



## **Progress Toward Health Equity:**

Efforts to Address Cardiovascular Disease Among  
American Indians and Alaska Natives

August 2011





The mission of the Urban Indian Health Institute is to support the health and well-being of Urban Indian communities through information, scientific inquiry and technology.

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# TABLE OF CONTENTS

I	INTRODUCTION
2	BACKGROUND
4	AIMS & FRAMEWORK
5	METHODS
	RESULTS
6	Research
7	National Initiatives
9	Efforts to Increase Awareness
10	Health Education Curricula
11	Other Programs
12	DISCUSSION
15	REFERENCES
20	APPENDIX

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# INTRODUCTION

## Urban American Indians and Alaska Natives

American Indians and Alaska Natives (AI/AN) living in urban areas are a diverse and growing population. Over the past three decades, AI/ANs have increasingly relocated from rural communities and reservations to urban centers. According to the 2000 Census, this so-called “invisible” population now makes up more than 67% of all AI/ANs living in the United States.

Urban AI/ANs are a very diverse group and include members, or descendants of members, of many different tribes. Represented tribes may or may not be federally recognized, and individuals may or may not have historical, cultural or religious ties to their tribal communities. The population as a whole is quite mobile; individuals may travel back and forth between their tribal communities or reservations on a regular basis. Urban AI/ANs are also generally spread out within the urban center instead of localized within one or two neighborhoods, and thus are often not seen or recognized by the wider population.

## Urban Indian Health Organizations

Established through Congress under Title V of the Indian Health Care Improvement Act in 1976 and permanently re-authorized by the 111th United States Congress in 2010, urban Indian health organizations (UIHO) are independent, not-for-profit entities with urban AI/AN majority boards of directors. UIHOs range in size and services from outreach and referral sites to comprehensive medical and dental clinics that serve the wider community. Often seen as centers for cultural activities and news, UIHOs offer AI/ANs living in these urban areas a place where they can receive health information and services in a culturally appropriate manner. Many UIHO clients are unable to access Indian Health Service (IHS) or tribally-run health services because of geographic inaccessibility, eligibility restrictions or federal recognition status. UIHOs serve a vital role in assuring access to primary medical care for the low-income, urban AI/AN population, yet receive approximately only 1% of the overall IHS budget.

## The Urban Indian Health Institute

In 2000, the Urban Indian Health Institute (UIHI) was established as a division of the Seattle Indian Health Board to study and document the striking health disparities affecting the urban AI/AN population. The UIHI serves and provides technical assistance to 34 UIHOs with service areas encompassing 100 select urban counties in 19 states across the country. The UIHI is one of 12 tribal epidemiology centers and the only organization providing surveillance, research and analysis of data focused on the nationwide urban AI/AN population. The mission of UIHI is to support the health and well-being of urban Indian communities through information, scientific inquiry and technology.

## Promoting Health Equity for American Indians and Alaska Natives

Responding to the persistent inequities in health outcomes among urban AI/ANs, the UIHI launched its Health Equity Project in 2010. With support from the U.S. Office of Minority Health, the project is focused on identifying and disseminating culturally appropriate successful models of care in urban AI/AN communities to prevent and reduce disease. The Health Equity project focuses on three diseases identified as critical focus areas for health improvement in urban AI/AN communities: cardiovascular disease, depression and a third community-identified disease topic. Additionally, the Health Equity Project will provide tools, trainings, information and facilitate partnerships to support UIHOs in delivering best practices or components of best practices to their clients.

The importance of documenting and recognizing these effective, culturally-targeted programs in reducing morbidity and mortality in minority communities is essential in order to achieve Healthy People 2020 goals and to realize the overall outcome of health equity for all.

# BACKGROUND

Cardiovascular disease (CVD) refers to numerous conditions affecting the heart or blood vessels. The most common among these include hypertension, heart attacks, heart failure, stroke and sudden cardiac death. Once rare among AI/ANs (Rhoades et al, 2000), diseases of the heart now comprise the leading causes of death among urban AI/ANs (Castor et al, 2006), and CVD is a leading cause of premature death among AI/ANs (U.S. Department of Health and Human Services, 2009). While improvements in health and quality of care have been demonstrated in recent decades, CVD among AI/ANs may be set to accelerate, threatening an epidemic comparable to diabetes (Galloway, 2005). The incidence of coronary heart disease among middle to older age AI/ANs in the Strong Heart Study (SHS) was almost twice as high as comparably aged Whites and Blacks (Howard et al, 1999). The Strong Heart Study also demonstrated the incidence of stroke among this cohort was higher than among Black or White participants in comparable studies (Zhang et al, 2008).

While these statistics are deeply troubling, they likely underestimate the true burden of disease and risk for urban AI/ANs. A number of limitations in data specific to the urban AI/AN population result in narrower disparities being represented than actually exist. In addition to the scarcity of data being collected on urban AI/ANs, problems such as racial misclassification, sampling techniques that exclude the most vulnerable and small population size plague the data that are available. Several studies have examined racial misclassification in the data sources we rely on, such as death certificates, and found AI/ANs to be incorrectly identified as another race in 30% to 70% of cases (Boehmer et al, 2002; Becker et al, 2002; Bertolli et al, 2007). Furthermore, many of the data sources we depend on employ methods such as telephone-based surveys that eliminate some of the most vulnerable populations including AI/ANs who, even in urban areas, were more likely to report not having home phone service than the general population in the 2000 census<sup>1</sup> (2.2% of all households versus 7.0% of AI/AN households). Additionally, small population sizes also limit the data that is available; respondent numbers can be too small to analyze and report, and often AI/ANs get collapsed into the “other” category if represented at all (Moy et al, 2006).

