

# The American Indian Cancer Foundation

## *Impacts and opportunities: Results from a discussion of the American Indian Cancer Foundation's health equity work*

In 2013, the American Indian Cancer Foundation (AICAF) received funding from the Center for Prevention at Blue Cross and Blue Shield of Minnesota through the Health Equity in Prevention (HEiP) initiative. Through its HEiP funding, AICAF is influencing the development of tribal policies and organizational practices using evidence-based and culturally-relevant approaches and changing social norms around commercial tobacco use within the American Indian community. They will also foster coalitions and networks at the local, regional, and state levels and educate and empower tribal leadership related to tobacco, cancer prevention, and health equity.

In January 2015, a group of 14 project stakeholders were invited to a Ripple Effect Mapping discussion about AICAF's health equity work. The discussion participants included members of AICAF's staff and individuals who work at: the Upper Sioux tribe, the Minnesota Department of Health, the Bois Forte tribe, the Lower Sioux tribe, the Mille Lacs tribe, the University of Minnesota Department of Medicine, the White Earth tribe, and the Fond du Lac tribe. The discussion was intended not only to provide the participants a chance to consider how successful the work has been in achieving its intended goals, but also to identify the indirect or unexpected project impacts.

### PROJECT IMPACTS

During the discussion, all participants had opportunities to describe AICAF's achievements and to discuss the indirect impacts of its work. The participants grouped each of these observed impacts into four main types of changes that had taken place as a result of AICAF's work: bringing people and groups together; building knowledge, awareness, and interest; helping inform new policies; and helping maintain traditional practices and acting as a bridge between the American Indian community and other organizations and groups. Participants were not asked to rank the relative importance of these impacts in relationship to one another. However, the graphic included in this summary does show how many times the participants identified a change in each key area and offers a few examples of key impacts identified by the participants. A discussion related to each area of change is included in this summary, and the specific impacts identified by the participants during the mind mapping exercise are listed in the appendix.

#### What is Ripple Effect Mapping?

Ripple Effect Mapping (REM) is an evaluation tool used to better understand the intended and unintended impacts of a project. It is particularly helpful when evaluating complex initiatives that both influence, and are impacted by, the community. REM is a facilitated discussion with project staff and local stakeholders that creates a visual "mind map" during the discussion that shows the linkages between program activities and resulting changes in the community.

This approach is intended to help demonstrate the project's impacts more holistically and to describe the degree to which different types of impacts are observed by project staff and community stakeholders.

# Ripple Effect Mapping: American Indian Cancer Foundation (AICAF)



**HELPS MAINTAIN AMERICAN INDIAN PRACTICES AND ACTS AS A BRIDGE BETWEEN THE AMERICAN INDIAN COMMUNITY AND OTHER ORGANIZATIONS AND GROUPS**



**BRINGS PEOPLE AND GROUPS TOGETHER**

"There is a fine line between becoming Blue Cross and Blue Shield and staying AICAF. We don't want to get so caught on the other side. It's important to keep our feet in both worlds, but culturally we need to keep that indigenous identity." — Participant

9%

49%

AICAF has helped break down silos within tribal systems.  
AICAF is engaging tribal communities, youth, and elders.  
AICAF brings together youth and adults from around the state through gatherings it hosts, such as the Powwow for Hope.

**AICAF's tribal health equity work**



**HELPS INFORM NEW POLICIES**

AICAF actively works to promote policy, systems, and environmental changes in Minnesota tribal communities. AICAF's Tribal Tobacco Use Project survey and other American Indian specific resources have been used to inform and support policy change.

9%

34%



**BUILDS KNOWLEDGE, AWARENESS, AND INTEREST**

AICAF is interested in spreading knowledge more broadly about what works well in the American Indian community.  
AICAF uses creative and culturally-responsive approaches to expanding knowledge.  
AICAF respects and integrates traditional tobacco use.



