Tribal College Health Initiative

A Study of Tobacco-Related Health Disparities in Three Different Tribes

LEGACY

Legacy

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Inter-Tribal Council of Michigan

The Inter-Tribal Council of Michigan (ITCM) is a 501 (c) (3) non-profit tribally designated consortium of Michigan's federally recognized tribes and has been in existence since 1966. Its mission is to promote the health, well-being and quality of life of Indian people in Michigan. The ITCM administers a variety of social services, health, education, and vocational programs toward this goal. The ITCM's Health Education and Chronic Disease Department manages an array of health promotion disease prevention programs targeting cancer, cardiovascular disease, commercial tobacco and effectively implements policy, systems and environmental change strategies in collaboration with the member tribes. ITCM was involved with the initial development, testing and implementation of the American Indian Adult Tobacco Survey and continues to assist tribes in implementing the survey and the results into health programming.

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LEGACY's Dissemination Reports

Legacy's past grant making and partnership efforts have resulted in knowledge about a broad range of tobacco control issues and emerging strategies and interventions. To share this knowledge with other organizations involved in tobacco control and public health, Legacy has published a series of dissemination reports and profiles. They highlight key lessons learned from a wide range of tobacco control projects that Legacy's partners and past grantees have implemented. To access Legacy's past dissemination reports, visit legacyforhealth.org/dreports.

Tribal College Health Initiative: A Study of Tobacco-Related Health Disparities in Three Different Tribes is the 14th publication in Legacy's dissemination series. This publication presents Legacy's Tribal College Health Initiative as a community-based research project and examines how the initiative collaborated with three tribal colleges and affiliated tribal communities to implement the American Indian Adult Tobacco Survey. It also highlights key lessons learned from the initiative and offers a summary of the key findings based on data gathered from this research project.

[Legacy recognizes and honors the fact that tobacco has a sacred cultural place in American Indian life in parts of North America. Many Native American tribes use tobacco for spiritual, ceremonial, and traditional healing purposes. Legacy, therefore, distinguishes traditional, ceremonial, and spiritual use of tobacco from its commercial use. Legacy promotes tobacco control efforts that are not geared toward targeting traditional tobacco.]

Table of Contents

Executive Summary **6-9**

Chapter 1 | Legacy Tribal College Health Initiative **10-13**

History and Overview 11

Three Tribal Sites 12

Objectives of This Report 13

Chapter 2 | Tobacco-Related Health Disparities in American Indian and Alaska Native (AI/AN) Populations: A Brief Overview **14-19**

Demography and Socioeconomic Inequity 15

General Health Disparities Facing AI/AN Communities 16

Tobacco-Related Health Disparities 16

Funding for Tobacco Control in AI/AN Populations 17

Need for Tribally Tailored Tobacco Control Program 17

Tobacco Control in AI/AN Populations and "Ceremonial" Versus "Commercial" Tobacco Use 17

Targeting of AI/AN Populations by Big Tobacco 18

Commercial Tobacco and Tribal Sovereignty 18

Resilience among American Indians and Alaska Natives 18

Chapter 3 | Research in Tribal Communities **20-23**

Introduction 21

The Value of Community-Based Participatory Research (CBPR) 21

Chapter 4 | Research Methodology: Implementation of the American Indian Adult Tobacco Survey in Three Tribal Communities **24-31**

Creation of the Adult Tobacco Survey Tailored to AI Communities 25

Seeking Approval from Tribal Leaders and Institutional Review Boards 26

Recruitment of Student Interviewers 26

Training of Faculty and Student Interviewers and Field Implementation 27

Tribe from the Aberdeen Area Indian Health Service Region: A Story from the Field 29

Chapter 5 | The Tribal College Health Initiative as Community-Based Participatory Research **32-35**

Introduction 33

Flexibility is Key 33

Tribal Ownership of Data 33

Established Relationships 33

Creating Community-Based Partnerships 34

Capacity Building in Underserved Populations 34

Chapter 6 | Challenges and Lessons Learned **36-39**

Introduction 37

Prioritizing Tobacco-Related Health Concerns 37

Participation and Recruitment 37

Cross-Site Collaboration 38

Working within Timelines and Building for Flexibility 38

Working with Tribal Colleges Versus with Tribes Themselves 38

Experience with a Tailored Academic Research Course 39

Data Ownership and Building for Mutual Benefit 39

Chapter 7 | Summary of Key Findings and Next Steps **40-47**

Smoking Prevalence Rates 41

Gender Disparities 42

Secondhand Smoke Exposure 44

Comorbidity 44

Comparison of Quit Methods 44

The Tribe from Aberdeen Area Indian Health Service Region 44

The Tribe from Bemidji Area Indian Health Service Region 45

The Tribe from Billings Area Indian Health Service Region 45

Need for Culturally Competent Prevention and Cessation 45

Next Steps to Utilize the Research Findings 45

Endnotes **48-51**

Executive Summary

This report presents the Legacy Tribal College Health Initiative (TCHI) — a research initiative implemented to gather tribe-specific data in three distinct tribes in the Northern Plains. American Indian (AI) populations represent a great diversity of tribal communities. However, public health researchers often treat AI populations as one large homogenous group. The generic national estimates of AI tobacco use rates do not truly represent substantial variation among geographically, culturally, and politically distinct tribes. These data mask the differences in tobacco use patterns among tribes and contribute to the lack of understanding of tobacco use in specific tribes. The TCHI was established in response to this critical need for gathering tribe-specific tobacco prevalence data.

The TCHI partnered with tribal colleges and engaged their faculty and students to collect data in three distinct tribal communities. This publication examines the findings, challenges, key outcomes, and lessons learned from this research initiative.

This publication focuses on:

Examining commercial tobacco use and tobacco-related health disparities facing tribal AI populations;

Showcasing TCHI's focus on building the capacity of tribal colleges by training tribal college students and faculty members to conduct the AI Adult Tobacco Survey (AIATS) in tribal communities;

Exploring the TCHI as a model for Community-Based Participatory Research (CBPR) in AI tribal communities; and

Presenting a summary of the key findings and conclusions based on the tribe-specific data collected through the TCHI.

Chapter 1 of this report provides the introduction to the TCHI.

It offers the history of the initiative and discusses the roles of a program advisory team which guided the planning and implementation of this research initiative. This chapter also describes the recruitment process of three different tribes and tribal colleges who participated in this research.

Chapter 2 offers an overview of the tobacco-related health disparities in AI populations in the U.S.

It highlights persistent and dramatic socio-economic disparities between populations on most Indian reservations and the rest of the general U.S. population: higher poverty rates and unemployment, and lower income and educational achievement.

It examines how these socio-economic disparities lead to health disparities in these populations. It also puts a spotlight on AI smoking rates which are the highest of any U.S. subpopulation and highlights the needs for culturally competent tobacco control programs in tribal communities.

Chapter 3 emphasizes the importance of addressing the legacy of historical trauma and the persistence of research abuse in tribal populations.

It describes the relevance of tribal worries about both the safety and the value of academic research in their communities, and a general distrust amongst tribes that research will actually serve tribal needs. In this context of the history of abuses and mistrust between researchers and tribes, community-based participatory research (CBPR) has the potential of being a promising model that incorporates collaboration and shared learning with tribal leaders and community members.

Chapter 4 outlines the development of the AI Adult Tobacco Survey and reflects on the research methodology used in the TCHI.

It describes how tribal colleges and tribal leaders from the three participating sites were engaged in the initiative and how college students were recruited and trained to implement the survey.

Chapter 5 and 6 highlight how the TCHI put into practice some of the fundamental principles of CBPR.

These sections also reflect on important lessons learned from and challenges faced by the initiative.

Chapter 7 presents the key findings which include: (See chart to the right)

The findings from the TCHI point to the critical need for better access to culturally competent tobacco cessation and prevention services in these communities. The tribal communities that participated in the TCHI are utilizing the data to inform and educate their communities. With their own tribe-specific data, they can implement targeted tobacco cessation interventions, public awareness campaigns, and policy changes that work for their communities and address their specific needs. The findings from this research provide evidence that these tribes can use to justify additional funding for future tobacco control efforts. The TCHI enabled these communities to be better prepared to identify their own tobacco-related health disparities and determine the most appropriate strategies for addressing them.

Key Findings

A **EXTREMELY HIGH RATES OF SMOKING AMONG ADULTS**

45.7 percent in the tribe from Bemidji Area Indian Health Service Region;

50 percent in the tribe from Aberdeen Area Indian Health Service Region; and

60 percent in the tribe from Billings Area Indian Health Service Region smoke.

B **EXTREMELY HIGH RATES OF SMOKING AMONGST WOMEN**

In the tribe from Bemidji Area Indian Health Service Region **40** percent of males smoke compared to **51** percent of females who smoke.

In the tribe from Aberdeen Area Indian Health Service Region **51.8** percent of males smoke compared with **50.8** percent of females who smoke.

In the tribe from Billings Area Indian Health Service Region **51** percent of males smoke compared to **69** percent of females who smoke.

C **ELEVATED COMORBIDITY**

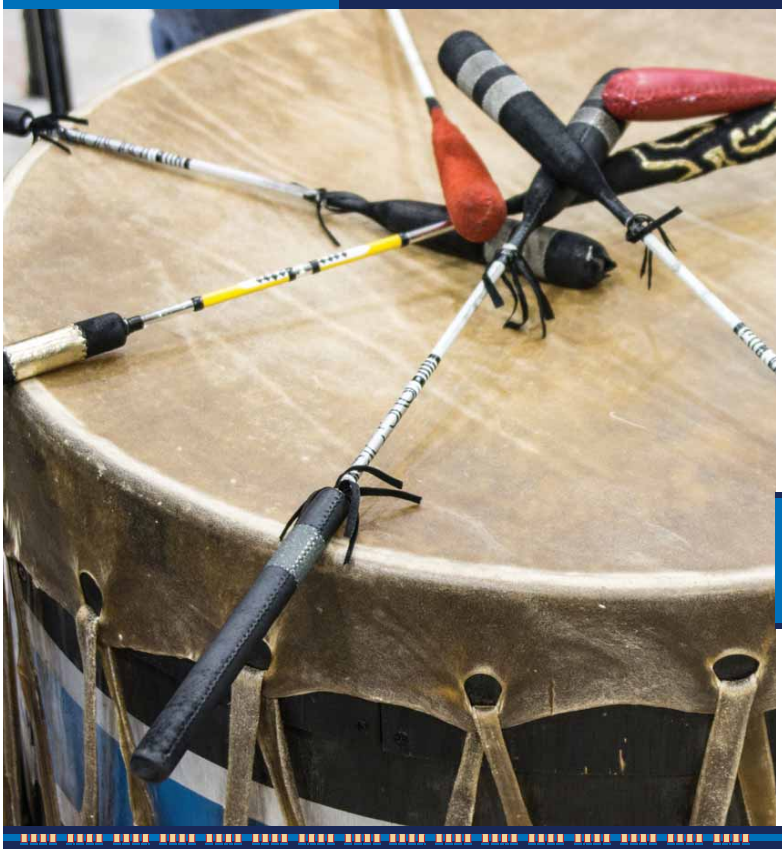
Significantly high percentages of adults who have chronic diseases or health conditions such as diabetes, asthma, high blood pressure and coronary heart disease smoke cigarettes.

