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### Abstract

In response to a Request for Proposals from the National Cancer Institute (NCI), the Inter Tribal Council of Arizona (ITCA) along with health care partners from the Phoenix Indian medical Center (PIMC) and academic partners from the Arizona Cancer Center (ACC) at the University of Arizona (UA), and the University of Nevada Las Vegas (UNLV) established a Community Network Program entitled the Southwest American Indian Collaborative Network (SAICN). The ultimate goal of the SAICN project was to *“eliminate cancer health disparities by closing the gap between the health needs of the community and cancer prevention and control made possible by a responsive health delivery and research system.”* At the close of the 5-year funding period for the SAICN project, a RE-AIM framework provided an important evaluative tool for identifying areas of potential long term impact.

### Keywords

Cancer – Prevention; Cancer disparities; Indians of North America; Tribal capacity building; RE-AIM; Southwest; New



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### **ABSTRACT**

In response to a Request for Proposals from the National Cancer Institute (NCI), the Inter Tribal Council of Arizona (ITCA) along with health care partners from the Phoenix Indian medical Center (PIMC) and academic partners from the Arizona Cancer Center (ACC) at the University of Arizona (UA), and the University of Nevada Las Vegas (UNLV) established a Community Network Program entitled the Southwest American Indian Collaborative Network (SAICN). The ultimate goal of the SAICN project was to *“eliminate cancer health disparities by closing the gap between the health needs of the community and cancer prevention and control made possible by a responsive health delivery and research system.”* At the close of the 5-year funding period for the SAICN project, a RE-AIM framework provided an important evaluative tool for identifying areas of potential long-term impact.

**Key Words:** Cancer disparities, tribal capacity building, RE-AIM

### **BACKGROUND AND SIGNIFICANCE**

In the last half of the 20th century, cancer has become a leading cause of death for American Indians over age 45 (Kaur & Hampton, 2008) and the 3rd most frequent reason for hospital stays (Steele et al., 2008). Despite some positive changes in cancer rates in recent years, disparities between American Indians and Non-Hispanic Whites persist in healthcare access, health status indicators, cancer risk factors, and use of cancer screening tests (Cobb et al., 2008). Further, cancer is responsible for more deaths among American Indians than health priorities that receive more attention in tribal communities, such as substance abuse or diabetes. Although American Indian communities have repeatedly described their need for improved health services, cancer care for American Indians is fragmented and not connected to the historical patterns of health, illness, and care found within their communities (Burhansstipanov and Olsen, 2004). There are also cultural barriers related to cancer and its prevention and early detection that have hindered early diagnosis and treatment.

The recent shift from importing mainstream programs into tribal communities to a focus on eliminating disparities and building community capacity, has paved the way for new funding streams, innovative strategies, and increased community participation. These new directions

increasingly recognize that tribal world-views and tribal priorities need to be part of the methods as well as the resultant activities (Chino & DeBruyn, 2006), particularly with regard to community-based research. Research can help focus on the socio-cultural context of health where the community itself participates in identifying and resolving public health problems such as cancer disparities.

One key to building tribal research capacity is successful partnerships between the community, nongovernment agencies, government agencies, and research institutions. Community participation not only helps ensure that the community is interested and invested in educational, preventive, and curative campaigns but also that research designs, methods, and interpretations are culturally, historically, and linguistically appropriate (Williams and Jackson, 2005). In tribal communities, the role of federal agencies is primarily funding and related to infrastructure but often overshadow local efforts. Non-government agencies are often peripheral if involved at all. The SAICN attempted to shift the status quo with strong working partnerships with tribal, local, state, federal and non-governmental organizations. At the end of the project, the primary question was – did these partnerships build capacity to eliminate cancer disparities?

## METHODS

As the federal funding for SAICN came to an end there was a need to identify capacities built for the short term and to consider the potential for long-term change. Since most federally funded projects are time limited, there is rarely an opportunity for an impact evaluation, which is culturally competent and provides an ethical commitment to fairness and equity to stakeholders (AEA 2011). To help project think prospectively and identify areas of potential impact, a RE-AIM framework (Glasgow et al., 1999) became an important evaluation tool. The **RE-AIM** framework includes five dimensions for assessing how well research translates into practice: Reach, Effectiveness, Adoption, Implementation, and Maintenance. Although usually a retrospective assessment, these dimensions were helpful for thinking about the possible long-term impact of the project.