Awareness of the risk factors for developing CVD is critical for understanding the complex issues surrounding CVD. Risk factors for developing CVD include the following health conditions and behaviors:

- Diabetes
- Hypertension
- Hypercholesterolemia
- Smoking
- Physical inactivity
- Excessive alcohol use

These risk factors are multiple, complex and interrelated, which can make it difficult to devise a multifaceted approach to the prevention, treatment and management of the disease. A disproportionately high prevalence of multiple CVD risk factors in the AI/AN community may explain why this population remains at such high risk for CVD, particularly among relatively young adults. Diabetes in particular has long since reached epidemic proportions. Among urban minority groups, risk behaviors, such as smoking, may also be coping mechanisms for economic and social hardship, chronic stress, and a lack of a positive cultural identity reflected in mainstream culture as a result of historical and ongoing structural oppression (Geronimus, 2000). The causes of the disproportionate burden of disease in the AI/AN population are multi-faceted and rooted in historical and social injustices. Major disparities exist between AI/ANs and the general population in social factors that influence disease such as income, education and employment. For example, 23.3% of urban AI/ANs live below the poverty level versus 13.6% of the total population<sup>2</sup> (U.S. Census Bureau, 2005-2009). Additionally, almost 33% of the general population has a bachelor's degree or higher compared to nearly 15% of the urban AI/AN population<sup>3</sup> (ibid).

<sup>1</sup> In 2010, only the short-form census was administered; therefore, this is the most up-to-date data available.

<sup>2</sup> Total population includes AI/ANs.

<sup>3</sup> Population estimates are calculated for those age 20 and older for both the general and AI/AN populations.

Culturally appropriate approaches to address health disparities hold the promise to reducing them. Each population has different risks, and different health behaviors that put them at risk, therefore culturally grounded approaches to health promotion are essential. In addition to targeting population-specific risk factors, culturally appropriate programs acknowledge and incorporate the health perceptions, preferences and communication styles of the target population. Culturally-based programs also understand and blend culturally-specific health decision-making practices into their approaches (e.g., involving family members).

Culturally appropriate interventions have frequently proven to yield statistically significant improvements for targeted health outcomes compared to health interventions not tailored to a specific community's cultural needs (Keyserling et al, 2002; Darling et al, 2004; Philis-Tsimikas et al, 2004). An in-depth literature review done by Kagawa-Singer found that greater cultural competence increases the accuracy of care and thereby its effectiveness, efficiency and success in providing acceptable and optimal programs (Kagawa-Singer, 1997).

# AIMS

The aim of this Environmental Scan is to provide an overview of programs that are experiencing success in preventing and treating CVD among AI/ANs across the nation. It is our hope that sharing these approaches will support health care providers, policy makers and advocates in promoting health equity for urban AI/ANs. Particular clinical outcomes regarding best practices for AI/ANs, however, are beyond the scope of this review, as very few clinical studies exist to determine whether particular CVD medications or interventions are effective among AI/ANs. Rather, this environmental scan is the first step toward identifying and disseminating ideas for programs and components of programs that can be adapted for local use at UIHOs in an effort to reduce CVD-related morbidity and mortality.

## FRAMEWORK

The UIHI recognizes that there are many avenues and communication channels for information regarding health promotion efforts for AI/ANs beyond peer reviewed journals. In an effort to perform a comprehensive review of practices currently in use in AI/AN communities, we included both databases of peer reviewed literature as well as “gray” literature (online, open source, government reviews, etc.). Additionally, many of the organizations doing innovative work in preventing and treating CVD among AI/ANs do not have the resources to conduct evaluations. Therefore, we applied a “realist review” framework, which is explanatory (i.e. how “x” works) rather than simply judgmental (how well did “x” work) (Pawson et al, 2005). This allows the inclusion of information regarding programs that have not been published in the academic literature and allows for an examination of the mechanisms of program delivery in practice rather than only in program outcomes.



# METHODS

Our first step was the identification of CVD-related programs targeting AI/ANs. Search terms included: “American Indian,” “Alaska Native,” “Native American,” “heart disease,” “cardiovascular disease,” “intervention,” and “program”. Searches were performed for peer-reviewed publications in the following databases: PubMed, Scopus, and Web of Science. Open-source and gray literature were identified through searches on the following websites: Centers for Disease Control and Prevention (CDC), Indian Health Service (IHS) and Google. These initial searches were performed between November 2010 and January 2011. If programs were mentioned in articles or other sources identified in the initial search, they were then further investigated in all databases by program name or citation in the original article to find more information. Each of the approximately 940 articles, websites, curricula, programs or other tools identified in the initial search results was reviewed. Many of the initial approximately 940 search results were duplications. Those with information available in English that were published or implemented after 1995 and specifically targeted CVD in AI/ANs were tracked in an Excel spreadsheet for further review. In some instances when very little program information was available through our search methods, UIHI staff contacted the program staff for further information. While there are certainly many more programs that are improving cardiovascular health among AI/ANs through the reduction of one or more CVD risk factors, this review only includes those programs in which CVD is specifically identified as a target health topic.

UIHI project staff evaluated the remaining 34 distinct programs identified in the review based on the following questions:

- What makes this program culturally appropriate for use in urban AI/AN communities? (Does it reflect the values, characteristics and preferences of this population)?
- Who was involved in its development and design?
- To what degree is this program based on scientific literature, available research, clinical expertise, and other evidence?
- What influenced the design and implementation of this program? What, if any, theoretical framework does it build upon?
- What success has this program achieved?
  - How is success defined, tracked and evaluated?
  - Has it reached its objective?
- Are the program activities a logical approach to preventing or managing CVD?
- What environment does the program occur in? (Individual/clinical, community, school, environmental, policy?)
- How sustainable is the program?

Upon secondary review 15 additional programs were eliminated for the following reasons: insufficient information (6), no specific mention of CVD (4), evolved into other programs already captured in the review (3), and not conducted in the US (2).