## Bringing people and groups together

During the discussion, participants shared that AICAF is a key convener of groups and community members. One of the main events it hosts is its annual fundraiser, the Powwow for Hope. At this event, people from around the state come together to honor loved ones who have fought cancer and their caregivers. Information and resources on cancer prevention are also made available. A participant shared that more people are becoming engaged in health and wellness as a result of the Powwow for Hope. AICAF also works to break down silos within tribal systems. Participants highlighted AICAF's work in creating a Health and Human Services Advisory Committee with the Lower Sioux community. The committee is a forum to collaborate on ideas, initiatives, and needs for the Lower Sioux community in the areas of health, wellness, mental health, chemical dependency, safety, and social service. In addition, the committee provides feedback to staff on current efforts, programming ideas, and grant funding opportunities, and assists in the strategic planning needs of Lower Sioux community. AICAF's recent work has also focused on bringing together American Indian youth and elders. Through its Tribal Health Equity report, AICAF identified that youth want to play an active role in addressing and reducing health disparities. In order to do this work, it is important that they learn from elders about the traditional ways and practices that support health and wellbeing.

*"[AICAF's gatherings have an impact] not just while [people are attending], but when they return to their communities." – Participant*

*"AICAF is not looking to reinvent the wheel. It is tightening the spokes so we all work together." – Participant*

*"We want to make sure we are connecting with elders in a meaningful way that is representative of native values."  
–AICAF staff member*



## Building knowledge, awareness, and interest

Participants highlighted that AICAF uses creative and culturally-relevant approaches to expanding knowledge. It worked with the Upper Sioux community to organize the Pink Shawls Initiative which brought together over 180 people. The initiative helped raise awareness about breast health issues in a culturally-relevant way. It also provided breast health education and promoted programs that increase access to screening through coordination and use of available resources. AICAF also worked with the Lower Sioux community on an event attended by over 100 people that brought a native chef to the community to prepare healthy, traditional indigenous foods. In addition, AICAF respects and integrates traditional tobacco use. A participant noted that AICAF "always starts meetings and gatherings with tobacco, prayer, and smudging. [They] are always conscious of respecting who we are as a native people." AICAF helped tribes think about ways they can focus on incorporating traditional tobacco use while limiting the use of cigarettes.

*"We are fortunate to have AICAF close to us. We need to spread the information [AICAF provides] even more broadly." – Participant*



## Helping inform new policies

Participants reported that AICAF has helped connect tribal members to information that has guided the development and implementation of policies. AICAF's Tribal Tobacco Use Project survey and other American Indian specific resources have been used to inform and support policy change processes. Changes in smoking policies have allowed tribal communities to talk about the key differences between using traditional tobacco versus commercial tobacco.

*"There are policies set up that say you can't smoke in that area, but you also need to understand in your heart that you shouldn't smoke, and if you smoke ceremonial tobacco, do so only ceremonially." – Participant*

## Helping maintain traditional practices and acting as a bridge between the American Indian community and other organizations and groups.

Some participants pointed out that AICAF helps maintain traditional American Indian practices through its work around health and wellness. Participants referenced the Pink Shawls project and AICAF's focus on traditional tobacco use as two key examples of this work. They also reported that AICAF is a key liaison connecting funders and health organizations with the American Indian community. The staff members have knowledge about traditional western approaches to health and culturally-relevant strategies from the American Indian community. They use this experience and knowledge to articulate and generate support for traditional practices and beliefs in health programming and policies.

*"I like that AICAF has members from every different tribe. We all are working together; we all are here for one cause. As far as the culture piece, we have AICAF, [an organization] that understands [our] culture, where we didn't have that before, and that's the biggest piece. With the Pink Shawls project, we hope that Blue Cross and Blue Shield understands what the shawl means for us."*  
– Participant

*"Getting into the broader issues that have created these disparities, I think a role that AICAF has played is that they understand the things you talk about in terms of the importance of culture. Their work on a different level is as a translator, with Blue Cross and Blue Shield and other funders, between what people within tribal communities are saying about the kind of work that needs to go on and the kind of work that funders and larger systems need to support."* – Participant

## FOOD FOR THOUGHT

Some of the challenges identified during the discussion related incorporating traditional American Indian practices into systems where health is approached with a western, medically-focused lens. A health provider mentioned how she works with patients who have cancer and spends time discussing what the disease means to them and how traditional approaches could help. Another participant shared the difficulty of working in the state health department where some view culture as separate from health and the treatment of disease. The participant noted that this way of thinking is opposite to how health and culture are viewed in the American Indian community. Another participant identified that some parents are hesitant to allow their children to receive the human papillomavirus (HPV) vaccine because they feel it may indicate that sexual activity at a young age is acceptable. The participant noted that AICAF can help frame this issue for parents and help guide conversations about what is most appropriate.

