CDC 2016

American Indian /Alaska Native

CANCER SUMMIT

APRIL 26-28, 2016
TRAVERSE CITY, MICHIGAN

SIX-MONTH FOLLOW-UP REPORT

Looking Back and Looking Ahead:
Collaborating to Advance Cancer Control in
American Indian/Alaska Native Communities

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Introduction

The Centers for Disease Control and Prevention (CDC) 2016 Cancer Summit titled "Looking Back and Looking Ahead: The State of Cancer Control in American Indian and Alaska Native (AI/AN) Communities," convened current and former Division of Cancer Prevention and Control (DCPC) tribal grantees from five CDC regions, CDC staff and Comprehensive Cancer Control National Partnership (CCCNP) members from April 26 to 28, 2016 at the Grand Traverse Resort in Traverse City, Michigan.

The George Washington University (GW) Cancer Center conducted phone interviews with 13 attendees from tribal organizations and stakeholders in October and November, approximately six months after the summit, to assess action plan progress, new partnerships and needed technical assistance since the summit. GW Cancer Center also surveyed six CCCNP representatives. This report summarizes the findings.

For a description of summit proceedings, presentation highlights and key decisions made by attendees, as well as evaluation results generated by attendees, read the CDC 2016 Cancer Summit Report—Looking Back and Looking Ahead: Collaborating to Advance Cancer Control in AI/AN Communities.

Summit Objectives

1. Provide a forum for open dialogue about topics of interest to all CDC DCPC tribal grantees
2. Provide an opportunity for DCPC tribal grantees and DCPC staff to work together in teams to collaboratively identify priority areas and strategies for AI/AN communities over the next ten years, including data; policy, systems and environmental (PSE) changes; tobacco; human papillomavirus (HPV); and colorectal cancer

Methods

The GW Cancer Center emailed all summit attendees on October 24, 2016, approximately six months after the summit was held, to recruit volunteers for 30-minute phone interviews. Volunteers scheduled a time for the interview using Google Appointments or by directly corresponding with the GW Cancer Center evaluator. Thirteen interviews were completed between October 25 and November 7, 2016.

The interviewer followed an interview guide developed with the cooperation of the AI/AN Summit Planning Committee, which asked demographic questions; about respondents' confidence level that most activities outlined in the action plans developed during the summit will be achieved on a scale of very confident, confident, unconfident and very unconfident; whether the planned activities were being implemented as a group or by individual organizations; about their readiness level to implement the planned activities on a scale of not ready, getting ready, ready, currently implementing activities and maintaining activities; about the key successes and challenges; the kinds of partnerships developed resulting from the summit; and about any needed technical assistance to achieve the planned activities.

Two members of GW Cancer Center staff analyzed and drew themes from the qualitative data using QSR NVivo 11. Individually identifying information was removed as findings were summarized.

At least one person from each CDC region represented at the summit was interviewed (*Figure 1*). There were also two stakeholders that may not directly be working on the action plans, who also provided updates. The majority of interviewees represented AI/AN programs, including the National Breast and Cervical Cancer Early Detection Programs, National Comprehensive Cancer Control Programs and Colorectal Cancer Control Programs. Some interviewees were also working on state programs and one identified as a coalition member. Other interviewees said they were state collaborators, received Health Resources and Services Administration and Good Health and Wellness funding, as well as sub-awards from state and regional entities. Further, 12 were program coordinators, managers or directors and one was a data manager. The interviewees were experienced, with 10 saying they have held the role for over two years, two between 12-24 months and one less than 12 months.

Region E updates

Region E (Fond du Lac Band and Lake Superior Chippewa) discussed and created their action plans as a group, but planned each activity to be implemented individually. One representative was interviewed. Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 2*. The interviewee was confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Systems

The interviewee reported that they are getting ready to implement activities related to systems change, and have established baseline data and quality measures for American Indian Cancer Foundation's (AICAF) tailored "I Quits" program, which will help demonstrate program effectiveness. A key activity of the "I Quits" program is to increase referrals to smoking cessation counselors. One challenge associated with this area of focus is the uncertainty of funding sustainability and changes in scope of work with the current grant period ending and the new CDC FOA being released.