D **LIMITED ACCESS TO CESSATION**

Of the total number of adults surveyed who had seen a medical provider in the past 12 months (96 percent), **63** percent were advised by their medical provider to quit smoking; none of them received an advice to use a quit line or counseling service; and only up to **20** percent of respondents were prescribed some type of medication or nicotine replacement therapy.

Chapter 1

Legacy Tribal College Health Initiative



HISTORY AND OVERVIEW

The Legacy Tribal College Health Initiative (TCHI) has its roots in an earlier Legacy initiative—the On the Ground Smoking and Cessation Project that started in 2006 as a three-year initiative and focused on three Historically Black College and University (HBCU) campuses in North Carolina. "This was a grassroots community engagement project that developed and implemented an interdisciplinary collaboration," said Amber Bullock, executive vice president, program development, at Legacy. "The goals of the program were multifold: to address tobacco use rates, to promote and foster smoking cessation and prevention, to develop and implement an awareness campaign, and to develop cessation programs."

"The goal of the College Health Initiative was to highlight the importance of subpopulation research as well as to build capacity among college students as it is related to health surveillance," said Ines Alex Parks, assistant director of program development with Legacy.

In 2008, Legacy held talks with key stakeholders within tribal organizations around how Legacy could help build their capacity for the collection of tribe-specific data. An idea emerged from these talks for an initiative focused on building the capacity of tribal colleges to conduct research in their own communities. "We had conversations with [Legacy] about how we could gather data specific to tribal communities, because [the AI ATS] had been developed for tribes, but it had never been supported with the funding needed to implement it," said Lisa Abramson of the Inter-Tribal Council of Michigan (ITCM). "The CDC should be commended for developing the AI ATS—this wonderful tool. A lot of work was put into it, a lot of consultation with tribal communities, but how do we help tribes to collect this data now?"

Tribal data ownership was a priority from those very first conversations. "We talked about the importance of the tribes owning the data, and therefore being able to do with it what they wish, which includes disseminating information, and using it to solicit funding," said Laura Hamasaka, associate vice president of priority populations and program development at Legacy.

Legacy created a core project advisory committee—consisting of health professionals associated with the National Native Commercial Tobacco Abuse Prevention network, some of whom were part of the team that created the AI ATS in 2000—to design and implement the Tribal College Health Initiative. This core committee consisted of representatives of the Inter-Tribal Council of Michigan, J.C.W. Research & Evaluation Group, Health Education and Promotion Council, Muscogee Creek Nation Health System, and the CDC. The ITCM served as the fiduciary and coordinating agency.

The TCHI aimed to engage tribal colleges and their affiliated tribal communities to implement the American Indian Adult Tobacco Survey (AI ATS) and collect tribe-specific data. The advisory committee provided training and technical assistance throughout the stages of the project including: 1) planning and survey protocol development; 2) data collection; 3) data analysis; and 4) reporting and data use.

Partnering with tribal colleges to collect commercial tobacco use data was an innovative approach. It was based on the idea of moving sharply away from the damaging paternalistic bent of past research in AI (American Indian) communities and toward the kind of true partnership built into a Community-Based Participatory Research (CBPR) model. "I always looked at it ... as an amazing opportunity, to get tribes really good data, but to also engage the community in a way that it hadn't been engaged before, and to give students a chance to be involved in a process that allowed them to see what it was to collect good and useful information for their tribal communities," said Abramson.

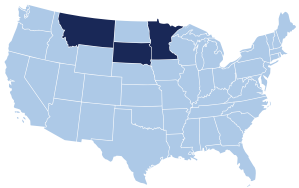
THREE TRIBAL SITES

The original project plan called for four to six participating tribal colleges, but in 2011 only two tribal colleges responded to the Request for Proposal. One of those sites decided it could not meet the project requirements with the funding available. After a second round of the Request for Proposal and targeted outreach, the project commenced with three tribal college sites. Tribes and tribal colleges have disparate levels of capacity and competing priorities—these dynamics likely created barriers to recruitment for participation in the project. For the sake of tribal privacy, participating tribes and tribal colleges are not identified in this report. However, we have identified the tribal service regions to which the participating tribes and tribal colleges belong.

- The tribe from the Bemidji Area Indian Health Service Region has less than 1,000 members on a three-acre reservation and many tribal members living off the reservation. A research coordinator at the tribal college managed the AI ATS project.

- The tribe from the Billings Area Indian Health Service Region has approximately 2,000 members on a large reservation. The dean of academics at the tribal college headed the project.

- The tribe from the Aberdeen Area Indian Health Service Region has approximately 3,000 adult tribal members dispersed across many small communities on a large reservation. This tribe partnered with a Native-owned research organization with extensive experience managing research studies in this population.



OBJECTIVES OF THIS REPORT

There is great diversity within the American Indian and Alaska Native (AI/AN) population—accordingly, there is also significant variability in rates of tobacco use among tribal communities. National estimates of AI/AN tobacco use rates mask substantial variation among geographically, culturally, and politically distinct tribes. National data, therefore, is not particularly helpful to tribes in understanding their members' specific tobacco use patterns. National commercial tobacco data cannot provide information about tribe-specific beliefs, attitudes, and behaviors. This research initiative was a response to the glaring need for stronger tribe-specific health surveillance data to identify local health risk behaviors and priorities.

This report describes the TCHI that partnered with tribal colleges and their students to collect data in three distinct tribal communities, each in the Northern Great Plains, and will present the findings of that research, the challenges faced, key outcomes, and lessons learned for the researchers involved.

Legacy intends in this publication to address four issues and impact areas:

- To examine commercial tobacco use and tobacco-related health disparities facing tribal AI populations of the Northern Plains;
- To showcase the initiative's focus on building the capacity of tribal colleges by training tribal college students and faculty members to conduct the AI Adult Tobacco Survey with tribal communities on tribal land;
- To explore this approach as a potential model for Community-Based Participatory Research (CBPR) in AI tribal communities; and
- To present a summary of the key findings and conclusions based on the tribe-specific data collected through the initiative.

An in-depth discussion of the research methodology and site participation will be presented in Chapter 4 of this report.

Chapter 2

Tobacco Related Health Disparities
In American Indian and Alaska Native (AI/AN) Populations: A Brief Overview

DEMOGRAPHY AND SOCIOECONOMIC INEQUITY

In 2010, 1.7 percent of the U.S. population identified as American Indian or Alaska Native (AI/AN).[1] According to the 2010 U.S. Census, "5.2 million people in the United States identified as American Indian and Alaska Native, either alone or in combination with one or more other races."[2] There are 564 federally recognized tribal entities in the United States,[3] and some 270 tribal languages exist.[4, 5] There are several hundred more tribes in the United States that have sought federal recognition but still remain unrecognized by the federal government.[6]

The AI/AN population is heterogeneous and diverse, and public health research and programmatic implementation must take this into account and avoid the pitfalls of one-size-fits-all approaches. The public health world often treats AI/AN populations as one large homogenous group despite the realities of vast diversity among these communities. This report will focus on a research initiative within three tribally distinct AI communities in the Northern Great Plains. Though much of the existing research takes this broad frame of "AI/AN"—and many of the sources cited here do the same—this initiative and publication focus solely on three AI communities in an effort to collect and disseminate tribally specific data.

American Indian/Alaska Native (AI/AN) populations suffer the highest poverty rates, lowest educational achievement, and lowest home ownership amongst all racial groups,[7] and as a result, they face the most depressed socioeconomic status (SES) of any subpopulation in the United States—an incomparable level of social and economic marginalization.[8,9] National statistics show persistent and dramatic SES disparities between populations on most Indian reservations and the rest of the U.S. population: higher poverty rates and unemployment, and lower median income and educational attainment.[10] Roughly half of AI/AN people live on reservations or in remote rural areas, making them the least urban of all U.S. subpopulations.[11] AI/AN populations in urban and metropolitan areas fare a bit better, but most remain in low-SES circumstances.[12]

Over the past few centuries, American Indian tribes were removed from their indigenous lands and resettled in new, unfamiliar lands against their will.[13] They lost their indigenous way of life and culture and were subjected to government-imposed assimilation.[14,15] Their economically depressed conditions are a direct result of a powerful matrix of negative forces: systematic injustice and discrimination, forced relocation, and exploitation [16,17] that have historically stacked the deck against the AI/AN population—an enduring legacy.

American Indian communities are worlds apart from the baseline SES level of the rest of the country. According to Dr. Yvette Roubideaux, "For most American Indians, relocation to rural reservations in the 1800s resulted in a loss of culture, traditions, and familiar ways of life and left them isolated in places that were far removed from the resources available in urban areas. Years of poor educational systems and lack of opportunity have resulted in seriously depressed socioeconomic conditions on most reservations."[18] Tobacco disproportionately affects low-SES populations in the United States,[19] and

with AI/AN people at the bottom of the SES scale, the burden of both general and tobacco-related health disparities weighs on these communities heavily.