# RESULTS

After the initial and secondary reviews, 19 distinct programs or activities were identified that represent a variety of efforts to address CVD among AI/ANs. These ranged from research studies that identify risk factors and prevalence of CVD to programs designed to increase awareness of CVD and its risk factors. These findings also included interventions aimed at changing behaviors to reduce the risk of developing CVD or to manage CVD to limit acute illness and death. We classified these findings into the following categories: research (6), programs supported by national initiatives to reduce health disparities (4), efforts to increase awareness (3), school or clinic based curriculum (3), and other novel approaches that do not fit into these categories (3). A vast majority of the programs highlighted in this report are funded through various US government agencies, primarily through the IHS, CDC, and the National Heart, Lung, and Blood Institute (NHLBI). Yet on an operational level most are carried out through partnerships between these government agencies and non-profit organizations, tribal governments, and academic institutions.

## Research

Research is aimed at increasing the knowledge base regarding CVD risk factors and prevalence. Unfortunately, very few of these research efforts occur in urban settings; a majority are undertaken in rural and reservation communities. Many of the research studies outlined in this report do not contain activities or interventions to directly impact the pattern of CVD in AI/AN communities. However, the findings of this work are crucial to understanding how to target resources and design appropriate interventions.

### **Building Healthy Hearts for American Indians and Alaska Natives**

In 1998, the National Heart, Lung, and Blood Institute released a background report illustrating the disparities in CVD risk factors and prevalence for AI/AN communities. This report describes the sociodemographic makeup of the AI/AN population, the impacts of CVD on AI/ANs, and CVD risk factors. Additionally, Building Healthy Hearts for American Indians and Alaska Natives includes descriptions of select programs from around the nation, recommended strategies based on AI/AN culture and perceptions of health, theoretical models for program implementation, and opportunities for future programs (NHLBI, 1998).

### **Strong Heart Study**

Since October of 1988, the NHLBI has supported the largest epidemiological study of CVD and associated risk factors in American Indians ever undertaken, the Strong Heart Study. Early phases of the SHS were designed to estimate not only CVD mortality and morbidity but also the prevalence of known and suspected CVD risk factors in 13 American Indian communities and assess the significance of these risk factors over the course of this long-term study. More than 200 scholarly articles have been published since the study began. The major findings showed that CVD prevalence and incidence were substantially higher than previously suspected. High rates of CVD risk factors were found, many of which continued to rise with aging of the study population (Rhoades, 2007). The SHS also identified gaps in knowledge about CVD risks, particularly in regards to family history (Schweigman et al, 2006). More recently the study has expanded to look at heredity and the role of genetics in the development CVD (the Strong Heart Family Study) as well as more detailed evaluation of cerebrovascular disease (the Strong Heart Stroke Study).

### **Native American Time to Treatment Intervention Evaluation (NATIVE) Study**

The Centers for Disease Control and Prevention's Division for Heart Disease and Stroke Prevention partnered with the Native American Cardiology Program at University Medical Center at University of Arizona to investigate barriers to timely treatment for heart attack in AI/AN communities. The CDC recommends seeking treatment immediately following a heart attack (CDC, 2010). Of the 145 patients followed in this study, 17 did not seek care until between 12 and 24 hours after onset of symptoms and

34 did not seek care for more than 48 hours (ibid). Further investigation found medical treatment was delayed for the following reasons: seeking care from a traditional healer; perception that symptoms were mild, misunderstanding of symptoms of heart attack, denial, lack of telephone, transportation issues, and hospital/ EMT delays (ibid). Understanding and addressing these factors influencing access to timely care is essential to reducing disability and death from heart attacks.

### **Childhood Project**

The Indian Health Care Resource Center in Tulsa, Oklahoma developed the Childhood Project in response to the high numbers of childhood obesity in their community. This project is aimed at identifying the risk factors of childhood obesity. It includes an extensive survey of child and family history, nutrition, and physical activity (IHS OSCAR, 2011b). Additionally, the Childhood Project collects blood samples from children in this study to assess lipid profiles, fasting blood glucose, and C-peptide (ibid). The hope is that by identifying risk factors, pediatricians and families can take steps to prevent the development of early onset CVD and diabetes.

### **Inter-Tribal Heart Project**

From 1992 to 1994, the CDC partnered with IHS and the Menominee Tribe, White Earth Band of Chippewa Indians, and Red Lake Band of Chippewa Indians on the Inter-Tribal Heart Project (ITHP). This study identified CVD risk factors in these Minnesota and Wisconsin tribes (Casper et al, 1996). The Menominee tribe built on the ITHP findings to identify priority areas for prevention efforts. In the 15 years since the end of the research project, the tribe has enacted a variety of activities to address CVD. The Menominee community's approach emphasizes wellness and the interconnected nature of illness (M Caskey, personal communication, March 21, 2011). The tribal clinic integrates itself in the community by providing classes and screenings in schools, worksites, and at other community gatherings (ibid). Additional activities include organized community fitness activities, health research and wellness presentations in community centers (ibid). Not only has the community seen a tremendous growth in activities to prevent CVD, the tribe also adopted a smoke free policy in 2000, nearly 10 years ahead of the State of Wisconsin (ibid). Since the Wellness Program Director first began conducting the Youth Risk Behavioral Survey in the community, he has seen a 67% decrease in teens who report smoking and those who do smoke are smoking less (ibid). Additionally, no one has been caught smoking on a school campus in the past year and a half (ibid). Project leaders attribute their success in part to a tribal administration that is supportive of prevention efforts and community members that have taken ownership of many of these wellness activities, often continuing classes and programs after the end of grant funding (ibid).

## **National Initiatives**

Many of the programs implemented in Indian Country are the result of initiatives led by the CDC, the NHLBI, and the IHS in an effort to eliminate health disparities. These funding sources provide opportunities for the development of culturally appropriate interventions based in communities. These initiatives are national in scope and are implemented locally in various iterations.

