabetes? (**Probe:** What might be helpful to you in managing your diabetes?)

3. Are other members of your family involved with the management of your diabetes? If so, who? (**Probe:** How do they help you?)

4. How do you feel about this person's involvement? Do you want more or less involvement?

5. What information and support would you, your family members, or your friends need to help you control your diabetes?

IV. Eye Examinations

1. Have you ever had your eyes examined? When was the first time? What type of eye exam was it?

2. When was the last time you had your eyes examined? Why did you get them checked? Do you get your eyes examined regularly? Why? Why not? (**Probe:** Have you been getting your eyes checked regularly since then?)

3. What type of eye care professional examines your eyes?

4. How often do you think you should get your eyes examined?

5. Have you ever heard the term "dilated eye exam" or "dilated pupil exam"? (**Probe** for what these terms mean to the participants.)

6. Do you think people with diabetes benefit from having regular eye examinations? Why? Why not?

7. Do you have problems with your vision? Have you ever been told your diabetes has affected your vision? (**Probe** about diagnosis and treatment.)

V. Knowledge of Diabetes-Related Eye Problems

1. Have you heard that people with diabetes can develop problem with their eyes? What have you heard? (**Probe** for symptoms and familiarity with diabetic eye disease—diabetic retinopathy, cataract, and glaucoma.)

   Where did you get this information? (**Probe** for family and friends, health care professionals, and other sources.)

2. Do you remember if you were told when you learned you had diabetes about the possibility of developing problems with your eyes related to diabetes? (**Probe** for specific information about eye complications and reducing the risk of blindness as well as the circumstances of diagnosis—doctor's office, clinic, etc.)

3. Did you seek additional information? Why? Why not? (**Probe** for channels such as mass media, group delivery, interpersonal, organizational, community, and pharmacy.)

4. Do you know any one with diabetes-related problems with their eyes? Are they friends, family members, living in your household? Did they become blind from diabetes-related problems with their eyes? How are they treating their eye disease?

5. Are you interested in receiving more information about eye problems caused by diabetes? Why? Why not? Where would you go to get more information about this?

VI. How To Reach People at Risk for Diabetes-Related Eye Problems

1. What term do you use to describe problems with your eyes caused by diabetes? Have you ever heard the term "diabetic eye disease (DED)"?

2. What do you think is important to know? What kind of information would you like to receive about _____? (**Note:** Insert term used by participants for DED. **Probe:** What information have you received that was helpful?)

3. What types of materials would be most helpful? Least helpful? (**Probe** for radio and TV spots, posters, billboards, bus cards, direct mail to homes, and toll-free telephone number for information.)

4. How should the information be shared with you? Which ones are most credible? (**Probe** for channels—mass media, group delivery, interpersonal, organizational, and community. **Probe** for interpersonal interactions—physician, pharmacist, family member, friend, and neighbor.)

5. Many programs use well-known people or spokespersons to help deliver messages. What do you think about this approach? Any spokespersons or community leaders who you would recommend? Any other spokespersons you would recommend? (**Probe** for someone with DED, physician, tribal leader, etc., and for national figure or local figure.)

6. Because there is so much health information and messages today, what type of message would get your attention? What types of visual images would help you understand this message about diabetic eye disease?

7. How important is it for your community to have information on diabetic eye disease? Do you think an education program on diabetic eye disease for American Indians and Alaska Natives is a good idea? Why? Why not?

8. What advice would you give to program planners about how to develop diabetic eye disease messages and materials for your community?

VII. Conclusion and Summary

1. We've come to the end of our discussion. Is there anything else you'd like to add to the topics we've discussed today?

2. Thank you for coming.

3. On your way out, please pick up your stipend for participating and a pamphlet/factsheet related to diabetic eye disease.

Thank you!

Appendix D:

Key Informant Interview Guide
American Indian and Alaska Natives
Community Leaders and Health Care Providers

(30- to 40-Minute Interview)

I. Introduction

Good afternoon and thank you for your time today. My name is _____.
I am interested in meeting with you today to get your opinions to a series of questions on diabetes management and other health problems associated with diabetes.

II. Purpose

The purpose of this interview is for the National Eye Institute's effort to develop a national diabetic eye disease education program for American Indians and Alaska Natives with diabetes. We are interviewing tribal leaders and health care professionals in Indian Country and Alaskan Native communities across the United States and in Alaska.