The following questions may be helpful for AICAF and its partners to consider as they plan their future work:

- How can AICAF continue to advocate for and articulate the importance of traditional health and wellness practices to funders and health organizations? How can AICAF continue to develop and expand its culturally-relevant programs?
- What are the key tools and support that tribes will need as they start to implement policy, systems, and environmental changes?
- As AICAF's tribal health equity work expands, what other organizations, groups, tribes, and individuals should it include in its work?

# APPENDIX: Project impacts identified by discussion participants



## BRINGS PEOPLE AND GROUPS TOGETHER

AICAF brings together youth and adults from around the state through gatherings it hosts, such as the Powwow for Hope, which is AICAF's annual fundraiser and community event that honors loved ones who have battled cancer and caregivers. It also focuses on providing information on cancer prevention and resources.

"[AICAF's gatherings have an impact] not just while [people are attending], but when they return to their communities." - Participant

The fundraising group for Powwow for Hope gained more volunteers this year. Many volunteers are interested in contributing.

"There has been an increase in promoting health and wellness, especially [through] events like Powwow for Hope. That event sparked something in people. People who were never engaged before now are more connected." - Participant

"I think AICAF has done a very good job, bringing us together, opening up the lines of communication, but now that we have [that], we have to hold on to where we are from too." - Participant

AICAF has helped break down silos within tribal systems.

There is increased collaboration and sharing of information across tribal departments (such as health and human services and social services) and with AICAF.

AICAF helped develop the Lower Sioux Indian Community Health and Human Services Advisory Committee, which is a forum to collaborate on ideas, initiatives and needs for the Lower Sioux in the areas of health, wellness, mental health, chemical dependency, safety, and social service. The committee also provides feedback to staff on current efforts, programming ideas and grant funding opportunities, and assists in the strategic planning needs of Lower Sioux Indian Community and AICAF.

The Committee helps contribute to building the community's readiness to implement healthy policies.

Even as silos are coming down, there are still institutional challenges to supporting collaboration and coordination of work.

"AICAF is not looking to reinvent the wheel. It is tightening the spokes so we all work together." - Participant

AICAF is engaging tribal communities, youth, and elders.

AICAF is continually obtaining community input to inform its programming and direction.

More people are coming to events around health, and there is more interest from tribal members about what AICAF is doing and how the members can help out.

Some tribes are more engaged than others.

AICAF is helping to strengthen connections between youth and elders and increase awareness and interest in health issues.

When young people move to urban areas, it can be hard for them to find people who can speak about and share tribal teachings and practices. AICAF tries to find ways to connect young people to elders and teachers who can share traditional tribal ways, particularly around traditional tobacco use.

AICAF's Tribal Health Equity report included a section focused on how youth can help address health disparities.

"Both youth and elders identified that connections to one another would be helpful in prevention work. Youth and AICAF plan to consult and work with elders on prevention of unhealthy behaviors and chronic disease. We want to make sure we are connecting with elders in a meaningful way that is representative of native values." -AICAF staff member

The connections between elders and youth need to be reinforced. There needs to be a focus not just on prevention, but also on native medicine and how to live and stay alive according to native ways.

"We don't think of [this] as culture; it's ways of being, ways of living. Elders teach the rest of us how to stay alive." - Participant

"We as elders need to communicate what we need to do outside of the English language. Let's talk more about where we come from, which is also where our future is. As long as I'm here, I will continue to talk about our ways." - Participant



## BUILDS KNOWLEDGE, AWARENESS, AND INTEREST

AICAF is interested in spreading knowledge more broadly about what works well in the American Indian community.