### **Racial and Ethnic Approaches to Community Health Across the United States**

The CDC began Racial and Ethnic Approaches to Community Health Across the United States (REACH US) to utilize community based participatory approaches in addressing health disparities in communities of color. In addition to other targeted health conditions, the CDC funds projects to develop, implement and evaluate programs that promote heart-healthy and stroke-free communities; prevent and control heart disease, stroke and their risk factors; and eliminate disparities. These programs emphasize the use of education, policies, environmental strategies and systems change. Two REACH US projects run by AI/AN communities to address CVD are highlighted in this report.

#### *Chugachmiut Alaska Native Cardiovascular Disease Prevention/Core Capacity Building Project*

This health education project served seven rural and remote Alaska Native villages in the Prince William Sound, Cook Inlet, and Resurrection Bay areas of Alaska. In partnership with the University of Alaska Sitka

and the Southeast Alaska Regional Health Consortium, the Chugachmiut Core Capacity Building Project has trained community wellness advocates to provide health assessment and education (CDC, 2007). Additionally, technical assistance and training for program implementation was provided in all Chugach communities (ibid). To increase support for this project, the Chugachmiut Core Capacity Building project partnered with various community resources such as health aides, traveling providers, community health advocates and village councils (ibid). Materials, including an interactive calendar for tracking activity, diet, weight loss, cholesterol, and blood pressure for participants to track their progress in these goals, were also developed and distributed. Holding over 312 events in the local communities, the project made nearly 4,000 local contacts with community members (ibid). Results from over 1,000 heart disease awareness tests showed that program participants were knowledgeable about heart disease and how to prevent it (ibid). Community support and involvement along with working at the individual and community levels simultaneously contributed to successfully raising awareness about CVD and its risk factors (ibid).

#### *Lifetime Legacy and Choctaw Nation Core Capacity Program*

Beginning with the development of resources, community coalitions and tracking of CVD prevalence with support from the CDC Core Capacity funding, the Lifetime Legacy program has evolved over the past nine years. In the second round of funding, the Choctaw Nation has built upon the successes of the Core Capacity Building Program to focus on personal, environmental and systems change to support cardiovascular health (T Baughman, J Bray, K Hearod, M Peercy, and B Plested personal communication, March 22, 2011). Utilizing the Community Readiness Model developed at the University of Colorado, the Choctaw Nation was able to identify substance abuse as the community's priority (Peercy et al, 2010). Project leaders developed curriculum and presentations focused on the relationship between substance abuse and heart health, responding to the community's needs, interests and concerns (T Baughman, J Bray, K Hearod, M Peercy, and B Plested personal communication, March 22, 2011). This has engaged the community and opened the door to more cardiovascular health education and intervention, including integrating Honoring the Gift of Heart Health curriculum, physical activities that engage elders and provide opportunities for empowerment, and to re-instill pride (ibid). Success has also been achieved in environmental changes, including shows featuring tribal leaders using commodities to create healthy meals airing on all tribal clinic and hospital TVs rather than soap operas (ibid). The Lifetime Legacy project is also working with schools to ensure healthy cafeteria menus (ibid). Momentum from the Lifetime Legacy project has supported the implementation of a no smoking policy on tribal land as well as a vending machine policy that ensures healthy options are available (ibid). Further community readiness assessment has shown an increase in all aspects of the community's readiness to combat CVD (Peercy et al, 2010). Data from an annual survey of tribal members at the Labor Day Festival also showed increase in physical activity among women, compliance with medical advice and a decrease in smoking (ibid).

#### **Healthy Heart Demonstration Projects**

As part of the Special Diabetes Program for Indians, IHS funds Healthy Heart Demonstration projects around the US. Healthy Heart projects focus on the reduction of CVD risk factors in AI/ANs diagnosed with diabetes. IHS supports demonstration projects that use current models of chronic disease management, clinical best-practice guidelines, and an integrated team approach to care. Below is an example of one such demonstration project.

##### *Heart Savers*

Indian Health Care Resource Center of Tulsa started the Diabetes Management and Cardiovascular Risk Reduction program (later renamed Heart Savers) in order to reduce cardiovascular complications in patients with diabetes. This program integrates the support groups, experiential learning and group exercise activities with individualized case management (IHCRC, 2007). Rather than having a nurse case manager, Heart Savers employs a counselor as the case manager in order to address the underlying issues that contribute to health behaviors (IHS OSCAR, 2011f). Additionally, their comprehensive team approach incorporates a variety of providers to address the exercise, nutritional, and medical components of achieving heart healthy lifestyles (ibid).

## **Well Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN)**

Heart disease is the number one killer of women in the US (NHLBI, 2011). Projects funded through the CDC's WISEWOMAN initiative provide screening and referral services as well as lifestyle interventions for low-income, underinsured and uninsured women between the ages of 40 and 64 years. These projects operate at the state and local level, as well as through tribal programs. Below is an example of a WISEWOMAN project run by and for Alaska Natives.

### *Traditions of the Heart*

The Southcentral Foundation partnered with the CDC to implement Traditions of the Heart, a 12-week health education curriculum for Alaska Native women. Building on and adapting existing intervention material, specifically Native Nutrition Circles and A New Life...Choices for Healthy Living, program staff developed the Traditions of the Heart curriculum (Stefanich et al, 2005). The curriculum was designed to focus on community assets and Alaska Native culture to address diet, active living, tobacco use and stress. In addition to the group classes, Traditions of the Heart also includes individual counseling, visual displays, a maintenance program, and incentives to reinforce healthy behaviors (ibid). An evaluation of this pilot project found significant increases in physical activity for participants of the program. Questionnaires administered at the beginning and end of the program found that almost all participants improved their nutrition, self-efficacy, stress management and stage of readiness for behavior changes (Witmer et al, 2004). Follow-up with participants after the classes found that the incorporation of traditional wellness and story-telling was critical to participant retention (Stefanich et al, 2005).

## **Efforts to Increase Awareness**

Efforts to increase awareness seek to improve knowledge about the presence, impact, risk factors, and/or steps to prevent disease. They can be a one-time event or an ongoing media campaign, or a combination of the two.