For the SAICN Evaluation, REACH was defined as the proportion and representation of tribal and non-tribal groups reached by the project. This includes participation rates; scope of participation; and differences in participation by individuals, groups, and communities. EFFECTIVENESS was defined by how activities affected key targeted outcomes through intended and unintended consequences (both positive and negative). The potential for ADOPTION was estimated by how well the activities related to an individual and/or group and if it was thought to be sufficient for successful adoption. IMPLEMENTATION focused on fidelity issues relating to the intervention protocol including how well the project understood the needs and realities of project partners and participants. MAINTENANCE was defined by individual/group changes resulting from the project and their ability to be sustained over time. Overall, the RE-AIM framework was an effective tool for estimating the potential for a long-term impact of the SAICN project.

This portion of the SAICN evaluation process included a series of key informant interviews with members of the SAICN project partners and ITCA staff. The in-person interviews included 36 questions covering the 5 RE-AIM dimensions described above. A total of 22 Interviews were conducted among individuals with varying levels of project involvement, roles, and responsibilities.

## RESULTS

### **REACH: Will relationships last?**

Building and sustaining partnerships are important to the long-term success of a project and were essential to the reach of SAICN activities. Respondents spoke positively about the project

partnerships and their role in the project's progress toward its goals. In particular, the tribal partnerships and those with cancer organizations were deemed to be the most effective. There was consensus that most of non-tribal entities who would be appropriate partners ended up participating in the project in some way. These partners created pathways for the project and participating tribes to access information on everything from data and statistics, to community health education, support for obtaining scarce resources, and recognition of the needs and contributions of the tribes to cancer prevention efforts in the State.

Not all partnerships came easy, however. The SAICN project was challenged by the multitude of project partners, varying levels of collaboration, and the need for a variety of outreach strategies. The project's ability to reach targeted tribal communities fell short of the initial plan. Rather than a multi-state effort, the participating tribes were primarily those with geographic proximity being an important factor. Respondents also suggested that these tribes were among those the most concerned about cancer in their communities. Although some respondents said that more could have been done, most agreed that many new and important connections were created.

System barriers prevented the development of some partnerships particularly within the Indian Health Service and with some of the federally funded tribal programs. The federal partners were challenged with the inability to travel to meetings or activities, making their participation sporadic at times. Personnel changes, work responsibilities, and support from administrators challenged partnership efforts and the progress of some project activities. However, most people and agencies invited to participate responded positively. The cancer organizations responded well and brought additional resources and the potential for on-going relationships to the project and the tribes.

### **EFFECTIVENESS: What will have a long-term effect?**

The most effective parts of the project were said to be those that focused on the tribal communities – particularly training and education. These activities resulted in several critically acclaimed products including a set of American Indian specific cancer awareness videos, and a resource known as “The Gathering Basket”. What made these products unique was that they were clearly designed by, presented by, and disseminated by community members in partnership with skilled American Indian professionals. The videos included tribal cancer survivors and local stories. The Gathering Basket was a CD-ROM containing a compilation of cancer prevention resources geared towards American Indians in the southwest. Small research grants awarded to participating tribes, provided seed money to identify priority research projects and build positive relationships with academic partners. These resources continue to be used and disseminated locally and regionally.

The least effective parts of the project were those focused on policy development. Although seen as critical to ultimately eliminating health disparities, policy change requires concerted and sustained effort and participation from decision makers at tribal, state and federal levels. This is likely beyond the scope of any community-based directive with a research-focused emphasis.

### **ADOPTION: What will be adopted:**

Confidence in the fit between SAICN and the targeted partner entities was generally noted as moderate to high. Respondents said it was important that cancer was the focus. As the project developed, the realization that cancer was of high interest and concern was apparent. Respondents also indicated the research activities and the seed grants helped the participating tribes get excited about the possibilities for what came to be called “tribally-driven” research (Mariella et al., 2010). Local health providers served as a pathway to link the academic partners with the community, successfully

merging three sources of knowledge and skills. These partnerships led to products such as the paper on Tribally Driven Participatory Research, and were pivotal to reframing more traditional approaches to research and empowering tribes in owning the research process.

The biggest challenges to participation and thus, adoption for the long-term are the geographic distances between partners, the limits on people's time and resources, and a pervasive undercurrent of distrust between the tribes and the university partners due to a history of research abuses. Although the project did a good job of mediating the process and bringing partners together, it took time, patience, and good communication. According to respondents, what helped engage stakeholders was the SAICN's approach to creative involvement, use of technology to bridge communication gaps, and the artful blending of cancer prevention science and medicine with tribal culture, tribal medicine, and tribal ways of life.

### **IMPLEMENTATION: What has been implemented?**

The most successfully implemented activities were identified as the Cancer 101 trainings and the small grant process. Respondents agreed that the education component was designed to reach people at different levels of understanding and need for information. They were focused on American Indians and enlightened everyone, not just those directly impacted by cancers. Education was seen as the key to implementing the project and extending its reach. The Cancer 101 trainings paved the way for other trainings, for training of trainers, and for engaging additional stakeholders in the process. The education activities were also one of the few components that were able to expand into Utah and Nevada tribal communities.