GENERAL HEALTH DISPARITIES FACING AI/AN COMMUNITIES

Levels of income, education, employment, and the places where people live, work, and play have direct impacts on health outcomes. These are known as social determinants of health.[20,21] Inequalities in the social determinants of health, which lead to health disparities, are the results of broader social and economic policies and programs.[22] People with social and economic disadvantages face greater disease risk and poorer health outcomes compared to those without such disadvantages.[23] As discussed earlier, tribal communities face extreme inequality on multiple social determinants of health and entrenched social and economic disadvantages that lead to poor health outcomes and health disparities.[24,25] "Losing land, culture, and lives through systematic government attempts to assimilate indigenous populations by changed diet, culture, and forced relocation can be linked to today's tribal health challenges."[26] And recent history provides a gloomy snapshot of AI/AN health challenges: Since at least the mid-1990s, rates of obesity, diabetes, and hypertension in this population have increased.[27] Many of the diseases disproportionately affecting the AI/AN population are preventable or treatable.

The Indian Health Services (IHS), which was created to provide health care for all AI/AN populations, does not receive sufficient resources from the Federal Government to meet the health care needs of its target populations.[28] According to Roubideaux, "Although the federal government has a trust responsibility to provide health care for American Indians and Alaska Natives, the Indian Health Service is substantially underfunded and understaffed."[29] Most AI/AN people do not have private health insurance, instead relying on the Indian Health Services—a weak safety net indeed, with federal funding for each AI/AN person roughly half the amount spent on the health care of federal prisoners.[30]

The high prevalence of alcohol abuse among AI/AN individuals[31] has a significant health and social impacts on AI/AN communities.[32] Compared to the general U.S. population, deaths caused by alcoholism are 5.24 times higher among AI/AN persons.[33] Moreover, mortality risks related to tuberculosis, vehicular accident, diabetes, and suicide are significantly higher among AI/AN persons than in the U.S. population.[34]

A host of socio-economic challenges affect these communities: Elevated unemployment and poverty rates, significantly greater prevalence of heart disease and diabetes, lower likelihood of preventive screenings, lower rates of leisure time physical activity, and elevated mental illness and drug and alcohol abuse are all realities for this subpopulation, both on and off the reservation.[35] These dramatic health disparities between AI/AN people and the rest of the U.S. population have persisted for five centuries—dating back to the arrival of Europeans in North America.[36,37,38]

TOBACCO-RELATED HEALTH DISPARITIES

While the smoking rates of the general population in the United States have fallen measurably as a result of tobacco control policy implementation, cessation therapies, and media campaigns; the tobacco use rate across AI/AN communities has experienced no such improvement.[39] In fact, AI/AN communities report the highest smoking rates of any U.S. subpopulation—with rates almost double the general population.[40] While much effort and resources have been devoted to tobacco control policy efforts and awareness for the general population and the largest subpopulations, a conspicuous lack of AI/AN-specific tobacco-related research and tobacco

control efforts have only contributed to the widening of this gap.

FUNDING FOR TOBACCO CONTROL IN AI/AN POPULATIONS

AI/AN youth in the United States face a high risk for tobacco-related health disparities. In spite of this, tobacco control is chronically underfunded in AI/AN communities. A severely under-resourced Indian Health Services Department cannot adequately address commercial tobacco use in the AI/AN population given competing health priorities. The need, however, is critical.[41]

NEED FOR TRIBALLY TAILORED TOBACCO CONTROL PROGRAM

Some evidence indicates that AI/AN smokers may have greater difficulty quitting than white smokers and that interventions constructed with non-AI/AN populations in mind may not be effective with Native tobacco users.[42] Smoking in tribal communities also begins at a young age (typically 14 years).[43] Forty percent of deaths (two of every five) in the AI/AN population are related to or caused by commercial tobacco use.[44] Therefore, culturally appropriate, and in some cases tribally tailored, interventions that account for the socioeconomic, historical, and psychological forces that contribute to high tobacco use rates are crucial to addressing disparities successfully.

TOBACCO CONTROL IN AI/AN POPULATIONS AND "CEREMONIAL" VERSUS "COMMERCIAL" TOBACCO USE

Any discussion of tobacco use in this population must account for the nuanced distinctions and cultural definitions of "sacred" or "ceremonial" tobacco use and "commercial" tobacco abuse. Ceremonial tobacco use takes a variety of forms in AI/AN communities: It can be offered as an honorific gift to the Creator or to a member of the tribe. It can be burned in a pipe, dish, shell, or fire—the smoke carries prayers to the Creator. It can be smoked or not smoked. Frequency of sacred tobacco use varies across tribal communities, from daily to only on special occasions.

American Indian tribes are sovereign nations with inherent powers of self-government. Legacy acknowledges and honors tribal sovereignty. Legacy supports the idea that tobacco-related programming must be implemented directly with the sovereign nations.

As it concerns tobacco control, tribal sovereignty has at least one significant benefit. It allows tribes to enact their own tobacco control polices and laws that can be more comprehensive and stringent than those enacted by the states or other local jurisdictions. However, it has two unfortunate side effects: It can lead to tribal tax policy that does not discourage tobacco use, and it usually keeps out state funding aimed at addressing tobacco-related health disparities. Tobacco control policies implemented by states do not need to be recognized by sovereign tribal nations. The ensuing economic benefits to tribal communities of untaxed or low-taxed tobacco sales hinder tobacco cessation programs and result in easily obtainable reduced-price tobacco products.[45]

In many cases there is insufficient family or social pressure in AI/AN populations to quit using tobacco.[46, 47, 48] Culturally sensitive and tailored tobacco cessation programs that account for the social, political, and cultural facets of smoking behavior represent a critical need in these communities.[49, 50] Lack of awareness or distrust of pharmacotherapy to aid cessation can also hinder quit attempts in tribal communities.[51] This distrust may be grounded in skepticism of modern medicine as well as historical racism and trauma inflicted by past research and other academic and scientific abuses.[52] These factors cannot be underestimated. Tobacco research, control, and intervention in AI/AN communities are complicated, and all efforts must be sensitive to this landscape in order to be successful.

TARGETING OF AI/AN POPULATIONS BY BIG TOBACCO

Tobacco companies' marketing efforts disproportionately affect low-SES communities with higher concentrations of point-of-sale marketing and a higher density of tobacco outlets[53, 54, 55] and with the AI/AN population sitting at the very bottom of this socio-economic ladder, the influence of tobacco marketing is especially strong. Myriad factors keep these communities comparatively saturated with relatively low-cost and readily available commercial tobacco products, exacerbating the monumental challenge of decreasing AI/AN tobacco use rates.

COMMERCIAL TOBACCO AND TRIBAL SOVEREIGNTY

The following are some important factors as regard to commercial tobacco in the context of tribal sovereignty:

- As dictated by tribal sovereignty, commercial tobacco can typically be purchased on tribal land without taxes and at prices far below the standard elsewhere in the United States.[56]
- Some commercial tobacco packaging and marketing efforts deliberately exploit tribal images and culture to appeal to the AI/AN population.[57]
- AI/AN tribal gaming casinos, bingo halls, and public spaces often do not adhere to statewide smokefree policies, as they are governed by the laws of sovereign tribal nations.[58, 59, 60]

RESILIENCE AMONG AMERICAN INDIANS AND ALASKA NATIVES

Despite persistent health disparities facing AI/AN populations,[61, 62] and limited resources and capacity available to address those disparities, health remains an important priority for the tribal nations.[63] This perspective should be taken into account in implementing any future tobacco control efforts geared toward American Indians and Alaska Natives.

Tribal nations have survived historic injustices and have demonstrated inherent strength in response to persistent socioeconomic adversity and disparity. According to Dr. Teresa D. LaFromboise and her colleagues, "Resilience in the face of adversity is not new to American Indian tribes. They have survived genocidal practices directed toward them, including massive redistribution of people away from their homelands and the imposition of the reservation system. They withstood drastic changes in sociopolitical, cultural, and physical environments and the added stress from oppression and hostility."[64] Some preliminary research has shown that factors such as enculturation into native tribal culture and traditions, strong cultural identity, community and family linkages and support structures in tribal communities contribute to inherent resilience among American Indians.[65, 66, 67, 68]

Public health and tobacco control programs for tribal communities must acknowledge and draw from these inherent characteristics.

Chapter 3

Research in Tribal Communities

INTRODUCTION

Any discussion of research within AI/AN communities must address the legacy of historical trauma and the persistence of research abuse in these populations. Forced and rapid assimilation has affected this population culturally, economically, and psychologically, and the erosion of culture has led to depressed health outcomes.[69] European settlers and the U.S. government have long threatened the well-being of AI/AN cultures. Researchers and service providers must strive to understand this history and appreciate why many AI/AN people are distrustful of outsiders who claim to have good intentions but may actually have ulterior motives.[70]

This wariness among AI/AN people reflects a checkered history of interactions with researchers, whose insensitivity and self-interest have long been a subject of concern in Indian country.[71] These research abuses linger in the collective memory, not simply as stories from generations past, but also from recent experience. A prominent example occurred on the Havasupai reservation in Arizona, where, beginning in 1990, researchers from Arizona State University (ASU) collected genetic specimens for a study on diabetes—a disease devastating this population. The researchers later, without consent, shared these samples with colleagues working on unrelated projects analyzing schizophrenia, inbreeding, and population migration.[72] The tribe brought a lawsuit against the university arguing that such conduct, though under the guise of scientific progress, offended and undermined their tribal values. The university spent several years and $1.7 million fighting the suit, and the tribe issued a "banishment order" banning ASU employees from setting foot on the reservation. In 2010, after years of legal battles, ASU settled with the tribe, returning the genetic samples, paying $700,000 in damages to a group of 41 tribe members, and agreeing to provide other forms of assistance to the impoverished Havasupai people.[73] This case highlights the persistent relevance of tribal worries about both the safety and the value of academic research in their communities, and a general skepticism that research will actually serve tribal needs.[74]

THE VALUE OF COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

The American Indian and Alaska Native Health Research Advisory Council (HRAC) at the U.S. Department of Health and Human Services recommends "increasing AI/AN researchers, increasing the amount of community-driven research, and increasing the capacity of AI/AN Tribal governments to conduct their own research and implement programs based on findings from their research."[75] In an effort to construct research initiatives that are sensitive to the legacy of abuses and mistrust between researchers and tribes, community-based participatory research (CBPR) has emerged as a promising model that incorporates collaboration and co-learning with tribal leaders and community members and aims for an approach with cultural competence. The CBPR approach stems from the work of Dr. Kurt Lewin, a social psychologist and Dr. Paulo Freire, an educator and philosopher. It emphasizes community engagement, mutual learning, action-reflection, and a commitment to sustainability.[76] According to the Kellogg Health Scholars Program, "CBPR in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the

unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."[77]

One of the most fundamental power shifts in research within AI/AN communities has been around ownership of data. According to Mohammed, S.A. and colleagues "The norm of one-sided, exploitative research has clearly begun to shift. Tired of being 'researched to death,' having little or no control over research studies, and typical 'parachute,' 'drive-by,' or 'helicopter' models of research where researchers drop in, quickly take what they need, and leave, many indigenous communities are reclaiming rights to their own knowledge production."[78]

Data ownership and sharing arrangements vary based on the community's needs and priorities; perhaps the best illustration of the principle of CBPR is how proponents of CBPR aim not to conduct research on a community, but rather with a community. Furthermore, this ownership of any resulting data allows the communities themselves to determine how it will be used to improve awareness and affect health outcomes.