III. Process

Because this interview will take about 30 to 40 minutes of your time, we prescheduled a meeting to accommodate your time and valuable input. I have a series of questions to ask. I did not develop these questions, so please feel free to respond without hurting my feelings. Your responses will not be connected to your name; they will remain anonymous. Please feel free to be honest with your answers.

Are you ready to begin?

IV. Questions

A. Overview of Community

1. Are you a (get title/degrees):
   - Community health representative?
   - Eye health professional?
   - Other health professional? (Specify.)

2. How long have you been serving in your role?

3. What services do you or your office provide?

4. What service areas do you cover?

5. How many health care professionals are available in this area? (**Probe** for doctors, nurses, nurse practitioners, community health aides, emergency department, etc.)

6. About how many health care professionals specialize in diabetes?

7. About how many eye health professionals are available?

8. Where are eye exams offered? (**Probe** for doctor's office, clinic, optical shops, etc. Distinguish between eye exams and screenings.)

B. Background on Tribe

1. In your perspective, what distinguishes your community from others?

2. Are there any specific philosophies toward health care that specific communities follow? (**Probe** for family, Western medicine, traditional medicine, or traditional healing.)

3. (Add cultural considerations here.) How willing are American Indians and Alaska Natives to talk about disease or health problems? (**Probe:** Do people talk about their problems [and with whom] or do they keep them to themselves?)

4. How familiar are you with American Indian and Alaska Native peoples in these communities using traditional practices (anything from their culture) to help manage their diabetes? If so, what do they do or use?

5. How convenient is it for the American Indians and Alaska Natives that you see to visit a health care professional?

C. Health of Community

1. What are the biggest health problems facing American Indians and Alaska Natives? In your opinion, where does diabetes rank?

2. How big of a problem is diabetes among American Indians and Alaska Natives?

3. Generally, do American Indians and Alaska Natives with diabetes seek medical care for their diabetes?

4. Do American Indians and Alaska Natives with diabetes in your community seek medical care for their vision?

5. What are the barriers to accessing care for diabetes or eye care services? (**Probe** for distance, visiting professionals, spiritual, cultural, resources, etc.)

6. Currently, where do American Indians and Alaska Natives get most of their information about diabetes?

D. Diabetes

Now I would like to talk more specifically about diabetes.

1. In your opinion, how prevalent is diabetes among American Indians and Alaska Natives? (**Probe:** Estimate percentage of people. Is diabetes more prevalent in older people?)

2. *(For non-eye health professionals)* Have you heard of eye complications from diabetes or diabetic eye disease or diabetic retinopathy? If so, what do you know about it? (*For eye health professionals)* What are you seeing in terms of diabetic retinopathy?

3. In your experience, how do people become aware they have diabetes? (**Probe:** How do they react? Can you remember any experiences?)

4. Do they seek immediate care? (**Probe:** How do American Indians and Alaska Natives manage diabetes?)

5. To your knowledge, are family members involved with the care? (**Probe:** Is this encouraged?)

6. Specifically, what information do people ask for when diagnosed with diabetes?

7. What information is available to American Indians and Alaska Natives diagnosed with diabetes in your community?

8. How is diabetic eye disease/diabetic retinopathy treated in your community?

9. In your opinion, who is at greatest risk for diabetic eye disease/diabetic retinopathy?

E. Messages and Channels—Marketing

1. What messages have been used in the past to inspire people to get examined for diabetes and get eye exams? (**Probe:** Were they effective? Provide analogy; tie into something currently being applied in the community such as "Control Your Diabetes For Life.")

2. What other health messages stand out as memorable here? (**Probe:** Why?)

3. Which communication options should be used to deliver eye care messages in this community? (**Probe** for TV, radio, health clinics, family members, etc.)

4. What types of materials would be most helpful? Least helpful? [**Probe** for print materials, media spots, billboards, direct mail, etc.]

F. Education Program Planning

1. Do you think it is a good idea to develop a diabetic eye disease/diabetic retinopathy education program for American Indians and Alaska Natives? (**Probe:** Why or why not?)

2. Would you support this education program? (**Probe:** Why or why not?)

3. What is the single most important piece of advice you could offer the people developing the education program?

V. Conclusion

That is the end of the questions! Thank you again for your time. Is there anything else that you would like to add to the topics we have discussed? Is there anyone else you feel we should interview in your community about these topics?

Your comments have been very helpful to the National Eye Institute (NEI), part of the Federal Government. The NEI sponsored this data collection and will be developing a national education program on diabetic eye disease/diabetic retinopathy with the American Indian and Alaska Native communities. Your efforts today will help to build that program. We will share our data collection results and plans for the education effort.