The project did a good job of reaching multiple levels of the population. There were activities for individuals and communities, there were activities focused on health care programs, administration, and tribal government, and there were broader conceptual products and activities that contributed to a more global understanding of the issues. Although working on the community level was often challenging, a greater challenge was seen by respondents as the need to educate federal agencies that are willing to fund project in Indian Country but don't fully understand the dynamics or the politics. Respondents indicated that the SAICN project did a very good job of ensuring that staff and participants had the training and resources needed to succeed.

### **MAINTENANCE: What will be maintained?**

Of all the knowledge gained through the project perhaps the most important noted by respondents was the understanding of how to help tribes implement their own research. The small grants process not only resulted in research findings but also affirmed that the tribal community was able to drive their own research and own their own data. The real world application of research skills in tribal settings was seen as an impetus for long-term change.

Respondents noted the products such as the videos will have lasting value to tribal communities and can serve as templates for other populations wishing to replicate the SAICN framework. The project learned how to bring the right people to the process at the beginning, how to ensure everyone was part of the process, and how to build and support the skills needed to develop tribal research efforts and above all, understand cancer in their communities. The SAICN staff and participants collectively have knowledge, skills, and resources unimaginable a few years ago. And, ordinary people are now doing extraordinary things. The favorite example of the respondents was the video participant who is now providing information on cancer to others. She was noted as saying that three years ago she never would have dreamed of this.



According to the respondents, the biggest structural change resulting from the project was communication. Addressing the continuum of communication needs – from internal information sharing to social marketing – was an important learning experience for the project team. The range of skills needed to inform families impacted by cancer and inform the academic community through peer-reviewed publications, are now part of the SAICN's repertoire. The project's participants and partners know where to get information about cancer and other health issues. They have an increased ability to respond to inquiries, obtain a variety of resources, and develop new partnerships. Many of the activities and products will now be sustained through the many programs within the Inter Tribal Council of Arizona.

## DISCUSSION

What do these results imply about the long-term impact of the project? How well did the project "close the gap" between community health needs and the systems that provide health services? The activities, partnerships, products and publications would indicate that significant strides were made. Momentum was established and new community leaders are already building on the foundation built by the SAICN project. Further, the experience of the SAICN project has given the project team and their partners a skill set and knowledge base that has allowed them to ask an array of new research questions. They are now able to conceptualize community based research strategies for locally identified problems. The promise of new research partners, a new generation of skilled Native researchers, and the ability of tribes to define, fund, and implement research will open an array of possibilities for continued progress in eliminating cancer disparities.

Although most of the participating tribal communities didn't and still don't have programs specifically oriented to cancer care and prevention and research continues to be a contentious subject, the SAICN project worked hard to address these issues. Community focused education and awareness activities helped the communities focus on key issues, separate fact from fiction, and develop a working vocabulary for discussions with family and health care providers. Conformance with NCI standards and partnerships with entities such as the American Cancer Society increased confidence in the information for both SAICN staff and community participants. Many of the projects provided a way to educate the college students working with the project and provided lasting tools for reducing health disparities.

There is still much we don't know about effectively changing health care policy and practice. A review by Bero et al., (1998) suggests that the passive dissemination of information is generally ineffective and as best results in only small changes in practice. These approaches, however, are common, and because they are easily quantifiable, funding priorities supports their continued use. Specific strategies and intensive efforts are needed, however, to ensure that practices and policies change. At a local level, where change is often most effective, Bero and colleagues suggest that attention needs to be given to the coordinated dissemination and implementation of evidence-based findings. Further, attention to the characteristics of the message, barriers to implementation, and preparedness of participants are essential.

One could argue that the SAICN project did this and more. In five years, the SAICN project accomplished a great deal. There were certainly the more tangible results such as the various products, toolkits, and publications. But more importantly perhaps for tribal communities (if not for the funding agency), were the less tangible but community-changing results. The evidence suggests that while the project was disseminating the more quantifiable elements of the project, a great deal of thought and effort went into affirming the validity of project strategies, developing coordinated

approaches, and working with communities on realistic levels.

The experience of the SAICN project has given the project team and their partners a skill set and knowledge base that has allowed them to ask an array of new research questions. They are now able to conceptualize community based research strategies for locally identified problems. And, the promise of new research partners, a new generation of skilled Native researchers, and the ability of tribes to define, fund, and implement research will open an array of possibilities for the ITCA and the continued success of the SAICN.

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