The TCHI followed many of the key principles of CBPR outlined above, and while the initiative was not conceived or framed at the outset as CBPR, this report will investigate the aspects of the project that resonate with the working definition of this research approach.

PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

According to Barbara A. Israel, et al., CBPR:

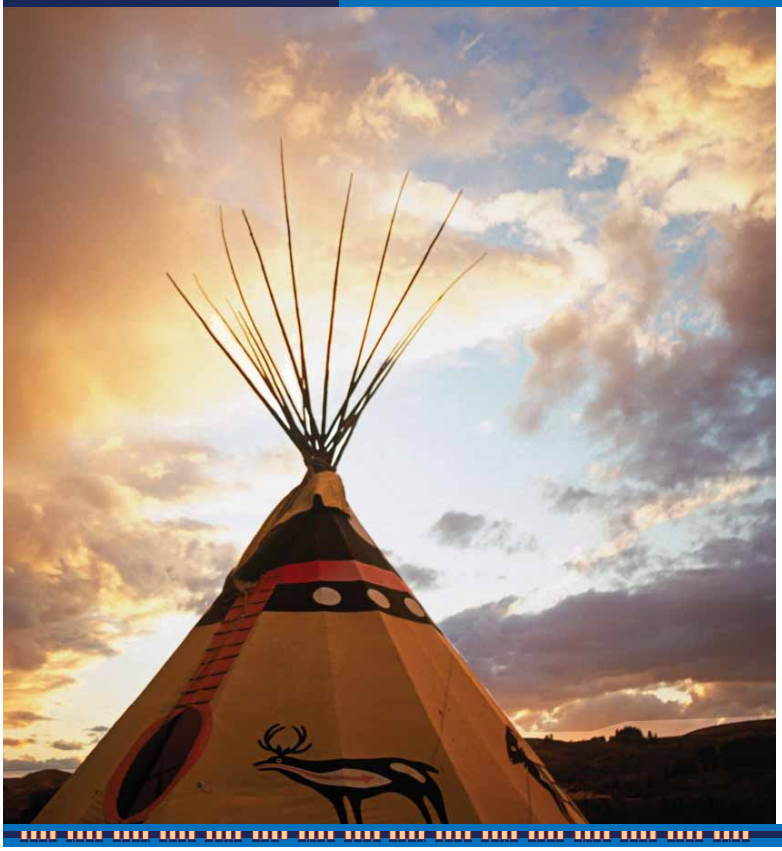
1. Recognizes community as a unit of identity;
2. Builds on strengths and resources within the community;
3. Facilitates collaborative, equitable involvement of all partners in all phases of the research;
4. Integrates knowledge and action for mutual benefit of all partners;
5. Promotes a co-learning and empowering process that attends to social inequalities;
6. Involves a cyclical and iterative process;
7. Addresses health from both positive and ecological perspectives;
8. Disseminates findings and knowledge gained to all partners; and
9. Involves a long-term commitment by all partners.

Source: Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., & Community-Campus Partnerships for Health. (2001). Community-Based Participatory Research: Policy Recommendations for Promoting a Partnership Approach in Health Research. Education for Health, 14(2), 182-197.

Chapter 4

Research Methodology

Implementation of the American Indian Adult Tobacco Survey in Three Tribal Communities



CREATION OF THE ADULT TOBACCO SURVEY TAILORED TO AI COMMUNITIES

In 2000, the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC) supported a project that partnered with five tribal support centers for tobacco control programs and other experts in the field of AI research to develop a survey tool (the AI Adult Tobacco Survey) that addressed the shortcomings of prior survey methods and collected data that would be relevant at the tribal level.[79]

"There had been public health advocates within Centers for Disease Control and Prevention who were arguing that the data quality that was available to the public health advocates on the ground at the tribal level was just really inadequate for being able to examine benchmarks," said Favian Kennedy, TCHI advisory group member and executive director of Health Education and Promotion Council.

The standard Adult Tobacco Survey (ATS) was an ill-fitting tool for health surveillance in tribal communities. "We looked at the original ATS that was used by the states for [the] mainstream population, and we realized there were several problems with it that made any data collected by tribes invalid," said Dr. Janis Weber of JCW Research & Evaluation Group, TCHI advisory group member and evaluator for the original CDC AI ATS working group. "If you happen to belong to a tribe that uses tobacco ceremonially, you probably have smoked a pipe 20 times if that's the channel that your tribe uses to smoke tobacco, but you may not smoke commercial tobacco … but if you answered yes to that question [about smoking], you're automatically deemed a smoker."

The AI ATS tool distinguishes between commercial and ceremonial tobacco use, it is designed to be administered using in-person interviews and it is adaptable, allowing tribes to tailor it to their needs. In 2004, the survey tool was conducted with 11 tribes. "Dr. Corinne Husten [then the head of epidemiology at the OSH/CDC] was a groundbreaker at the time," said Weber. "She understood that by law and by treaty the tribes are sovereign nations. So they were allowed to develop data sharing agreements, and if they owned the data … if they wished to share the data with CDC, fine, but if they didn't, the tribes own the data. The entire framework upon which the American Indian Adult Tobacco Survey was built was a community-based participatory model. The protocols insist that members of the tribe are the interviewers."

The TCHI used this culturally responsible survey to gather information on general health, commercial tobacco use, smoking cessation, health care provider screening and referral, risk perception, and opinions on tobacco policies in three distinct tribes. In keeping with the working protocol, each of the tribes would own the data collected, and it would be up to them to decide whether and in what capacity to share it, even with Legacy.

"The goals as we understood it were to provide tribal colleges with an opportunity to build capacity and infrastructure in public health, public health surveillance," said Weber. Kennedy echoed this notion. "We had all thought it would be very important to really connect the intra-tribal stakeholders in a specific community so that they might be able to benefit from the data, like tribal health, Indian Health Service, the epidemiology centers in a particular tribal

nation or region," he said. "Our job was to actually build public health infrastructure and to help the tribes begin to develop approaches to address tobacco use."

SEEKING APPROVAL FROM TRIBAL LEADERS AND INSTITUTIONAL REVIEW BOARDS

Each site needed approval from its respective tribal boards and councils, as well as approval from at least one Institutional Review Board (IRB), such as the tribal IRB, the tribal college IRB, and/or the Indian Health Service IRB. The specific process followed was unique to each site based on each tribal board or council's requirements of research projects, which IRB was being utilized, and what agency took the lead on the project.

"When you go to a tribal community, they're going to want to know exactly what you want and exactly what you want it for, and how it's going be useful for their community," said Abramson. The length of time needed to complete IRB paperwork and receive approval varied by site as well, depending largely on which IRB reviewed the application, the tribal agency's level of experience with the IRB process, and the specific project implementation plans being proposed by the tribal agency.

The core project team provided each site with a template for a tribal resolution and a data sharing agreement that the coordinating agencies could use as needed to get the process started. The team provided the necessary technical assistance, ranging from presenting information and answering queries at tribal board meetings to submitting an IRB application to IHS. The tribal boards were supportive of the project and recognized it as an opportunity to address a critical health issue. Buy-in from key tribal leadership was easy to obtain due to the approvals needed for the application phase and the rapport already built with the tribal colleges and AI-owned research agency.

The most common questions raised were regarding data ownership. "We talked with them about what their right was as a tribal community to own that data," said Abramson. "We clearly delineated what our funder would need, and what their ownership was." The data sharing agreement for all sites clearly stated that all data collected through the project would be the property of the tribe, and the project team had to be granted permission from the tribe to access, work with, report on, and share the data in any way.

RECRUITMENT OF STUDENT INTERVIEWERS

The tribal college sites primarily recruited students from the tribal college who were also members of the tribal community. These tribal student interviewers were paid for their contribution to the project. Each site used a combination of different recruitment methods. For example, the research coordinator at the Bemidji Area Indian Health Service Region recruited students by posting job descriptions on campus and by word-of-mouth advertising through faculty members. The project coordinator at the Billings Area Indian Health Service Region site, who was the dean of academics at the community college, recruited students by notifying instructors, posting flyers, and talking directly to students.

At the site located in the Aberdeen Area Indian Health Service Region, the research project was designed as a semester-long course for college credit. A core project team member served as faculty of the college to provide instruction for the course. Students received three credits of independent study in health surveillance and monitoring in addition to the compensation for being an interviewer. The section on page 29 provides more details on the recruitment and training approach used by this particular site.

TRAINING OF FACULTY AND STUDENT INTERVIEWERS AND FIELD IMPLEMENTATION

By design, the TCHI aimed to engage the community in the research process from the absolute grassroots, boots-on-the-ground level. This required training of tribal college students to prepare them to perform this type of health-related surveillance work. Many of the students were completely unfamiliar with community-based data collection, though some student researchers from at least one site had participated in local outreach during the most recent U.S. Census. The tribal college sites focused on recruiting students from the tribal colleges who were also members of the community. "If they're at a tribal college, they might not necessarily be a community member or a member of the tribe, but they are … essentially part of the community," said Abramson. "They know the people, and they know in general how to be respectful in people's homes."

The interviewer trainings lasted two days and used a common agenda and instructional tools. "They did really walk the student through every phase of gathering data, [and] identified potential problems that have been encountered in the past or potentially could be encountered here," said Abramson. "They did a lot of role playing and mock interviews. They did a thorough job in preparing the students for that actual task."

