

# THE NATIONAL EYE HEALTH EDUCATION PROGRAM: INCREASING AWARENESS OF DIABETIC EYE DISEASE AMONG AMERICAN INDIANS AND ALASKA NATIVES

With the highest prevalence of diabetes in the United States, American Indians and Alaska Natives are at greatest risk for diabetic eye disease (DED), a leading cause of blindness. The National Eye Institute (NEI) conducted formative research to understand DED-related knowledge, identify approaches to managing this disease, and design a communication plan to increase awareness and reduce DED among these populations. The NEI conducted qualitative research at five locations in Indian country with representatives from national organizations, tribal members, and healthcare providers. While diabetes ranked high on their list of primary community health issues in need of attention, study participants had only a basic level of diabetes-related knowledge, acknowledged the need for DED education, and underscored the importance of the use of interpersonal and culturally appropriate communication strategies. This is the first exploratory qualitative research study to examine the status of diabetic eye disease among American Indians and Alaska Natives whose primary purpose was to inform the design of a national DED communication campaign. (*Ethn Dis.* 2006;16:920-925)

**Key Words:** American Indians, Alaska Natives, Cultural Appropriateness, Diabetic Eye Disease, Focus Groups, Program Development, Qualitative Research

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## INTRODUCTION

American Indians and Alaska Natives have the highest prevalence of diabetes in the United States, exceeding 50% of adults in some groups.<sup>1</sup> Diabetic eye disease (DED), a group of eye problems causing severe vision loss or even blindness, is a complication associated with diabetes. The National Eye Health Education Program (NEHEP), coordinated by the National Eye Institute (NEI), one of the federal government's National Institutes of Health (NIH), works to prevent vision loss through education programs that increase awareness of the importance of regular eye exams. Diabetes and its complications affect American Indians and Alaska Natives to a greater degree than the general US population and than any other ethnic population in the United States.<sup>2-6</sup> As DED often has no early warning signs, the NEI recommends annual comprehensive dilated eye exams for all people with diabetes so that DED can be detected before vision loss occurs.<sup>7</sup> As a result of the rising rates of diabetes and its accompanying complications among American Indians and Alaska Natives, the NEHEP has begun an outreach effort focused on reaching these populations with DED messages. Accordingly, the NEI conducted formative research with American Indians and Alaska Natives to gain a better understanding of these populations' DED-related knowledge, awareness, and approaches to managing this disease.

## METHODS

The NEI convened a work group on American Indian and Alaska Native

outreach in June 2002 to initiate strategic planning and cultural understanding to design an effective outreach strategy. This work group included representation from national organizations representing the target audience, federal agencies, the Tribal Leaders Diabetes Committee (TLDC), healthcare providers, community members, and educators working in Indian country.

The work group provided guidance on refining the target audience and reaching American Indians and Alaska Natives diagnosed with diabetes, establishing 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. Work group members recommended formative research in the form of focus group discussion sessions and one-on-one key informant interviews.

## Site Selection Criteria and Objectives

The goal of the formative research was to acquire feedback from a broad geographic representation of tribes across Indian country, including urban and rural settings and self-governance and Indian Health Service systems. The objectives of this formative research were to learn about and measure current awareness and understanding of diabetes management, benefits of early detection of eye disease, barriers to receiving or accessing diabetes-related eye healthcare, motivators for behavior change, and preferred communication channels.

NEHEP team members selected the following data collection sites:

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- Fort Totten, North Dakota (Spirit Lake Lakota Nation)
- Anchorage (Alaska Native Medical Center and Southcentral Foundation) and Dillingham, Alaska (Bristol Bay Area Health Corporation)
- Atmore, Alabama (Poarch Creek Nation)
- Seattle, Washington (Seattle Indian Health Board)
- Denver, Colorado (Diabetes Prevention in American Indian Communities Conference).

North Dakota was the location for pretesting the data collection tools. During the scheduling of focus groups and interviews, NEHEP team members developed a research protocol for review by communities' institutional review boards.

### Recruitment and Data Collection

Staff used a recruitment instrument to screen for two focus groups at each site (except in Colorado) with a goal of recruiting  $\leq 10$  participants per group. At each site, the focus groups consisted of one with younger individuals (ages 20–39 in North Dakota, ages 30 to 39 in the other three locations) and one with older individuals (ages 30–49 in North Dakota, ages  $\geq 50$  in the other three locations). When recruiting participants in North Dakota, the NEHEP team had difficulty finding American Indians and Alaska Natives in their 20s with diabetes. Younger and older participants were selected to participate in separate focus groups based on the working hypothesis that the newly diagnosed or younger participants would report different attitudes and care-seeking behaviors than the less recently diagnosed or older participants. This hypothesis was based on experience from focus group research with other populations and proved to be accurate. Segmenting the focus groups by age resulted in findings that supported a two-pronged outreach effort based on knowledge, attitude, and resulting

behavioral differences between the two different age groups.

