



Catalogue no. 11-522-XIE

**Statistics Canada International Symposium
Series - Proceedings**

**Symposium 2004: Innovative
Methods for Surveying
Difficult-to-reach Populations**

2004



STRATEGIES FOR SURVEYING AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

Jacelyn Macedo, MA, Lorene Reano, MPH, Janis Weber, PhD, Alyssa Easton, PhD¹

ABSTRACT

Gathering reliable information on smoking is vital to interventions that seek to reduce its use, however there is a gap of information in many communities that are at greatest risk for tobacco abuse, due to the methodological, cultural, financial and other challenges associated with surveying hard to reach populations such as American Indians and Alaska Natives (AI/AN). In response, the Centers for Disease Control and Prevention (CDC) held meetings with expert panels and tribal representatives from the CDC funded Tribal Support Centers for Tobacco Programs to collect representative information from (AI/AN) populations regarding an Adult Tobacco Survey (ATS) that would be tailored to American Indian and Alaska Natives. A case study will describe the development and pilot of the first American Indian and Alaska Native Adult Tobacco Survey.

KEYWORDS: American Indians Alaska Natives; Cultural Competence; Research Methodology; Smoking.

1. INTRODUCTION

Obtaining reliable and valid information on smoking is vital to interventions that seek to reduce its use. There remains, however, a critical information gap in many communities at greatest risk for tobacco abuse. This is due to the methodological, cultural, financial and other challenges associated with surveying hard to reach populations, such as American Indians and Alaska Natives. This paper uses a case study to identify the challenges encountered when sampling low-incidence populations and recommends strategies to meet these challenges successfully. The authors hope to engender an understanding of the importance of implementing culturally appropriate surveys with methods that ensure estimates are both representative and valid and a recognition of the diversity and complexity of research processes that are unique to Indigenous populations.

2. THE AMERICAN INDIAN/ALASKA NATIVE ADULT TOBACCO SURVEY

The Centers of Disease Control and Prevention awarded six Adult Tobacco Survey (ATS) supplemental grants to six Tribal Support Centers for Tobacco Programs (TSC). The purpose was to develop an American Indian/Alaska Native (AI/AN) version of the national survey, pre-test and then implement the survey in tribal communities served by the Tribal Support Centers for Tobacco Programs. The rationale for this project was to address the lack of current and accurate data for AI/AN populations and to create a culturally appropriate survey tool.

We do know, from dated studies, that rates of smoking among American Indians and Alaska Natives (AI/AN) are high, funding for cessation, prevention and surveillance is low, and smoking related mortality and disease are common. According to the Centers for Disease Control (CDC) January 2004 Morbidity and Mortality Weekly Report (MMWR) based on surveillance data compiled in 2001, AI/AN adults have a 40.4% prevalence of commercial tobacco abuse. With the highest tobacco abuse prevalence among all racial/ethnic groups, it should come as no surprise that cardiovascular disease is the leading cause of mortality, and lung cancer is the leading cancer mortality among AI/ANs (Office of the Surgeon General, 1998). American Indian and Alaska Natives have

¹Jacelyn Macedo, MA, California Rural Indian Health Board, 4400 Auburn Blvd, Sacramento, CA, USA, 95841; Lorene Reano, MPH, Centers for Disease Control and Prevention, Office on Smoking and Health, 5300 Homestead Road, NE Albuquerque, NM 87110; Janis Weber, PhD, Research Triangle Institute, Community Health and Evaluation, 3040 Cornwallis Road, Research Triangle Park, NC 27709; Alyssa Easton, PhD, Centers for Disease Control and Prevention, Office of Smoking and Health, 4770 Buford Highway, NE Atlanta, GA 30341-3717.

the poorest survival rate from cancer in any racial or ethnic group, due to high poverty, low income, shortage of healthcare funding and limited access to specialist healthcare (Indian Health Services, 2000). Institutional discrimination, both direct and indirect, additionally affects American Indian and Alaska Native survival rates.