The core project team conducted the on-site trainings for each participating site. They covered the development and importance of the AI ATS, basic concepts in survey methodology (sampling, following protocols, objectivity), and the logistical aspects of collecting survey responses (survey tracking, quality assurance, data management). Since many interviewers had no previous experience with standardized research protocols, explaining the scientific principles underlying the procedures (e.g., the use of random samples to generate population-level estimates) was also included in the training curriculum.[80]

In some cases, the training sessions also served as an opportunity for self-selection—some potential interviewers decided that they weren't up to the task. "Once people

According to Dr. Stacy Thorne, health scientist with the CDC, the federal office that oversaw the construction of the AI Adult Tobacco Survey, "CDC staff worked together with Tribal Support Centers for Tobacco Control Programs, tribal leaders and organizations, and tribal community members to ensure that the project was informed by accepted scientific practice and culturally appropriate strategies. As a result, the experiences and successes shared in this collaboration are now available to all tribes, tribal organizations, and other organizations. CDC continues to work with tribes to ensure that the AI ATS integrates competent methods of communications preferred by American Indian populations, with the goal of achieving widespread use of the survey among U.S. tribes and communities."

got into the training, they decided pretty quickly whether they could do this or not," said advisory board member Cynthia Tainpeah of the Muscogee (Creek) Nation Department of Health. "Some people dropped out. They decided that this was not for them." Those who stayed on, however, were committed to the project overall and had a certain level of excitement. "The students were very receptive," said Tainpeah.

> "I think just going out and speaking with elders, and having a topic that they could share … that impacted both generations, I think was very important. They were excited about learning more about the traditional use of tobacco, even within their own communities." - Cynthia Tainpeah, Health Administrator, Muscogee (Creek) Nation Department of Health

The tribal site from the Aberdeen Area Indian Health Service Region had a very different training and field execution process—the partner research organization worked with the tribal college and core project team to develop a semester-long independent study course on public health surveillance and monitoring.[81] Partner organizations Missouri Breaks (an AI-owned and operated research agency based in the Aberdeen Area region) and the Health Education and Promotion Council (HEAPC) hit upon this novel idea. HEAPC's Favian Kennedy led the course at this tribal college site. Students earned three units for their work, which included 19 hours of in-class training. Students were also paid for their fieldwork. "We were able to create a situation where the students were extra incentivized," said Kennedy. "We were able to give them experience that they would not have had otherwise." Kennedy had conducted the AI ATS in this same community in 2005, presented the tribe with the data set, and returned the data to the tribe for full ownership. The relationships and rapport previously built were beneficial for executing the Legacy project at this site. The course and its syllabus were designed to be fully adaptable to a range of public health surveillance initiatives, and, given the proper funding and support, this instructional model could prove to be broadly applicable to other research projects. Any survey could be plugged into this model and be conducted the same way.

Kendra Enright of Missouri Breaks provided the logistical support and technical assistance in the field for the Aberdeen group. The student researchers in the group met their data collection goal rapidly, completing the fieldwork in six weeks and collecting 400 surveys over a geographic range comparable in size to the state of Connecticut. "The tribal community is the hub of the reservation, but we have 19 other communities up to 90 miles away," said Enright. Students covered each of these tiny towns and homesteads, surveying every third household, even in the most remote corners of the reservation. "We stressed the importance of good data," said Enright. "Clean research gives you good results, and without clean research you don't have results. There's too many variables in there." Enright also believes that a stretch of unusually mild winter weather contributed to the speed with which the surveys were collected.

This integrated, curriculum-based approach proved to be a truly innovative way to gather data—an approach that adheres closely to the ideals of CBPR. Capacity to carry out this type of research was built on at least three levels: within the individual students, within the tribal college and the partnering organization, and within the tribe itself. The syllabus created for this course was designed to be flexible enough to accommodate a wider range of public health surveillance priorities, thus creating a tool that would far outlive the limited timeline and impact of the Legacy project itself. The approach taken at the site is worthy of further examination in the section below to highlight how it could serve as a model for other CBPR initiatives in other tribal areas.

TRIBE FROM THE ABERDEEN AREA INDIAN HEALTH SERVICE REGION: A STORY FROM THE FIELD

Roletta Pretty Weasel and Leslie Morrison Veit came to the Legacy project through a tribal college, where they were both students at the time of the research initiative. Each was drawn to the project initially due to a personal connection to the effects of commercial tobacco use. Both of Veit's parents died from tobacco-related illnesses. Pretty Weasel is a former smoker, and her health is compromised—with asthma and lung disease—from this history of use. Both students were pursuing fields of study that naturally overlap with this sort of community-based field research. Pretty Weasel is working toward a bachelor's degree in social work with a minor in chemical dependency. Veit is studying to be a medical assistant.

Both students, however, were new to face-to-face surveillance work. "At first I was nervous, but when I got to the door I'd just start visiting with them and trying to hold a conversation with them, and explain things to them and make them more comfortable to talk about the things we needed to talk about," said Veit. "It was good to meet people who I never knew existed, and there are a lot of little communities."

Pretty Weasel was sent primarily to areas with which she was familiar. "I have a lot of relatives in that area, and I was getting to meet them again, getting to know them again," said Pretty Weasel. "I'm fluent in my local language, and sometimes I think you can get more information out when you speak in your own language. You don't just walk in and sit down and we do this clinical thing about questions and answers, and then get up and walk away. You sit, and you talk and you visit, and you share a cup of coffee with them." She blew two tires on rough gravel roads, driving 50 miles each way on some days to reach the far outlying areas of her community. Pretty Weasel and Veit carried an invaluable currency with them in the field as members of the community, thus facing greatly diminished barriers of trust and rapport building.

As much as they were collecting valuable data, Pretty Weasel and Veit felt like they were also distributing vital information—such as quitline resources—of which residents in the most remote parts of the reservation were not aware. "We're kind of out in the middle of nowhere, and we got out to parts of the reservation that wouldn't ordinarily receive this sort of information," said Pretty Weasel.

> "I think having people that they know or that they're familiar with bringing the information is a lot more accepted. If someone from the outside comes in and does research and leaves again, you're never going to see that person again, so how are you going to trust what they bring you?" - Pretty Weasel

The value of community researchers could not be underestimated in this context—their ability to bridge gaps of culture and rapport and build trust were critical to the success of the initiative. Even though the method of having community members survey their neighbors may not meet the standards of Euro-American–centric research frameworks, it is particularly important for a research initiative in an AI community. This level of community involvement in research is necessary to truly understand and capture Native perspectives and concerns. Highlighting the limitation of Euro-American research standards in Native research contexts, LorrieAnn Santos writes, "For the most part, Native viewpoints are not respected or understood because their concerns often require more time,

consideration and effort, and do not fall within the structure of the Euro-American research tradition."[82]

At times Pretty Weasel had to navigate intimate social situations in the course of her fieldwork, like the time she had to figure out how to make an exit from a house party after collecting her surveys, or the time she went to a local powwow specifically because she knew that certain members of the community with whom she had been unable to make contact would be in attendance. "Word of mouth is quite rampant around here," said Enright of Missouri Breaks. "You could compare this with Facebook, and it's probably that fast or faster." Due to this informal communication dynamic, the community had an elevated level of awareness of the project and therefore were not blindsided by researchers showing up on their doorsteps with clipboards.

Enright says the speed with which the student researchers collected their data was due to a high level of engagement with the issue and the community. "It's something I'm passionate about," said Pretty Weasel. "It's something I believe. This gave me a time to openly tell them about tobacco and help them get information. I smoked and I suffer a lot from my years of tobacco use, and I even shared that with them."

The research team at this site found daunting rates of commercial tobacco use—roughly 50 percent of adults are smokers. In the two counties where the surveillance took place, poverty is pervasive. Based on per capita income, these two counties are among the five poorest in the nation. The tribal site team from the Aberdeen Area Indian Health Service region is particularly interested in unpacking the complicated dynamics at play between extreme poverty, joblessness, and tobacco use. How do people afford cigarettes when they are living in extreme poverty? "It's because they'll go without something to be able to get those cigarettes," said Enright. Bills go unpaid, said Pretty Weasel, "like water and other necessities because that tobacco is more important," she said. Commercial tobacco addiction persists despite poverty so extreme that it would appear economically impossible.

Despite these grim realities, the team found that local residents overwhelmingly want to quit their tobacco use. "It's over 70 percent," said Pretty Weasel. "We need to find a way to help them, whether it's community action, whether it is health care providers, or a quit line. The answers we got—they were like eight years old when they started smoking, and some of them are in their 80s and they're still smoking. [Commercial] tobacco has been around a really long time."

According to Stephanie Bliss of the Inter-Tribal Council of Michigan, all three sites may have been better served if this semester-long research course approach had been implemented from inception.

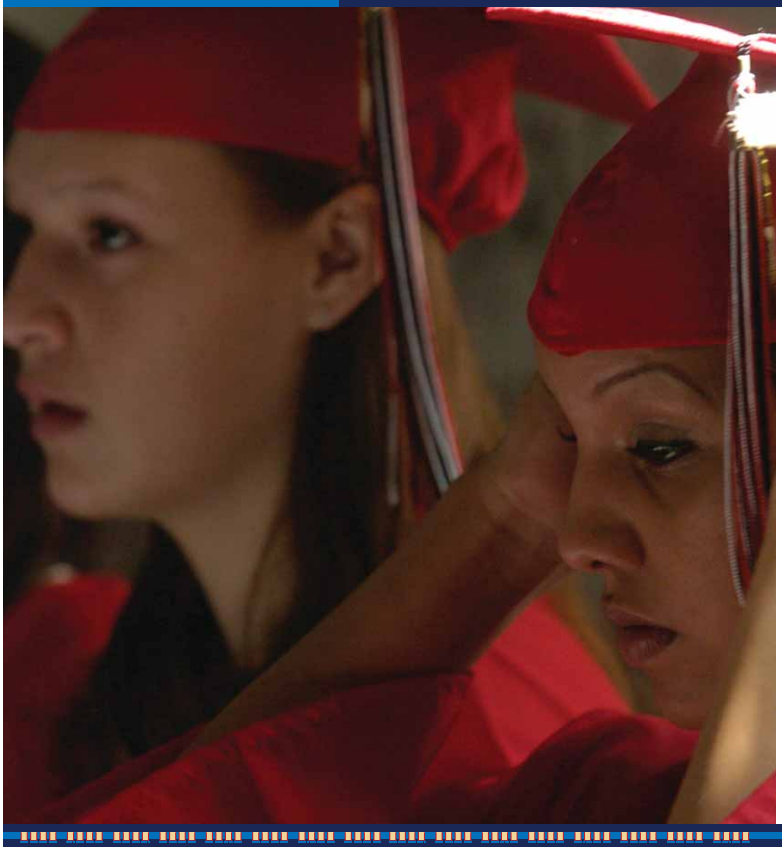
"That would have had to have been agreed upon at the very beginning of the project, before the colleges came on board," she said. "They would have had to discuss the idea thoroughly and made sure that the colleges had the staff, time, and other necessary resources available."