### **Pow Wow for the Heart**

For the last three years the Spokane, Washington NATIVE Project has sponsored a pow wow that emphasizes heart health (NATIVE Project, 2011). Rather than fry bread and Indian tacos, a healthy turkey dinner is served. Free blood pressure and cholesterol screenings are provided, as well as prizes for dancers, drummers and youth participation in activities (ibid). Pow Wow for the Heart brings attention to the burden of heart disease in AI/ANs, provides valuable health information in a culturally appropriate context and helps identify people at risk for CVD while providing resources to reduce this risk.

### **Blackfeet Reservation Media Campaign**

To increase awareness of the signs and symptoms of heart attack and the need to call 911 on the Blackfeet Reservation, the Montana State Department of Health and Human Services developed a culturally appropriate media campaign. The campaign ran for 20 weeks and included a variety of advertisements, promotional and educational materials. Reservation residents were surveyed before and after the campaign, revealing a significant increase in awareness of three or more heart attack signs (CDC, 2008).

### **Go Red for Women—Storytellers Program**

In addition to other educational, scientific and developmental initiatives, the American Heart Association (AHA) sponsors an awareness campaign that consists of messages from real women—storytellers—about their experiences with heart disease (AHA, 2011). The Storytellers Program encourages leaders in Indian Country to use their voice to engage AI/ANs in learning about heart health and ways to lower the risk of CVD. The program provides resources for Storytellers to share information with their community, host awareness events, and advocate for their community's health needs (ibid). By capitalizing on the influence of Indigenous leadership, the Go Red for Women Storytellers Program seeks to mobilize communities around reducing AI/ANs women's risk for cardiovascular disease.



# Health Education Curricula

Standard curriculum, which specify lessons and their contents, are a powerful resource for health educators and organizations seeking to increase knowledge and build skills around heart health. Curriculum using clinical guidelines and best practices, based on theories of behavior change, and grounded in culturally appropriate activities provides local organizations with the building blocks of a successful CVD intervention. Below we describe curricula that were designed or adapted for use in AI/AN communities.

## Pathways

The Pathways study was a pilot of a school-based physical activity and nutrition curriculum tested in various locations for third, fourth, and fifth grade AI/AN schoolchildren. Pathways curriculum was formulated through a collaboration of academic institutions, Tribal Nations, American Indian schools and AI/AN families and is grounded in social learning theory as well as AI/AN traditions (Davis et al, 1999). The four components of the curriculum, classroom instruction, physical activity, food service and family involvement, are intended to address risk factors for CVD in multiple environments (Caballero et al, 2003). While evaluation of the curriculum did not find significant changes in percent body fat, there were significant increases in knowledge of healthy behaviors, reported physical activity and cultural identity at the schools where the curriculum was tested as compared to control schools (Story et al, 2003; Davis et al, 1999). The consumption of healthy food also increased at intervention schools as reflected in school menus that added fresh fruits and vegetables (Caballero et al, 2003).

## Physical Activity Kit

The University of New Mexico Prevention Research Center, IHS and representatives from various Tribal Nations partnered to develop the Physical Activity Kit (PAK)-Staying on the Active Path in Native Communities. Based on best and promising practices from the CDC Guide to Community Prevention Services, PAK utilizes a lifespan approach to promote culturally appropriate activities for all ages (IHS OSCAR, 2011d). The kits contain a variety of activities that include strength, flexibility and cardiovascular exercises. Feedback from field test groups showed that the kit was successful in promoting positive changes related to physical activity, was easy to implement, and that it was fun and engaging (IHS, 2011). In addition to age appropriate lessons and activities, PAK also provides tools for marketing the program in communities, action plan checklists for implementation, and train-the-trainer sessions across the country (ibid).

## Honoring the Gift of Heart Health

Based on adult learning theory, health behavior theory, and clinical guidelines and best practices, the NHLBI adapted a comprehensive educational curriculum that emphasizes changes to modifiable CVD risk factors, such as blood pressure, cholesterol, and weight management, as well as signs of heart attack. Working with a multidisciplinary team with experience and understanding of cultural norms and perceptions of health, the NHLBI used an iterative process and pilot testing to adapt a curriculum originally developed for Latinos to reflect American Indian cultures (Wallace et al, 2008). The curriculum centers around the story of an American Indian family, and materials incorporate family activities as well as ways to fit healthy practices into busy lives and tight budgets. The 10-week curriculum focuses on nutrition, tobacco cessation, physical activity and traditional recipes to combat cardiovascular disease. Support for successful implementation includes: training for community health educators, teaching manuals, group activity guides regarding various CVD risk factors, visual aids, brochures, a motivational video and fact sheets. Most of these materials can be adapted to ensure cultural relevance in specific regions. A curriculum tailored for Alaska Natives is also available. University of Colorado at Denver's Center for American Indian and Alaska Native Health offers training, support and resources for staff interested in implementing the curriculum. In autumn 2011, an updated and expanded curriculum will be released and will include information on diabetes as well as evaluation tools.

### *Blood Pressure Education Classes*

The Catawba Service Unit (South Carolina) of the IHS provides blood pressure education classes for patients with hypertension and cardiovascular disease. These classes aim to help patients manage their existing CVD and reduce the risk of future complications. Integrating the Honoring the Gift of Heart Health curriculum, classroom topics include definitions and causes of CVD, medication and treatment adherence, nutrition, strategies to increase physical activity, stress management, and symptoms of stroke and heart attack (IHS OSCAR, 2011a). In addition to a healthy meal preparation demonstration, the class uses several approaches to connect with participants including written materials, regionally appropriate recipes, storytelling, videos, group sharing, visual aids and practice reading food labels (ibid). Each class includes a blood pressure check and at the end of the session, and participants can take a blood pressure cuff to monitor their blood pressure at home (ibid). Referrals from providers, small class sizes, and alternating class hours between day and evening support active participation (ibid).