A participant was at the Title VI (a federal program that provides money to tribes for diabetes prevention or elder nutrition programs) conference in Washington D.C. and referenced AICAF's work.

"We are fortunate to have AICAF close to us. We need to spread the information even more broadly." - Participant

Other participants were interested and wanted to know how to get AICAF to attend the conference and share information about their work.

Places around the country want to know what primary prevention, intervention, and treatment look like within the American Indian community.

"Wouldn't it be great if AICAF could provide that information? Here is what primary prevention looks like in this community. What does eating better and exercising more mean to us?" - Participant

In the American Indian community, a physician has seen increased awareness of cancer screening, prevention, and behaviors linked to cancer, such as eating more fruits and vegetables as a result of AICAF's work.

AICAF uses creative and culturally-responsive approaches to expanding knowledge.

A native chef came to the Lower Sioux Indian Community and gave a presentation and prepared indigenous healthy foods. Over 100 people attended this event.

People showed up to see something different and learn about and try traditional food.

The Upper Sioux community worked with AICAF to hold the Pink Shawls Initiative which brought together over 180 people. Pink Shawls raises awareness about breast health issues in culturally-relevant ways at community events within American Indian communities. It also provides breast health education and promotes programs that increase access to screening through coordination and use of available resources.

AICAF has helped bring awareness to the Upper Sioux community about how much cancer afflicts the tribe, which was especially helpful because the Upper Sioux is a small community.

AICAF respects and integrates traditional tobacco use.

Some tribes still gives cigarettes as gifts to drummers at powwows. It would be better to offer traditional tobacco instead but it's difficult to find enough traditional tobacco as a replacement. AICAF has helped tribal health department staff connect to Clearway as a resource. At the very least, that opens up that conversation with the community and leadership. In the future, tribal communities hope to see more traditional tobacco instead. Bringing forward awareness is important.

"AICAF always starts meetings and gatherings with tobacco, prayer, and smudgings. [They] are always conscious of respecting who we are as a native people." -Participant

The Powwow for Hope and Culture Committee on Bois Forte are working together to respect traditional tobacco use.



## HELPS INFORM NEW POLICIES

The Bois Forte tribe has a new policy that all powwows will be smoke free and there is no smoking within 50 feet of tribal buildings.

These policies have allowed the community to talk about tobacco use, especially traditional tobacco use versus commercial tobacco use.

"There are policies set up that say you can't smoke in that area, but you also need to understand in your heart that you shouldn't smoke, and if you smoke ceremonial tobacco, do so only ceremonially." - Participant

The Fond du Lac tribe is going smoke free in its buildings as of February 15th, 2015. AICAF's Tribal Tobacco Use Project survey and other resources have been used to inform and support policy changes.





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"What do culturally-based services for American Indians look like? Is it pamphlets? Videos? Medicine people? We hopefully represent our communities. We need to integrate that piece somehow into tribal health equity because we are not the Indian Health Service or Blue Cross and Blue Shield. We are AICAF. We need to hold onto that and be aware that it will get blurred but we need to take that next step." - Participant

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"I like that AICAF has members from every different tribe. We all are working together; we all are here for one cause. As far as the culture piece, we have AICAF, [an organization] that understands [our] culture, where we didn't have that before, and that's the biggest piece. With the Pink Shawls project, we hope that Blue Cross and Blue Shield understands what the shawl means for us." - Participant

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"Getting into the broader issues that have created these disparities, I think a role that AICAF has played is that they understand the things you talk about in terms of the importance of culture. Their work on a different level is as a translator, with Blue Cross and Blue Shield and other funders, between what people within tribal communities are saying about the kind of work that needs to go on and the kind of work that funders and larger systems need to support. We can't operate in a silo, and as we're saying all these things are important, there's a whole other system at work that is trying to do away with cultural beliefs. This is a role that AICAF can play. We need to look at Blue Cross and Blue Shield's policies and approaches to see how you're not supporting that. American Indian people have been put in places and ignored. Blue Cross and Blue Shield does their work and creates all of these funding opportunities in isolation of what people have said. Bridging those two different worlds is a key piece to what health equity efforts are about." - Participant

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