Hindsight, of course, is twenty-twenty, and the success this approach had at the Aberdeen Area tribal site provides a critical case study for other practitioners of public health survey work on tribal land.

Chapter 5

Tribal College Health Initiative

As Community-Based Participatory Research



INTRODUCTION

As noted previously, the TCHI followed many of the key principles of community-based participatory research, though the initiative was not conceived at the outset as CBPR. Even so, many aspects of the project resonate with the working definition of this research approach. CBPR, says Abramson of the ITCM, is something that you know when you see it, but it is not necessarily a term they use in the field. "When I read about community-based participatory research, I read about all the elements and I'm like, 'Oh, we do that,'" she said. "As a tribal organization, that's how we operate because we know that that's what works." Abramson says that Legacy deserves credit for a truly inclusive, collaborative, and grassroots approach from the beginning. "The way that it was initiated with input from tribal communities, with input from people involved with tribal communities—that was really key," she said. "We were asked. [Legacy] simply asked us what would work. Legacy didn't approach us to say that they were going to give us funding to do it. They said if it was going to be done, how would it happen? It wasn't an easy thing to conceptualize, necessarily, and it really took a lot of discussion."

The following sections present the key elements of the initiative that speak to the core principles of CBPR.

FLEXIBILITY IS KEY

A flexible approach is necessary, said Abramson, when working in AI communities. "I think sometimes we can have an idea about what we think can happen from this rigorous research standpoint," she said. "The reality is maybe the communities just aren't ready for that or just won't find it acceptable. So how do you craft a project that will be useful for the tribe and that is also going to be useful for whatever organization that's providing that funding?"

TRIBAL OWNERSHIP OF DATA

It is impossible to ignore the fundamental mistrust of researchers on the part of AI communities—countless experiences like those of the Havasupai tribe discussed earlier linger in the collective memory. The proposition of tribally owned data, however, can greatly influence buy-in and perceived value by these communities. "That mistrust still exists," said Tainpeah of the Muscogee (Creek) Nation Department of Health. "[American Indian] people are really cautious when it comes to non-Indians in any area, not just this area, but in any area that is asked to do research. Having specific tribal data will enable that tribe to write grants other than just tobacco related. Having tribal specific data has proven to be very beneficial for tribes that have previously completed the AI ATS—it would be tribal members asking tribal members, and this information would be used for the tribe and not an outside entity." That element of sovereignty and determination was critical for the project.

ESTABLISHED RELATIONSHIPS

"It would be very difficult for [outsiders] to come out here and to be able to navigate the tribal governmental systems as well as just interacting with the people at the ground level," said Kennedy of the Health Education & Promotion Council. "The community participatory part really comes

into play in terms of what is done with the data, and you have to establish relationships with people ahead of time before you ever have the data to create interest in that data once you have it." Here, then, the ownership of the data ideally translates into truly community-based efforts toward addressing health disparities. These communities now know that it is possible to be self-determined to collect, analyze, and report on their own data, and then use it to improve community outcomes.

CREATING COMMUNITY-BASED PARTNERSHIPS

Partnering with tribal colleges was an innovative approach to accessing the target communities, and one worth replicating, said Kennedy. "I think it was an outstanding idea from Legacy to really build capacity of the tribe, specifically with the tribal college element to engage in health surveillance and monitoring around tobacco. I think that connecting [the tribal colleges] with other tribal agencies and other agencies that may be willing to support an effort like this is probably the greatest success of this project."

Stephen Yanni, land grant director of the local community college, who oversaw the data collection at the tribal site from the Bemidji Area Indian Health Service Region, explained the appeal of this project as twofold. "This was an experiential learning opportunity for our students, this is a component we always try to build into any of these external types of projects," he said. "The second issue was, of course, gathering information specific to this community that could ultimately be beneficial to us and the health and well-being of the community itself, whether it's in trying to encourage policy changes or bringing in prevention funding if the data showed the need for it.

> "The fact that it can bring some real-world research experience to our students is extremely valuable," Yanni continued. "That's a big component of this—providing an opportunity for our students to experience data collection within a tribal community and learn all of the ins and outs and pitfalls and best practices associated with gathering information within tribal communities." - Stephen Yanni

As a proposed next step, Weber of JCW Research & Evaluation Group recommended that if resources allowed, it would be advisable to convene a small group of people who had worked on the original AI ATS to create a roadmap—with the benefit of the lessons learned in the Tribal College Health Initiative—for an approach that marries the original survey tool with a goal of enhancing the capacities of tribal colleges to participate in community-based health surveillance.

CAPACITY BUILDING IN UNDERSERVED POPULATIONS

Kennedy points out that this project increased capacity and targeted health disparities in grossly underserved and isolated areas. "Public health messaging seldom reaches these places, and generally the funding is not enough to make the public health [effort] more than transient," he said. Still, incremental progress is happening, and the entire landscape of AI tobacco research and control has evolved in the last decade. "This project is a part of the whole movement that started with the development of the American Indian Adult Tobacco Survey—part of this whole idea that we need data for communities," said Abramson. "There are significantly more tribal policies and tribally driven policies limiting exposure to secondhand smoke within tribal communities, building policies [for] smokefree areas, smokefree buildings. It started with the push for educating communities, but also the push for getting communities their data. This project contributes to that movement and that momentum.

"The data is really important," Abramson continued, "but engaging in the process is also very important because that is educating the community about the need for change within their policy. CBPR is really two things: It gives people information, but the community also learns from the process. If you look at what was being done in the early 2000s and what's being done now, it's night and day. These issues are on the map. People are talking about them."

Chapter 6

Challenges and Lessons Learned

INTRODUCTION

The TCHI broke new ground with its collaborative community-based approach to tobacco health-related surveillance. Often with innovation on this scale, there are many bumps in the road and changes in direction. The initiative was beset by several challenges—some of which required a course correction during the execution, and others that emerged fully only in hindsight. The following sections outline these challenges and their associated lessons in order to improve the potential for success of future initiatives that may follow the model established by the TCHI.

PRIORITIZING TOBACCO-RELATED HEALTH CONCERNS

A general, overarching challenge is effectively encouraging the development of discourse around tobacco issues in communities facing persistent, depressed socioeconomic status and severe general health disparities. Weber, of AI background herself, was on the team that built the original AI ATS and has conducted the survey with and analyzed the data for dozens of tribes. Weber explained just how daunting these persistent general disparities can be. "When we were [at the tribal site from the Billings Area Indian Health Service Region], they couldn't care less about tobacco because of the [other health] issues they have," she said. "Most the interviewers smoked, and, to a person, each of [the] interviewers had a story, and when you're working with tribal people you look at the stories. They were talking about their mothers who had breast cancer and who died at the ages of 30 or 40 because they received their health care from Indian Health Service. IHS has no prevention or public health component. They're a direct provider, and they're chronically underfunded. There's 80 percent unemployment there—chronic poverty. There's so much wrong, it's like a third-world country, and if the only pleasure they get is smoking a damn cigarette, who cares? That's the attitude."

PARTICIPATION AND RECRUITMENT

A further challenge in these communities is the possibility of research fatigue and the level of incentives offered. "[The tribal site from the Bemidji Area Indian Health Service Region] is a community that has been surveyed a lot," said Abramson. The people of that community are accustomed to incentives to participation that, in some cases, far exceeded what was available through TCHI, she said. That site had difficulty recruiting participants, and despite extended deadlines, increased resources, and on-site technical assistance from the advisory committee, the site failed to meet the target goal of completed surveys. The advisory group deemed the number of surveys collected (70) to be sufficient for productive data analysis, however. "You have to be flexible with tribes that have been surveyed, but haven't participated in AI ATS," said Abramson. "They didn't have any of that data, which would have been helpful to them."

Yanni, the coordinator at the tribal site from the Bemidji Area Indian Health Service Region, outlined some of the initial challenges his team faced with outreach and execution of the survey. "A letter was sent out to all adults 18 and over living within the county who were members of the tribe," he said. "They were asked to call the phone number if they were interested in participating. That additional step of

them having to call in and, and say yes, we'll participate, seemed to be enough of a barrier where at times it was a struggle. We sent out a number of subsequent mailings trying to entice more participation—the biggest challenge was just getting the participation level that was necessary. Once it was clear that we weren't going to hit our numbers with that approach, and we actually brought on a couple more research assistants and we did more of a proactive approach in terms of reaching out to folks who had been identified through the random sample, whether it was a phone call, or whether it was going to a place of business or a home, or I think we even used Facebook."

CROSS-SITE COLLABORATION

Several partners in the TCHI believed that a more integrated planning and execution among the three sites would have improved outcomes and streamlined processes. "I think our project would have benefitted from having those phone calls with the other colleges and communities that were doing the same thing we were right from the get-go," said Yanni. "I think they had … some good approaches. In one of them, the data collection was a class project, and that seemed to be a very effective route to go, and maybe that's something that we would have looked at as another way of moving forward. We were under the assumption that we were given this methodology and … this is really how they wanted us to move forward."

WORKING WITHIN TIMELINES AND BUILDING FOR FLEXIBILITY

Weber cautions against researchers, academics, and public health practitioners who may not necessarily come from an AI background working on initiatives in AI communities with preconceived rigid timetables and deadlines in mind. At the very least, they ought to be prepared to be flexible, she said. "Tribes don't see time like the mainstream does. That's not what is important to them. Family and community [are] more important, so if there are ceremonies, if there are funerals, if there are weddings, work comes second."

One idea that surfaced among the team members was for the technical assistance at the sites to be immersive—a two-day training followed by a period of time where the trainers would remain in the field with the interviewers to ensure comfort with the process and troubleshoot on the fly. "If anything came up, right away they'd be able to discuss any barriers," said Bliss. "That didn't happen, so folks were trained and then they kind of went off on their own, and I think that that was a bit of a problem because I think people were probably nervous. Maybe they had a few rejections." Ongoing support and training in a context like this—with unique variables arising in the field—can be crucial for success.