## Other Programs

This environmental scan has also identified programs whose approaches do not fit into the above categories, but are working towards the prevention, treatment and management of CVD in AI/AN communities.

### **SEARHC Traditional Knowledge Camps**

Through a partnership with the Southeast Alaska Regional Health Consortium, the Alaskan village of Klukwan sponsors Traditional Knowledge Camps several times each year. By restoring and disseminating traditions to residents, the Traditional Knowledge Camps hope to reduce chronic disease risk in the community (IHS OSCAR, 2011e). Camp activities include experiential learning of subsistence lifestyle skills and reestablishing other important links to Tlingit culture (ibid). Along with these practices of culturally oriented health promotion, health screenings and exams are also provided by a community health aide (ibid). Compared to baseline measurements, preliminary data has shown mean decreases in blood pressure, weight, total cholesterol and tobacco use among participants (ibid).

### **Wisdom Steps**

A partnership between multiple Minnesota Tribes, three urban areas and the Minnesota Board on Aging, Wisdom Steps focuses on little changes AI/AN elders can take to improve their health (Office of the Surgeon General, 2001). Elders are encouraged to set individualized goals and strategies to reach and maintain their optimal health (Minnesota Board on Aging, 2010). Wisdom Steps promotes health screenings, provides education, including information, advocacy and application assistance for Medicare, and offers small incentives as recognition for participating in healthy living activities (ibid).

### **Native American Cardiology Program**

The Native American Cardiology Program (NACP) was established in 1994 in response to the changing health needs of AI/ANs living in the southwestern United States. NACP continues to work to eliminate health disparities in AI/AN communities and to improve quality of care by addressing a major barrier to specialty care in the southwest – distance. The program has facilitated a pilot project for provision of distance echocardiography, reducing the need for travel to cardiology appointments for patients (IHS OSCAR, 2011c). NACP also manages a registry of patients with pacemakers and defibrillators to ensure appropriate follow up (ibid). Clinician training offered by the NACP builds skills among providers serving rural areas and increases patient access to specialty care (ibid). Additionally, the NACP works with the state of Arizona and the IHS to provide telemedicine outreach, consulting and education to both patients and providers (ibid).

# DISCUSSION

The findings of this environmental scan point to several themes that run throughout CVD activities targeted for AI/AN communities as well as areas that, if developed and supported, could increase the reach, understanding and impact of these activities. The themes are outlined below.

## **Partnerships**

The findings of this review clearly show that the employment of multilateral partnerships between governments (US and Tribal), not-for-profit organizations and academia is a driving factor behind development and implementation of culturally tailored interventions, programming and research. Each of these partners brings unique knowledge, skills and resources that contribute to success. Additionally, these partnerships ensure that efforts are not duplicated. Respectful, equitable partnerships that acknowledge the strengths and roles of each collaborator show tremendous results as evidenced by the adaptation and subsequent, nearly ubiquitous, dissemination of the Honoring the Gift of Heart Health curriculum.

## **Diversity within Programming and Integration into Existing Programs or Structures**

Implementing a range of tactics allows for interventions to operate on the multiple environmental levels in which we live: the individuals knowledge, skills, and behaviors, the family and work environment, the community, and the policy environment. Messages, structures and systems in each of these environments need to consistently support healthy lifestyles for change to occur. This strategy was used across the programs identified in this review, showing integration of multiple tactics into interventions. Incorporating a variety of activities is important for engaging and maintaining participation. Policy at the organizational, local, state, or national level can support healthy choices. Creating more tools and opportunities for AI/ANs to influence and shape policy in ways that benefit AI/AN communities is essential.

Another way in which organizational policies and structures support program success is by incorporating CVD activities into already existing programs and activities. Integrating activities with often co-morbid conditions, such as diabetes and obesity, is particularly useful for implementation in several ways. Activities that address multiple conditions or health behaviors together maximize the use of resources in a highly efficient manner. Integrating activities can serve as a more holistic approach to disease management as well as a means to coordinate care.

## **Cultural Components and Group Activities**

To varying degrees all activities in this report are grounded in or incorporate AI/AN traditions, such as sharing personal experiences in talking circles, traditional activities such as games, and cultural symbols including imagery and foods. Family and community involvement, not only in the development and implementation but also in the actual intervention or activity itself acknowledges the tradition of collective well-being and knowledge. Literature in another health topic area, outside the scope of this Environmental Scan, has found that a connection to AI/AN cultural heritage, which can be strengthened through traditional activities and social support networks, offers protection against poor health outcomes (Walters & Simoni, 2002; Oetzel & Duran, 2004).

In addition to traditional ways of learning, group activities also help facilitate the development of social support networks as well as accountability in implementing and maintaining healthy behaviors. Coupled with individualized goal setting, risk assessment and counseling, community-centered activities hold tremendous potential to impact the health of urban AI/ANs.

## **Adapting Existing Materials**

Adaptation of existing materials, such as health messaging, curriculum or programs, has the potential to

increase resources available locally. Adaptation cannot simply be translation, a superficial exchange of words and pictures to fit a stereotype of AI/AN people. Adaptation runs the risk of further alienating communities by objectifying cultures and traditions. When adapting curriculum, outreach materials or other health promotion activities it is important to keep AI/AN concepts of health and ways of being central to the adaptation process. Existing materials to address CVD can provide local efforts with the building blocks for successful programming and can relieve development burden.

### **Community Involvement**

Many of the programs described in this report referenced the importance of community involvement in the development of activities. However, very few described what that process of community involvement looked like – to what degree and how the community set priorities, identified appropriate methods and participated actively in the formation of programming. The Lifetime Legacy Project provides an example of a detailed explanation of how the community's priorities were measured and how those priorities were incorporated into the intervention activities.

In addition to participation, an important role community members play in programming is as staff. Programs identified in this review that were not run by the community itself, often employed and trained community members to perform outreach, screening and education activities. This is critical not only for acceptance and trust of the program, but also for building capacity in the community.