Furthermore, the AI/AN population are one of the smallest minorities, comprising only 1.5% of the total United States population (Ogunwole, 2002). The epidemic abuse of commercial tobacco among this small population severely impacts AI/AN communities. Commercial tobacco abuse negatively affects elders, adults, children and infants, leading to illness, disease and premature death. The Indian Health Service reports that smoking causes two out of five AI/AN deaths (Hodge and Glover, 1999). The CDC January 2004 MMWR reported that AI/AN youth have a 27.4% prevalence rate of commercial tobacco abuse, which is the highest rate of any other racial/ethnic group. Although the CDC's National Center for Health Statistics study from 1990 to 1999 shows a 33% national decline of smoking among pregnant women, American Indian women continue to have the highest smoking rates during pregnancy and showed the least rate reduction over the nine-year period (Office of the Surgeon General, 2001).

Although these studies illuminate the tobacco related disparities between AI/AN and the general U.S. population, the data is not current and national AI/AN rates may not accurately reflect the regional smoking differences across Indian Country. Previous national studies have attempted to measure commercial tobacco use among American Indian adults, but in most studies, the number of American Indians that participated was so low that specific data related to the population was irrelevant. There are over 560 federally recognized tribes in the United States, each with their own distinctive culture, language and identity. Due to the diverse nature of Indian Country, it is important to further evaluate tendencies among the specific communities to identify reasons for smoking and uncover other tobacco-related information such as smoking cessation, age initiation, community norms around smoking and smoke-free tribal policies.

Healthy People 2010 is a blueprint and benchmark for the improved health of all communities across the United States. The second goal of *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) is to eliminate health disparities among different segments of the population. Tobacco use is included among the leading health indicators in *Healthy People 2010*. American Indians and Alaska Natives (AI/AN) have been identified as a priority population with regard to tobacco use. Recognizing that such surveillance data is essential in order to reach Goal Two in *Healthy People 2010*, the Centers for Disease Control and Prevention, Office on Smoking and Health (CDC/OSH) set monies aside to award grants to specific populations, including American Indians and Alaska Natives, to revise and implement the Adult Tobacco Survey (ATS) in their communities. Among all specific populations identified, there are common unifying themes: limited data, lack of culturally appropriate survey instruments, unique methodological considerations, lack of access to medical care and specialist care and disproportionate tobacco-related health disparities. These characteristics also affect applications for public health care practice of prevention and cessation promotion in these communities.

3. CHALLENGES

A critical component in successfully surveying AI/AN communities is the recognition of specific challenges inherent to these populations. Researchers must acknowledge and accept these challenges, and be willing to adapt methodologies to the cultural realities of AI/AN populations. Indeed, scientific rigor and cultural competence are not diametrically opposed to each other. Heretofore, the dominant research paradigm has been the western scientific model and researchers attempted to "fit" cultural realities into the model. If we simply adjust our angles of vision, the dominant research paradigm becomes the cultural realities, and we can situate the western scientific model into these realities. Examples of this new angle of vision follow.

While each American Indian and Alaska Native tribe has separate and distinct cultures, there are some shared commonalities with regard to social structure and organization. Successful research strategies include understanding and respecting these structures and organizations. Elders hold very important roles in the social structure of AI/AN communities. They are the keepers of the wisdom, history and traditions. In social gatherings, elders are the first to speak, first to enter ceremonial areas, first to receive gifts and the like. This fact is important to understand for those engaged in qualitative research (e.g., focus groups) as participants will defer to elders.

AI/AN communities hold children in high regard; they represent the future of the tribes. In any research venue, whether face-to-face interviews, focus groups, Talking Circles, or cognitive interviews, expect children to be present. It is common for parents and grandparents to bring infants, toddlers and older children with them into research venues. It is the researcher's responsibility to adjust to that fact.

Group research activities such as focus groups are very structured in mainstream societies, particularly with regard to number of participants allowed. AI/AN communities often see group activities (even research) as combinations of social gathering and decision making arenas. Tribal ways of communication call for these types of gatherings; thus, the researcher may find that it is difficult (and even rude) to attempt to limit the number of participants for group research activities. Researchers will be more successful if they adapt methodologies to substitute Talking Circles for focus groups – learn the correct methods of communication used by the population rather than expect the population to learn your methods.

Seasons are an important part of AI/AN community life. Successful research strategies include understanding the implications of seasonal life for the populations. Tribal communities hold sacred ceremonies during specific seasons of the year. These ceremonies are an integral part of community life and are sacrosanct. In addition, many tribal communities are dependant upon seasonal hunts and/or fishing seasons, both for traditional reasons as well as subsistence reasons. The researcher must understand these seasons – adjustment of the researcher's schedule to respect such traditions is a necessary strategy for success.