In fall 2002 and spring 2003, the NEHEP team conducted eight focus groups with American Indians and Alaska Natives with diabetes in four of the five data collection sites. Only key informant interviews were conducted in Anchorage at the Alaska Native Medical Center and in Denver at a national conference. Focus group moderators helped to capture a 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 the target audience with health promotion messages. Specific questions related to health issues affecting the community, reasons for not seeking health care, cultural remedies for treating diabetes, sources for health information and medication, level of family involvement in diabetes management, terms used to describe problems with eyes caused by diabetes, and health communication approaches.

The NEHEP team audiotaped each focus group and assured participants of the confidentiality of their comments. A note-taker documented key points and quotes. The NEHEP team analyzed and coded the transcripts and notes for themes that emerged across and within study sites and for categories of participants. The final findings and conclusions reflect agreement among all study team members.

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, nutritionists, diabetes educators, eye care professionals, nurses, health educators, healthcare administrators, executive directors, tribal council leaders, and other community influencers. Interviewers of key informants probed for information about interviewees' community or tribe

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*For a report of this study, including study participant quotes, visit:*

*[www.nei.nih.gov/nehep/ded.asp](http://www.nei.nih.gov/nehep/ded.asp)*

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as it pertained to the community's health, diabetes-related resources and services provided, and communication channels. Questions posed related to the number of health professionals who specialize in diabetes per geographic area, locations where eye exams are offered, cultural considerations in health, willingness of community members to talk about disease, diabetes ranking among multiple health problems, barriers to accessing care for diabetes or eye care services, treatment experience, members at greatest risk, and successful health communication techniques.

To the NEI's knowledge, this is the first exploratory qualitative research study to examine the status of diabetic eye disease among American Indians and Alaska Natives spanning such a wide geographic range whose primary purpose was to inform the design of a national DED communication campaign.

### RESULTS

A total of 70 American Indians and Alaska Natives (35 women and 35 men) participated in eight focus groups, and 58 key informants participated in in-depth interviews at five study sites representing a diverse cross-section of Indian country in the United States. See Tables 1 and 2. For a complete report of participant comments, readers should visit: [www.nei.nih.gov/nehep/ded.asp](http://www.nei.nih.gov/nehep/ded.asp).

Table 1. Summary of focus groups (N=8 groups, N=70 participants)

Date 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, Fort Dakota Nation, Fort Totten	Alaska Natives in the village of Dillingham (Yu'pik Eskimos, Athabaskan Indians, Aleut) (Focus groups were not conducted in Anchorage.)	American Indians, Poarch Creek Nation	American Indians, Seattle Indian Health Board 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)

Table 2. Summary of key informant interviews (N=58)

Data Collection Site	Spirit Lake, North Dakota	Village of Dillingham and Anchorage, Alaska	Atmore, Alabama	Seattle, Washington	Denver, Colorado*
Key informant interviews	n=8	n=17	n=9	n=7	n=17
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 Maricopa Nations)]. After the conference: a representative each from IHS, American Diabetes Association, CDC-New Mexico office, and National Institute of Diabetes and Digestive and Kidney Diseases (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.

## Diabetes Management and What It Means for the Primary Audience

The NEI learned that while an infrastructure is in place for providing healthcare services to American Indians and Alaska Natives such as that provided by the Indian Health Service (IHS), more could be done to expand diabetes-related services across Indian country. The financial burden of comprehensive health insurance and transportation barriers impede many American Indians and Alaska Natives from accessing adequate diabetes care, regardless of tribe resources, demographic composition, location, or size.

All data collection sites ranked diabetes high on their list of primary community health issues in need of attention. They reported rising numbers of individuals with diabetes in their communities, with an alarming increase of this disease among young people. While focus group participants across study sites understood diabetes as seen through the experiences of elders, they had only a basic level of knowledge regarding the full implications of this disease.

Regardless of data collection site, women surfaced as invaluable assets to the health of American Indian and Alaska Native families and communities. Women are the primary caretakers of family members with diabetes as well as the main seekers of care and information. However, when women have diabetes, the care that they receive is lacking.