Specific processes for community participation in the development of programming initiated by institutions are limited in the literature identified in this review. Detailed processes would be useful to include in reporting of successful programming rather than only in separate literature about community-based participatory research or collaborative processes. The development and implementation of programming conceived and driven by the community was limited in this review as it requires time and resources to share this information widely. Limitations on resources needed for dissemination often limit the reach of these programs.

### **Modes of Dissemination**

Many of the activities identified in the review were found on the IHS Online Search, Consultation, and Reporting System or OSCAR. This database serves as one of the few centralized, easily accessible resources where communities can share and learn about local efforts to combat disease among AI/ANs. Very few of the programs highlighted in this report were identified in peer-reviewed journals. Those that were published in these journals were partnered with an academic institution to varying degrees.

For some health professionals national conferences and trainings may not be a feasible mode of sharing program ideas, successes and lessons learned as associated costs limit attendance. This barrier can be addressed by providing travel support for attendance. Providing tools for attendees to bring back to their sites could help to ensure the lessons of the conference are disseminated throughout the health systems that attendees represent. Additionally, publicizing or posting summaries of meeting or conference minutes can help to disseminate the lessons learned. For example, minutes and conference summaries were the source of some of the programs identified in this review. Ensuring time for roundtable discussions and peer learning on agendas would be a beneficial way to help community-developed programs share their experiences. Providing more easily accessible and user-friendly avenues for active dissemination of innovative practices is critical for spreading successful approaches to health promotion.

### **Champions**

Funding for public health is not always in line with the disease burden. Strong advocates make the case for increased attention, financing and support to address specific conditions. Identifying leadership and program advocates within the community who can serve as champions for the program was also identified as an important part of institutional or organizational uptake of programming. Leadership support or program championship was not very clearly or directly defined or discussed in the literature identified in this review. Only

one program identified in this review focuses on developing and supporting community-based champions for cardiovascular disease – the Go Red for Women Storytellers program. Strong, influential supporters of causes or programs are powerful catalysts in the fight against CVD and other pressing health issues. Champions play a key role in impacting not only individual acceptance of and participation in programming, but also the policy environment that influences access to care as well as personal health behaviors.

## **Evaluation**

Roughly half of the activities identified in this review included evaluation or outcomes data. These evaluations captured data on knowledge, behaviors, community and individual readiness for changes, policies, services available, as well as clinical measures such as lipids, weight and blood pressure. This range of evaluation measurements demonstrates the importance of the various levels on which change occurs and emphasizes the importance of a holistic approach to health.

While evaluation data is crucial for program enhancement, accountability and general understanding, it is also important that the methods of the data collection and reporting are acceptable to communities. The evaluation questions posed and decisions about what to measure should be carefully considered to take into account the structural and systemic influences on individuals, families and communities.

Increased financial resources to support additional staffing, skill building and training at community-based organizations can help support enhanced evaluation efforts. Stronger evaluation data and greater staffing capacity will likely also support dissemination of programming ideas and strategies to combat CVD.

The scarcity of financial resources impacts the ability to invest in infrastructure, staff development and training, and additional supportive activities, such as transportation, that increase a program's success. Limitations in funding and training specifically also make it difficult to measure the outcomes and impact of innovative work.

## **What are Best Practices?**

In an era where emphasis is placed on best and evidence-based practices it is necessary to consider what these terms mean in urban AI/AN communities. The source of the evidence and who will be served by the practice need to be well matched. Through expanded funding and training for evaluation it will be possible to rename and redefine the language of best and evidence-based practice to more accurately reflect AI/AN knowledge, traditions, and values. The power of language developed by AI/AN organizations and providers to identify the methods best suited to AI/AN communities should not be discounted by mainstream funders. This reframing of best practice criteria can help prevent the push to superficially adapt best practices developed for other populations by simply changing the imagery and language rather than truly adapting the framework to reflect AI/AN perceptions of health and well-being. It is important to note that while community-driven approaches to address disease, and the risk behaviors that contribute to disease, are essential to prevent the widening of the gap in health outcomes, the structural and environmental realities that create and reinforce risk factors must be addressed through fundamental changes to mainstream policies to eliminate health disparities and achieve health equity (Geronimus, 2000).



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## APPENDIX

Program Name	Organization	Activities/Products	Target Audience	Link to Website
<b>Building Healthy Hearts for American Indians and Alaska Natives</b>	National Heart, Lung and Blood Institute	Report	Health care professionals	<a href="http://www.nhlbi.nih.gov/health/prof/heart/other/na_bkgd.htm">http://www.nhlbi.nih.gov/health/prof/heart/other/na_bkgd.htm</a>
<b>Strong Heart Study</b>	National Heart, Lung and Blood Institute	Community surveillance, physical examinations, report, peer reviewed journal articles	Health care professionals	<a href="http://www.nhlbi.nih.gov/resources/docs/shs_db.htm">http://www.nhlbi.nih.gov/resources/docs/shs_db.htm</a>
<b>Native American Time to Treatment Intervention Evaluation (NATIVE) Study</b>	Native American Cardiology Program at University Medical Center and Centers for Disease Control and Prevention's Division for Heart Disease and Stroke Prevention	Community surveillance	Health care professionals	<a href="http://www.cdc.gov/ostlts/tribal_public_health/documents/january26-27_2010TCAC_MeetingMinutes.pdf">http://www.cdc.gov/ostlts/tribal_public_health/documents/january26-27_2010TCAC_MeetingMinutes.pdf</a>
<b>Childhood Project</b>	Indian Health Care Resource Center	Community surveillance	Health care professionals	<a href="http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=92D80612-D635-B94A-91C18FA8E7584A4F">http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=92D80612-D635-B94A-91C18FA8E7584A4F</a>
<b>Center for Alaska Native Health Research (CANHR)</b>	Center for Alaska Native Health Research at the University of Alaska Fairbanks	Community surveillance	Health care professionals	<a href="http://canhr.uaf.edu/Research/CANHR-I.html">http://canhr.uaf.edu/Research/CANHR-I.html</a>
<b>Inter-Tribal Heart Project (ITHP)</b>	Centers for Disease Control and Prevention, Indian Health Service, Menominee Tribe, White Earth Band of Chippewa Indians, Red Lake Band of Chippewa Indians	Community Surveillance, health education/promotion	Health care professionals	See references