Bliss also recognized some challenges with the compensation. "Each site was able to decide how they wanted to pay the people working on this project," she said. "For example, [the tribe from the Bemidji Area Indian Health Service Region] paid their interviewers per completed survey, and we're talking about rural areas here, so if one person were to get in their car and drive to three places to do interviews and they were rejected three times, they still were paid for their gas; however, they weren't paid for their time."

WORKING WITH TRIBAL COLLEGES VERSUS WITH TRIBES THEMSELVES

Though the general consensus was that working with tribal colleges was a successful approach and one worth replicating, one member of the advisory board believed that, though there is great room for success with this innovative approach, hindsight highlighted some key features that must be included to ensure success. Weber, who had been on the team of researchers and experts who created the original AI ATS tool, believes that working with tribes and tribal councils has proven successful over her years in the field, but working with tribal colleges can be a worthwhile approach if executed with a few considerations in mind: the tribal colleges are representative of the local tribe; the tribal colleges demonstrate a commitment to working directly with the tribes toward addressing public health disparities; and the tribal colleges agree to data sharing agreements that ensure that the tribes own the data. In Weber's view, the importance of these elements only came fully to light in hindsight.

Yanni had some specific thoughts on future partnerships involving tribal colleges—though he believes this collaboration can be quite effective, there are some critical caveats. "A lot of tribal colleges are confronted with the issue of fairly low numbers of faculty and staff, folks who are typically pretty bogged down with teaching loads or other work that's part of their responsibility at the college," he said. "There's a range of capacity within tribal colleges, and most of us at tribal colleges, we're getting hit pretty regularly by folks who want to come in and partner on research projects, and the partnership can take many different forms, and some tribal college staff may want to be more involved in the foundation-building portion of a particular project rather than being asked to come in after the fact."

EXPERIENCE WITH A TAILORED ACADEMIC RESEARCH COURSE

The site from the Aberdeen Area Indian Health Service Region was the third and final site to join the initiative—a late addition after another tribe backed out of the project declaring the funds provided in the contract to be insufficient. This site proved to be innovative in its approach, with research conducted as part of a semester-long course at the tribal college. Once the multiple approvals and applications to IRBs cleared, Kennedy, who is based nearby, was able to launch this academic research class. The facilitation provided by Missouri Breaks, the AI-owned third-party research agency, may have been critical to the Aberdeen Area Indian Health Service Region's success. This agency had the requisite local network, track record, and research experience to partner effectively on the TCHI. Furthermore, there was substantial capacity built between the research agency and the participating tribal colleges to implement community research in partnership. "We made numerous contacts at these two colleges, and we now know the process to get it approved and to administer a research project like this," said Enright, whose agency has since partnered with the college on a "digital storytelling" project.

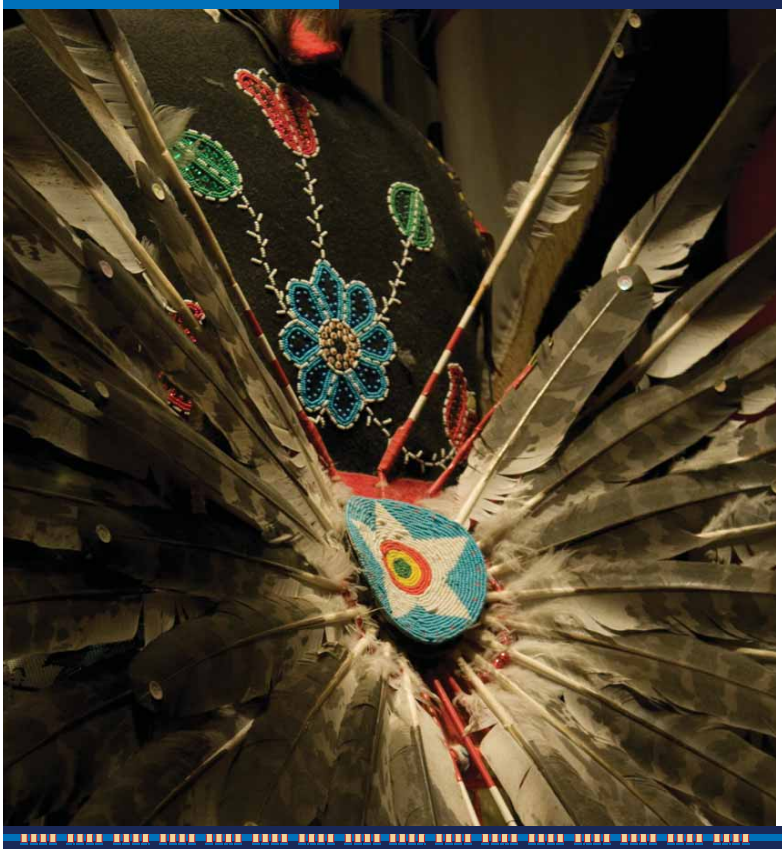
DATA OWNERSHIP AND BUILDING FOR MUTUAL BENEFIT

From the inception of the TCHI—in fact, from the very first exploratory conversations around the possibility of working in AI communities—Legacy has worked from the understanding that any data generated from research conducted within AI communities should be owned and controlled by the communities themselves. This approach has for at least a decade become the status quo for public health and academic research in AI communities and is one that Legacy fully supports. In addition to data sharing, the entire design of the initiative was consensus-driven—co-constructed by a key group of stakeholders in the AI/AN research and public health community.

Weber also emphasizes that the focus of any research in tribal communities should be on the full empowerment of the tribes to make their own decisions on how to address the health disparities of their communities. "A lot of funders have now discovered Indians have all these health disparities," she said. "So everybody wants to get on the bandwagon so they can publish about the Indians, but it's not about publishing. I've been working with them exclusively for 12 years, and I've never published anything because they own the data. Funders need to fund these things so that there can actually be culturally appropriate help, not for their own publishing purposes."

Chapter 7

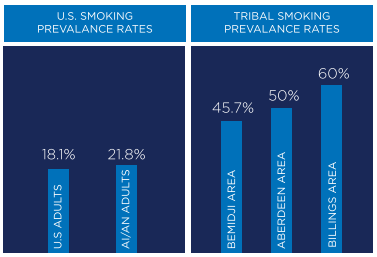
Summary of Key Findings and Next Steps



Each of the three sites chose to share data summaries with Legacy for the purpose of this publication. Again, sites have not been identified in the course of this report and will not be identified in the presentation of these data summaries. The aim here is to begin to establish a comparative portrait of tobacco use and its effects in these distinct tribal communities and in comparison to national data.

SMOKING PREVALENCE RATES

As of 2012, according to the CDC, 18.1 percent of U.S. adults smoked cigarettes.[83] Based on the national survey conducted by the CDC, the smoking prevalence among AI/AN adults was 21.8 percent in 2011.[84] The overall smoking prevalence rates for the adult community members of the three tribes surveyed in the TCHI are dramatically higher, as seen in the inset graph.



Smoking rates for the tribes from these service regions were drastically higher than the smoking rates among adults in the associated states, as shown in the following table:[85]

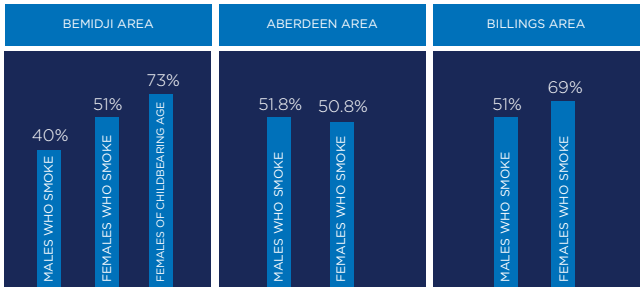
States Covered under Bemidji Area Indian Health Service Region and Adult Smoking Rates in 2012: Illinois: 18.6 percent; Indiana: 24 percent; Michigan: 23.3 percent; Minnesota: 18.8 percent; and Wisconsin: 20.4 percent	**States Covered under Billings Area Indian Health Service Region and Adult Smoking Rates in 2012:** Montana: 19.7 percent and Wyoming: 21.8 percent
States Covered under Aberdeen Area Indian Health Service Region and Adult Smoking Rates in 2012: North Dakota: 21.2 percent; South Dakota: 22 percent; Nebraska: 19.7 percent; and Iowa: 18.1 percent	It is important to note that no state-level data on the smoking prevalence among AI/AN populations were available.

GENDER DISPARITIES

When controlling for gender, current smoking prevalence for the general population in the United States is 20.5 percent for men and 15.8 percent for women.[86] In terms of the national smoking prevalence among AI/AN adults, 25.5 percent of AI/AN men and 18.7 percent of AI/AN women smoke.[87]

Data collected in two of the three tribal sites show measurably higher smoking prevalence among women than men.

The graph below illustrates these rates when looking at the gender split. These alarmingly elevated female smoking rates run dramatically counter to national statistical trends and deserve focused research and intervention.



"Exposure to secondhand tobacco smoke has been causally linked to cancer, respiratory, and cardiovascular diseases, and to adverse effects on the health of infants and children."

Source: U.S. Department of Health and Human Services, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General. Executive Summary. Retrieved from http://www.surgeongeneral.gov/library/reports/50-years-of-progress/exec-summary.pdf

THE TRIBE FROM ABERDEEN AREA INDIAN HEALTH SERVICE REGION:

43 percent of adults with asthma continue to smoke cigarettes.

48 percent of adults who have suffered a myocardial infarction continue to smoke.

49 percent of adults with high cholesterol continue to smoke.

49 percent of adults with high blood pressure continue to smoke.

62 percent of adults with diabetes continue to smoke.

58 percent of adults who have had a stroke continue to smoke.

35 percent of adults with coronary heart disease continue to smoke.

THE TRIBE FROM BEMIDJI AREA INDIAN HEALTH SERVICE REGION:

40 percent of adults with asthma continue to smoke.

33 percent of adults who have suffered a myocardial infarction continue to smoke.

31 percent adults with high cholesterol continue to smoke.

44 percent of adults with high blood pressure continue to smoke.

31 percent of adults with diabetes continue to smoke.

66 percent of adults who have had a stroke continue to smoke.