## Benefits of Early Detection of Eye Disease

Most focus group participants in this study, in particular the younger ones, did not understand the connection between their diabetes and eye-related problems (a long-term consequence of diabetes). They therefore agreed on the importance of a health campaign communicating the connection between diabetes and DED and the

need for regular eye exams. Health professionals interviewed described the need for increased awareness of the benefits of early detection of diabetic eye disease.

## Barriers to Receiving or Accessing Diabetes-Related Eye Health Care

American Indians and Alaska Natives commonly respond with denial, anger, and fear after receiving a diabetes diagnosis. As diabetes requires daily attention and care, these populations would benefit from self-reliance and self-management. The findings also showed a disconnect, at times, between patients who were proactive about their health (eg, committed to a healthy diet and physical activity) and providers who sensed apathy and lack of initiative among patients (eg, that patients expect providers "to do everything").

Specific to the patient and health-care professional relationship, the research revealed that 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. Other barriers encountered by health professionals include language and confronting social stigma related to having the disease. Understaffing of key personnel (eg, optometrists, ophthalmologists) and high staff turnover rates are additional factors contributing to a lack of continuity in care.

## DISCUSSION

### Motivators for Behavior Change

Study participants offered their recommendations for a national DED education program that would effectively begin to reverse the undesired trend toward rising rates of DED. They suggested that education messages about diabetic eye disease include ways to prevent diabetes and its complications,

an explanation of the symptoms of diabetes, the logic of getting annual eye exams, and the consequences of not treating diabetes. Participants felt that tips for self-management, as well as reporting rates of diabetes among American Indians and Alaska Natives compared to other populations would also get attention and motivate patients. Participants added that social support from personal and professional networks, as well as continuity of health visits, are critical to the consistent and proper management of diabetes. They commented that 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. Most study participants noted the power of a personal connection with an individual health professional in the proper management of diabetes. Regular visits to the same healthcare provider, they said, is a sure bet to improving appointment and care compliance.

Participants in this study provided suggestions for ideal information and messages that would resonate across Indian country. Because 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, DED messages should be included within a broader holistic and preventative health approach in general. A number of study participants pointed out that when traditional medicines such as herbs, sweats, or stomp dances are used, they are more to manage general illness or stress than to treat a specific disease such as diabetes. One site employs a traditional counselor to help patients access traditional medicine when they express such interest. A number of participants felt that traditional medicine could be combined with Western medicines for an integrated approach to treatment. A few noted that

because diabetes is not a “traditional disease,” it does not have a traditional solution.

Study participants emphasized the importance of message tone when communicating information about DED. They reported that positive messages conveying hope (eg, that prevention of complications is possible; that support systems are available, such as co-workers, classmates, communities, social or civic groups, and family members) and that are encouraging (eg, of self-reliance) would be most effective.

Messages that are straightforward, strong and hard-hitting, positive yet realistic, and truthful (not sugar-coated and emphasizing serious consequences of improper diabetes management) also merit attention. Participants warned against bombarding people with too much data and assuring messages are culturally sensitive. For example, messages could be personalized to a specific tribe or community (Alaska Natives are not American Indians) or reference tradition (eg, berry picking, fishing, healing ceremonies) or they could be presented in a language native to the tribe.

### Preferred Communication Channels

Across all focus groups, interpersonal outreach was mentioned as the most effective method of reaching people at risk for DED. Study participants mentioned workshops, one-on-one counseling, support groups, social gatherings, and appointment reminders as being particularly effective. Participants reported preferring the use of testimonials from “ordinary” people in the local community who have diabetes and advised against using celebrities or spokespeople for such efforts, especially for reaching youth with prevention messages. They emphasized the value of presenting information in a conversation, group discussion, or storytelling format when possible, as written materials will not appeal to American

Indians or Alaska Natives with limited literacy skills.

Participants agreed that a multifaceted approach that reaches community members from many disparate angles assures consistency of messages across communication channels and increases the likelihood that American Indians and Alaska Natives will be exposed to DED messages. Many participants suggested disseminating information through local radio and take-home videos, as well as at social gatherings, powwows, church events, and bingo nights. Involving children in education and outreach efforts, they elaborated, is also essential because they will have to address this disease in the future. A national DED education program must collaborate with culturally appropriate groups and activities already in place and involve the whole healthcare team. Study participants expressed concern that a duplication of efforts might delegitimize any new program and welcomed a complementary approach consisting of partnerships with existing programs or key influencers already involving community members in their efforts.