Program Name	Organization	Activities/Products	Target Audience	Link to Website
<b>Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.)</b>				
<b>Chugachmiut Alaska Native Cardiovascular Disease Prevention/ Core Capacity Building Project</b>	Chugachmiut Native Organization	Health education/ promotion, professional training, community assessments, events	Alaska Natives Health care professionals	<a href="http://www.cdc.gov/nccdphp/dach/chhep/pdf/voices_101007.pdf">http://www.cdc.gov/nccdphp/dach/chhep/pdf/voices_101007.pdf</a>
<b>Lifetime Legacy and Choctaw Nation Core Capacity Program</b>	Choctaw Nation of Oklahoma	Community surveillance, health education/promotion curriculum, physical activity, community assessments, nutrition, policy, peer review journal article	American Indian students, elders, and adults Health care professionals Schools	<a href="http://tribalselfgov.org/2008_subpages/whatsnew2010/Testimony_TSGAC_HHSATBC_2012_Peercy.pdf">http://tribalselfgov.org/2008_subpages/whatsnew2010/Testimony_TSGAC_HHSATBC_2012_Peercy.pdf</a>
<b>Healthy Heart Demonstration Project</b>	Indian Health Service and multiple demonstration sites	Case management, medication management, smoking cessation, physical activity, weight management	American Indian/ Alaska Native adults	<a href="http://www.ihs.gov/medicalprograms/diabetes/index.cfm?module=sdpi_pt_8">http://www.ihs.gov/medicalprograms/diabetes/index.cfm?module=sdpi_pt_8</a>
<b>Heart Savers</b>	Indian Health Care Resource Center of Tulsa (IHCRC)	Case management, health education/promotion curriculum, weight management	American Indian/ Alaska Native adults	<a href="http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C8154281-D72E-AC4B-31E10D533D969083">http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C8154281-D72E-AC4B-31E10D533D969083</a>  <a href="http://www.ihcrc.org/healthEducation/heartSavers.html">http://www.ihcrc.org/healthEducation/heartSavers.html</a>
<b>Well Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN)</b>				
<b>Traditions of the Heart</b>	Southcentral Foundation and the Centers for Disease Control and Prevention	Health education/ promotion curriculum, counseling, lifestyle assessment, peer review journal articles	Alaska Native adult women	<a href="http://www.cdc.gov/WISEWOMAN/docs/success_stories.pdf">http://www.cdc.gov/WISEWOMAN/docs/success_stories.pdf</a>

Program Name	Organization	Activities/Products	Target Audience	Link to Website
<b>Pow Wow for the Heart (Healthy Heart Pow Wow)</b>	NATIVE Project	Pow wow, screenings	American Indians Alaska Natives All audiences	<a href="http://www.nativeproject.org/index.html">http://www.nativeproject.org/index.html</a>
<b>Montana Cardiovascular Health Program</b>	Montana Department of Public Health and Human Services Cardiovascular Health Program	Awareness campaign	American Indians	<a href="http://www.cdc.gov/omhd/reports/2008/CDCTBCR2008.pdf">http://www.cdc.gov/omhd/reports/2008/CDCTBCR2008.pdf</a>
<b>Go Red For Women Storytellers Program</b>	American Heart Association	Awareness campaign	American Indian/ Alaska Native women	<a href="http://www.heart.org/HEARTORG/General/Go-Red-For-Women-Storytellers-Program_UCM_311785_Article.jsp">http://www.heart.org/HEARTORG/General/Go-Red-For-Women-Storytellers-Program_UCM_311785_Article.jsp</a>
<b>Pathways</b>	National Heart, Lung and Blood Institute, multiple academic institutions, and multiple American Indian communities	Health education/promotion curriculum, physical activity, nutrition and family involvement	American Indian students	See references
<b>Physical Activity Kit (PAK): Staying on the Active Path in Native Communities...a Lifespan approach</b>	Indian Health Service and University of New Mexico Prevention Research Center	Health education/promotion curriculum	American Indians/ Alaska Natives Health care professionals	<a href="http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C196B140-EE3A-A322-44BCB0749EDE5C69">http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C196B140-EE3A-A322-44BCB0749EDE5C69</a>  <a href="http://www.ihs.gov/hpdp/index.cfm?module=dsp_hpdp_resources_physicalactivitykit">http://www.ihs.gov/hpdp/index.cfm?module=dsp_hpdp_resources_physicalactivitykit</a>

Program Name	Organization	Activities/Products	Target Audience	Link to Website
<b>Honoring the Gift of Heart Health (HGH)</b>	National Heart, Lung and Blood Institute	Health education/ promotion curriculum	American Indian/ Alaska Natives Health care professionals	<a href="http://www.nhlbi.nih.gov/health/public/heart/other/amer-indian_risk_information.htm">http://www.nhlbi.nih.gov/health/public/heart/other/amer-indian_risk_information.htm</a>  <a href="http://www.nhlbi.nih.gov/health/pubs/pub_slctpro.htm#ai">http://www.nhlbi.nih.gov/health/pubs/pub_slctpro.htm#ai</a>
<b>Blood Pressure Education Classes</b>	Catawba Service Unit	Health education/ promotion, blood pressure test	American Indians/ Alaska Native adults and elders	<a href="http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C815403F-D0EA-2F79-6F59E6684F2072C7">http://www.ihs.gov/oscar/export_pdf.cfm?Submission_UUID=C815403F-D0EA-2F79-6F59E6684F2072C7</a>

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- ☐ Health and Health-Influencing Behaviors among Urban AI/AN (2008)
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