0 percent of adults with coronary heart disease continue to smoke.

THE TRIBE FROM BILLINGS AREA INDIAN HEALTH SERVICE REGION:

58 percent of adults with diabetes smoke.

65 percent of adults who have high blood pressure smoke.

59 percent of adults who have high cholesterol smoke.

37 percent of adults who suffered a myocardial infarction smoke.

38 percent of adults who have suffered a stroke smoke.

20 percent of adults with coronary heart disease continue to smoke.

SECONDHAND SMOKE EXPOSURE

In the general U.S. population, exposure to secondhand smoke has vastly decreased since the period 1988-1991, when 87.9 percent of nonsmokers had measurable levels of cotinine (a nicotine byproduct) in their systems. During 2007-2008, 40.1 percent of nonsmokers in the general U.S. population had measureable levels of cotinine.[88] While the TCHI did not measure cotinine levels on tribal sites, the survey tool did measure opinions of risk perception of secondhand smoke and attitudes toward and access to smokefree places. The following sections present a summary of findings as regard to the risk perception of secondhand smoke and views toward smokefree places.

Tribe from Bemidji Area Indian Health Service Region: 23 percent of respondents reported that smoking is allowed in some portion of their home. 60 percent believed that indoor work areas should be smokefree, and 25.7 percent believed that bingo halls and casinos should be smokefree. 75.7 percent of adults believed that secondhand smoke causes lung cancer in adults.

Tribe from Aberdeen Area Indian Health Service Region: 33 percent of respondents reported that smoking is allowed in some portion of their home. 74 percent of respondents believe that indoor work areas should be smokefree. 48 percent believe that bingo halls and casinos should be smokefree. 90 percent believed that secondhand smoke causes lung cancer in adults.

Tribe from Billings Area Indian Health Service Region: 39 percent of respondents reported that smoking is allowed in some portion of their home. 69 percent believed that indoor work areas should be smokefree, and 25 percent believed that bingo halls and casinos should be smokefree. 83 percent believed that secondhand smoke causes lung cancer in adults.

Overall, the AI communities profiled in the TCHI show elevated risks of secondhand smoke exposure compared to the general U.S. population, and the data indicate a pressing need for an increase in secondhand smoke education.

COMORBIDITY

Across the three sites of the TCHI, elevated comorbidity (coexistence of smoking and chronic disease) rates were found. In light of the earlier discussion of dramatic health disparities between AI/AN communities and the general U.S. population, these statistics pointing to an exacerbation of chronic disease by tobacco use are alarming and deserve greater attention. See inset table on page 43 for detailed summary of comorbidity rates across the three tribal areas surveyed.

COMPARISON OF QUIT METHODS

According to the CDC, in the general population, 48.3 percent of smokers who saw a health care provider in the past year were advised to quit.[89] Another CDC study showed that among the patients who were identified as smokers, 20.9 percent received tobacco counseling during their physician visit, and only 7.6 percent of them received a prescription or an order for a tobacco cessation medication.[90] The following sections presents data on quit methods that are used in each of the three tribal sites.

THE TRIBE FROM ABERDEEN AREA INDIAN HEALTH SERVICE REGION

Of the adults surveyed who had seen a medical provider in the past 12 months (43 percent of total survey), 48 percent were advised by their medical provider to quit smoking; 32 percent received suggestions to use a quit line or counseling service; and only up to 20 percent of respondents were prescribed some type of medication or nicotine replacement therapy.

THE TRIBE FROM BEMIDJI AREA INDIAN HEALTH SERVICE REGION

Of the adults surveyed who had seen a medical provider in the past 12 months (96 percent of total survey), 63 percent were advised by their medical provider to quit smoking; none received suggestions to use a quit line or counseling service; and only up to 20 percent of respondents were prescribed some type of medication or nicotine replacement therapy.

THE TRIBE FROM BILLINGS AREA INDIAN HEALTH SERVICE REGION

Of the adults surveyed who had seen a medical provider in the past 12 months (59 percent of total survey), 52 percent were advised by their medical provider to quit smoking; 18 percent received suggestions to use a quit line or counseling service; and only up to 19 percent of respondents were prescribed some type of medication or nicotine replacement therapy.

Even though the data from these tribal communities on quit methods are comparable to the national data, closer examination is necessary. The fact that only 48 percent of smokers who visited health care providers were advised to quit, only 20.9 percent received tobacco counseling during their physician visit, and 7.6 percent received a prescription of a tobacco cessation medication does not represent a golden standard for the delivery of tobacco cessation counseling and treatment. National rates are too low a benchmark for any kind of comparison. Moreover, given that the prevalence rates in these tribal communities are more than twice the prevalence rates in the general population, the need for better access to culturally competent tobacco cessation services becomes far more critical to these communities.

NEED FOR CULTURALLY COMPETENT PREVENTION AND CESSATION

The statistics show dire need for targeted, culturally appropriate tobacco education, outreach, and cessation programs. The AI ATS was actually administered in 2005 at the tribal site in the Aberdeen Area Indian Health Service Region, so there exists baseline data against which to compare these new numbers in that case. The preliminary comparison and analysis, however, is not encouraging. "There hasn't been much change in the percentage of people smoking," said Enright. "It was like a three-point difference between '05 and '12. We were all just kind of shocked by that because there's been so much education out there." This state of affairs underscores a greater need for culturally tailored approaches and dedicated resources for commercial tobacco prevention and cessation in these tribal communities. The education campaigns in this region thus far have failed to make a significant impact on the smoking rates of the population. Enright believes the chronic poverty of the region may be the biggest contributing factor to stubborn tobacco use rates—implying that without an overall elevation of SES, these rates may not change significantly.

Kennedy is hopeful that initiatives like the TCHI will begin to chip away at these persistently high prevalence rates." These communities now have excellent resources," he said. "They have surveillance summaries. They have community-friendly fact sheets that provide them basic information about the harms of commercial tobacco use. Those resources would not have been in place had Legacy not provided the funding."

NEXT STEPS TO UTILIZE THE RESEARCH FINDINGS

Dissemination of the data collected is in its nascent phase for the three sites of the

TCHI. The data will be used in a range of ways specific to the tribes' needs. "We have some folks who are putting together their presentations utilizing the data, and that information is then going to be presented to at least two different audiences within the community," said Yanni. "One would be the tribal leadership and college leadership, and the other would be an attempt to bring in more general community members."

Kennedy and Enright have already begun to focus on the policy implications of the data collected at the tribal site in the Aberdeen Area Indian Health Service Region. "We knew that they had been working on tobacco policy initiatives for quite a while," said Kennedy. "We had put additional items in this survey that spoke to perception about public policy. The tobacco coalition is using the data to promote smokefree policy. I know that the [tribe in the Bemidji Area Indian Health Service Region] is really concerned about secondhand smoke, so they're moving in that direction."

Enright elaborated: "When I look at the amount of people that have chronic diseases that still smoke, I think that right there is a big issue," she said. "Now, we can take this information and come up with brochures that deal with smoking and pregnancy, or smoking and asthma, or smoking and obesity, smoking and prenatal [care], smoking and heart disease—something like more targeted groups. I'm also working on an asthma project, and I can use a lot of the information from this tobacco study when I do education with people with asthma."

Kennedy elaborated in an interview on these recommendations. "There's a saying that failure to really achieve our goal with tobacco control is not related to the science, it's related to the failure to implement what we know works," he said. "We have a very good tool. We have a very good approach, and we know it works. But you really need to have someone on the ground that is committed to the protocol and is going to also understand why deviating from that protocol could cause problems in terms of the fidelity of your data."

Weber points to the community-based work of Muscogee (Creek) Nation and Cherokee Nation in Oklahoma as a model for tribal leadership taking proactive policy and tobacco control steps once armed with the comprehensive localized data produced by the AI ATS. Thorne of the CDC agrees with this assessment of Cherokee Nation. Since conducting the survey, the tribe members have been incrementally implementing tobacco-free policy in the community. "They have a smokefree campus—everything is smokefree," she said. Therein lies the potential of this data—it provides the foundation to begin to mitigate the astronomical tobacco use rates and associated chronic health outcomes by changing commercial tobacco social norms in one of the most historically marginalized populations in the United States.

The tribal communities that participated in the TCHI are each at different stages of working with the data they collected. Armed with this data, they can begin to implement targeted interventions, awareness campaigns, and policy changes that conform to their communities and address their specific needs. Furthermore, owning this data will allow them to apply for additional funding to support these efforts. The academic research course and the related syllabus created for the Aberdeen Area tribal college is now an established model that could be implemented in other tribal colleges to conduct community-based health surveillance work focused on a range of health disparities. In keeping with one of the fundamental, if unstated, goals of community-based participatory research, the initiative left these communities better equipped to identify their own tobacco-related health disparities and determine the most appropriate methods for addressing them.

RECOMMENDATIONS FOR THE FUTURE PREPARED BY FAVIAN KENNEDY AND KENDRA ENRIGHT FROM THE ABERDEEN AREA INDIAN HEALTH SERVICE REGION SITE:

- Tribal colleges needed a greater amount of time to respond to the RFP, which would have allowed for the participation of more tribes and possibly a unified approach across sites.
- Better incentives could be offered to the sites that increase capacity following the conclusion of the project, such as computers.
- Future projects must have a clearly defined principal investigator to ensure adequate project management and oversight.
- The AI ATS manual should be updated with lessons learned.
- The CDC should require some sort of publication for financial support.
- The CDC should investigate more rigorously AI commercial tobacco use patterns since they appear to diverge from those of the general public.
- The sections that collect data on "other tobacco products" need to be further streamlined. At present, there is a lot of redundancy.
- Additional questions regarding emerging tobacco products should be included.
- The AI ATS implementation manual should outline a minimum standard for quality assurance review that includes: 1) a minimum number of hard-copy surveys to be reentered, 2) specific data-cleaning procedures that must be followed, and 3) tests to ensure data meets expectations of a normal distribution that need to be employed at specific intervals in the data collection phase.
- The quality of surveys where the interviewers independently collect surveys has very frequently been questionable. The best results occur when sites offer intense training paired with ongoing, close technical assistance and oversight, a process that substantially encourages the building of a tribe's capacity to collect its own data as well ensure accountability.
- The site supervisor must have experience in health surveillance and monitoring to ensure fidelity of data.

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