Laughter is an important part of AI/AN communication. The western research model is quite staid, even stodgy. Among tribal populations, laughter is essential for learning, teaching and healing. Expectations that tribal populations will accommodate the staid, impersonal type of research protocols are sure to be dashed. Successful methodological strategies include understanding and respecting the laughter and humour that is inherent in AI/AN forms of communication.

4. STRATEGIES: DEVELOPMENT STAGE

To address some of these challenges, CDC established an AI/AN Workgroup consisting of tribal representatives, American Indian and Alaska Native researchers, tobacco control experts and TSC Adult Tobacco Survey (ATS) coordinators. Panel members had the necessary skills and experience working with the participating Native communities to work on a revision of the ATS. The workgroup reviewed the National Adult Tobacco Survey and recommended changes to the survey that were specific to American Indians and Alaska Natives.

There were numerous recommendations from the experts. First, they suggested that the AI/AN ATS address the use of tobacco products for ceremonial or traditional purposes distinct from the habitual, abusive use of commercial tobacco products. Inclusion of the use of traditional healing methods in tobacco cessation strategies was also an important issue raised by the panel. According to the members, the existing survey also needed to incorporate tribal affiliation questions and community norm questions that included intergenerational influence. Another panel recommendation was to address tobacco use and availability issues for AI/AN populations that may be unique, such as early initiation of use, availability of “low cost” tobacco products at smoke shops, tribal casinos and other venues. Finally, they recommended that the tribes should own the data generated by the ATS and the decision to share the data should rest with the tribes or tribal organizations. They wanted researchers to consult tribes prior to submission of a funding application, encourage tribes to submit letters of support for the project, attain official tribal approval and commitment to collaborating and participating in the AI/AN Adult Tobacco Survey and ensure tribal participation in all phases of the survey.

The ATS researchers followed these recommendations, utilizing several different methodological strategies throughout each stage of the project from development, pre-testing, collection, analysis and dissemination.

For three years, the TSCs had already been establishing trusting relationships with tribes. The ATS research project built upon the foundation set by this relationship. It added legitimacy, promoted community buy-in and ensured continued involvement by tribes and tribal organizations. We consulted and recruited tribes for participation at the ATS and pre-testing sites. TSCs approached tribal councils and presented the ATS project at tribal council meetings.

We developed data-sharing agreements, signed by tribes, TSCs and CDC. We hired local AI/AN staff to coordinate the project. Since the project activities required direct interactions with tribes and tribal members, it was critical to hire coordinators who had membership or affiliation with local tribes. Later, such coordinators would hire community members for other project roles, such as focus group facilitators or site survey supervisors.

5. STRATEGIES: PRE-TESTING STAGE

One of the main outcomes for the American Indian ATS project was the creation of a culturally appropriate survey instrument. The expert panel meeting and continued input by the TSCs and tribal communities were the first steps taken to accomplish this outcome. The instrument modifications made during these first steps were not minor question-tweaking, but involved American Indian culturally specific changes and additions. These changes insured that American Indians could understand and answer the ATS questions accurately. From these suggestions, the original ATS instrument was altered significantly, even the original ATS for state-based populations. This led to a pre-test of the modified AI/AN ATS. Again, tribal or village interviewers and contractors were hired and trained to perform the pre-testing activities. The TSCs reviewed and revised the pre-testing reports. Each of these strategies ensured that research training and capacity building in AI/AN communities was the highest priority.

6. STRATEGIES: DATA COLLECTION AND ANALYSIS STAGE

Culturally competent data collection strategies are vital elements in the success of the AI/AN Adult Tobacco Survey. Historically, non-Native researchers have not engendered trust among AI/AN tribes and communities. Thus, we trained Native interviewers to conduct the face-to-face interviews with respondents. The training manual for interviewers follows a conversational, story-telling style, including ample opportunities for interviewer interactions, in deference to Native ways of learning. Face-to-face interviews are the most appropriate method of gathering data among AI/AN populations for several reasons, including respect for Native ways of communication, possible language barriers with elders and lack of telephone service in many homes on reservations. Furthermore, researchers collaborated with Native staff to create scientifically rigorous methods for a data collection trail of evidence (plans for drawing random samples, protecting confidentiality of respondents, securing data, codebook development and data input), ensuring both cultural competence and adherence to the scientific method.