### Recommendations Related to Qualitative Research Logistics

Members of the work group, as well as interviewees in this study, reminded us that historically the relationship between researchers and tribes has resulted in numerous conflicts and abuses. The NEHEP team is privileged to have been invited to visit several of these American Indian and Alaska Native communities and to learn from their experiences. We extend the following recommendations related to the logistics of conducting research that we hope will begin to lay a new foundation for building and securing trusting relationships between researchers and American Indian and Alaska Native communities:

- Factor ample time for the preparation and review of a protocol package

for study tribes’ institutional review boards.

- Pre-test data collection instruments and the proposed research method and its management at a pilot site.
- Be sensitive about the timing for scheduled study site visits. Fall and winter may not be appropriate seasons in which to conduct qualitative research because tribal elections occur during those months, a time when a community’s attention will be focused on local politics.
- Work with a liaison to the community to ease the communication and logistic planning for the site. NEHEP team members with pre-established relationships with American Indian and Alaska Native communities served as liaison between community members and researchers.
- Recruit a moderator of the same ethnic background as the participants to improve the comfort level and candidness of participants commenting during focus groups.
- Over-recruit for participation in focus group discussion sessions to ensure adequate participation. If all recruited participants arrive for the focus groups, however, include all of them for the sake of cultural consideration. (Some participants travel long distances to participate in such research efforts.)
- 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. (When recruiting from small, close-knit communities, recruiting from the same family may be inevitable.)
- Recruit an equal number of women and men to provide a balance of gender-based perspectives.
- Identify an arrival cut-off time for focus group participants who may be running late.
- Share research findings with study communities, both for individual study sites and for all sites combined.

## Note on Strengths and Limitations of Qualitative Research

Inherent to qualitative research, such as the focus groups and key informant interviews conducted for the NEHEP, are methodologic strengths as well as limitations. Qualitative research was especially powerful in providing detailed insights into American Indian and Alaska Natives' perceptions and motivations. This method allowed us to capture the complexities of the thinking and behavior of American Indians and Alaska Natives better than would have been possible had we administered a quantitative survey. In the focus groups we conducted, group interaction and dynamics helped elicit in-depth thought and discussion as well as brainstorming because American Indians and Alaska Natives were able to build on one another's ideas.

Key informant interviews, by nature of the one-on-one exchange, demand participants' undivided attention while allowing for participants to be isolated from the influences of what others say.<sup>8</sup> During key informant interviews, moreover, participants may not be as forthcoming about some issues, since they do not have the anonymity they would in a blind survey. Finally, qualitative research is not intended to be representative of a larger audience. Findings from qualitative research, such as from the study reported here, are not generalizable to the population but provide insight into a small group's thoughts, feelings, and behaviors.

## PROGRESS TO DATE

Findings from this formative qualitative research study disclosed a multitude of issues with which American Indians and Alaska Natives with diabetes must contend. For example, study participants cited a lack of comprehensive health insurance coverage and a shortage of funding for

diabetes programs as major roadblocks to adequate care for DED. While crucial to address, such broad and systemic problems identified are beyond the scope of the NEHEP's focused mandate of effectively disseminating DED messages.

The NEHEP developed an American Indian and Alaska Native DED communication plan and strengthened its partnership of public and private organizations by inviting several national American Indian and Alaska Native organizations to join. In Summer 2004, a radio public service announcement on DED aired on *Native America Calling*, broadcast daily to 67 tribal and public radio stations throughout rural Alaska and Indian country in the lower 48 states. In Fall 2004, *Native America Calling* featured eye care as the topic for the call-in show. NEHEP team members have presented on the developing program at national health conferences. Additional activities have included attending large, regional powwows to provide DED messages through interpersonal contact and educational materials. The NEHEP has been preparing other health materials to meet the preferences of unique American Indian and Alaska Native communities.

## CONCLUSION

An education program that complements and is developed in collaboration with organizations, programs, and initiatives already investing resources in reaching American Indians and Alaska Natives with diabetes-related information fosters the program's longevity. Assembling representatives from multiple organizations and agencies to discuss program development and facilitate collaboration helps to sustain any program implemented.

Additional research is needed to examine the impact of community-specific interventions on DED health-

seeking behaviors and the inclusion of the active participation of local community members in the design and implementation of any diabetes-related effort. Future research should explore questions such as whether eye exams among American Indians and Alaska Natives with diabetes increase after exposure to certain DED messages and interventions, such as health information provided in a community-based presentation, in a powwow environment, or through tribal media.

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