Upon completion of data collection, the TSCs and CDC will provide statistical programs and training to participating tribes in order to promote sustained research capacity within the tribes and villages. If the tribe does not have its own research unit, collaboration with Native epidemiology centers or Native universities is a strategy we will employ in order to utilize Native resources and ensure cultural appropriateness and methodological soundness. Finally, we will invite Native leaders to review the draft report in order to receive their input for the final draft.

7. STRATEGIES: DATA DISSEMINATION STAGE

Data dissemination is a crucial stage in determining the power dynamics inherent in participatory research. Who has the power to disseminate the information? What entity decides what information should be made public? In the United States, federally recognized tribes are sovereign nations and have the power to determine their fates. Any research project involving tribes must recognize tribal self-determination. The CDC, project personnel and project officers acknowledged tribal sovereignty and structured plans for data dissemination with tribes. Tribes will retain ATS data ownership; dissemination will ensure the return of all data to tribes, and the tribes will decide how to utilize the data. A data sharing agreement, established between the TSCs and the participating tribes, legally bound these guidelines in a contract.

Furthermore, the tribes will receive CDC and TSC assistance in reporting the findings to the tribes, tribal councils and larger Native community. The CDC and TSCs will provide training to tribes on uses for the data. We have planned trainings in grant writing, policy development, publishing and health program development. The CDC will explore resources to help additional tribes or villages to conduct the AI/AN ATS and fund the same tribes or villages

to monitor over several years. The CDC and TSC will continue to provide technical assistance to tribes and villages. Finally, the TSC will thank and gift tribal or village councils and communities for their participation.

8. FINAL THOUGHTS

The benefits from implementing these survey research strategies in Indian country far outweigh the extra time or money. The purpose of scientific inquiry is to gather valid and reliable data. A myriad of cultural pitfalls can render scientific inquiry invalid for Native populations: these include lack of trust, cultural misunderstandings, ignorance toward a population's methods of communication, learning and knowing and disrespect (even unwitting) resulting from lack of knowledge regarding traditions, ceremonies and symbolism. The collaboration between AI/AN Tribes and the Centers for Disease Control and Prevention/Office of Smoking and Health on the AI/AN Adult Tobacco Survey is a good faith attempt to develop cutting-edge strategies to incorporate scientific rigor into the cultural realities of Native populations. The culturally appropriate methodologies that have emerged from this collaboration will serve scientific inquiry well.

REFERENCES

- Centers for Disease Control and Prevention, United States Department of Health and Human Services (2004), "Cigarette Smoking Among Adults – United States", *Morbidity and Mortality Weekly Report (MMWR)*, 53(3), 49-52, Washington, D.C.
- Hodge, F. and Glover, C. (1999), "The National Cancer Institute's Research Efforts in Native American Communities: Approaches Used and Lessons Learned", in: Claudia Glover and Felicia Schanche Hodge (eds.) *Native Outreach: A Report to American Indian, Alaska Native and Native Hawaiian Communities*, National Cancer Institute Monograph, NIH Publication 98-4341.
- Indian Health Services, United States Department of Health and Human Services (2000), *Trends in Indian health 1998-1999*, Rockville, MD: United States Department of Health and Human Services, Indian Health Services.
- Office of the Surgeon General, United States Department of Health and Human Services (1998), *Tobacco Use Among U.S. Racial/Ethnic Minority Groups – African Americans, American Indians and Alaska Natives, Asian Americans and Pacific Islanders, and Hispanics: A Report of the Surgeon General*, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
- Office of the Surgeon General, United States Department of Health and Human Services (2001), *Women and Smoking: A Report of the Surgeon General*, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
- Ogunwole, S. (2002), *The American Indian and Alaska Native Population: 2000 Census Brief*, U.S. Department of Commerce Economics and Statistics Administration, U.S. Census Bureau, Washington, D.C.
- United States Department of Health and Human Services (2000), *Healthy People 2010: 2nd ed. With Understanding and Improving Health and Objectives for Improving Health*, 2 vols., Washington, D.C.