Area of Focus 2: Collaboration

The interviewee reported that they are not ready to implement activities related to collaboration, but have started to communicate with department leaders in medical, community health services and administrative services to develop a cancer leadership team. One challenge associated with this area of focus is that several advisory committee

Table 1. Demographic data of interviewees (N=13)

	n	%
Regional Representation		
Region E: Fond du Lac Band of Lake Superior Chippewa	1	9.1
Region F: Cherokee Nation and Kaw Nation	1	9.1
Region H: Cheyenne River Sioux and Great Plains Tribal Chairmen's Health Board	3	27.3
Region I: Hopi Tribe, Navajo Nation and Tohono O'Odham Nation	3	27.3
Region J-1: Southeast Alaska Regional Health Consortium, Alaska Native Tribal Health Consortium, Arctic Slope, Southcentral Foundation and Yukon-Kuskokwim Health Corporation	2	18.2
Region J-2: Native American Rehabilitation Association, South Puget Intertribal Planning Agency, Northwest Portland Area Indian Health Board and California Rural Indian Health Board	1	9.1
Other		
Inter-Tribal Council	1	7.7
Summit Speaker	1	7.7
Program/Organization Representation*		
AI/AN National Breast and Cervical Cancer Early Detection Programs	5	38.5
AI/AN Comprehensive Cancer Control Programs	4	30.8
State Comprehensive Cancer Control Programs	2	15.4
AI/AN Colorectal Cancer Control Programs	1	7.7
AI/AN Coalition Member	1	7.7
State National Breast and Cervical Cancer Early Detection Programs	1	7.7
Other CDC Grantees	2	15.4
Job Role		
Program Coordinator/Manager/Director	12	92.3
Data Manager	1	7.7
Length in Role		
< 12 Months	1	7.7
12-24 Months	2	15.4
> 2 Years	10	76.9

*totals may not add up to 100% because multiple responses were selected

leaders are retiring and new members will have to be educated and trained, which will be time– and resource-intensive. Further, as mentioned earlier, due to the uncertainty of funding sustainability and potential changes in scope of work with the current grant period ending and the new CDC FOA being released, efforts are being put on hold.

Area of Focus 3: Policy

The interviewee reported that they are maintaining and evaluating activities, and that there have been "highlight achievements" in policy. State Health Improvement Plan (SHIP) from Minnesota has enabled them to hire an additional smoking cessation counselor, who is working closely with the cancer program outreach worker on smoke-free and second-hand policy initiatives with ClearWay. Fond du Lac also passed a tribal ordinance to increase smoke-free zones around tribal office to 25 feet, except for casinos. The first floor of the Fond du Luth Casino has become smoke-free. They originally agreed to implement the policy for one year. However, after recognizing that the smoke-free policy had no negative financial impact, they have continued this policy, and have even started to promote the smoke-free first floor on their website as well as on major highways around Duluth. Further, large public events such as powwows and community gatherings are assuming 100% smoke-free policies as standard of operations.

Partnerships

The interviewee did not report any new partnerships resulting from the summit, but said that the meeting was "so valuable," as it offered an opportunity to come together and share information: "we could really see how much progress has been made. For those that were new, hopefully it gave them an understanding about what has transpired since the early 2000s when the majority of tribal programs had nothing… including no databases."

Technical Assistance Suggestions and Other Comments

Fond du Lac works closely with and receives tailored technical assistance from AICF. The interviewee urged federal programs and funders to continue their work to understand "the sovereign nations and the huge variety" of populations, circumstances and needs.

Region F updates

Region F (Cherokee Nation and Kaw Nation) discussed and created their action plans as a group, but planned each activity to be implemented individually. One representative was interviewed. Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 3*. The interviewee was very confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Policy and Health System

The interviewee reported that they have implemented and are now maintaining health system procedures and policies to increase screenings and decrease the no-show rates for colposcopies. However, getting patients into the clinics remains a challenge, because they are afraid of the screening procedure. In response, the interviewee reported that they are developing communication strategies to promote screenings.

Area of Focus 2: Systems

The interviewee reported that it took 11 months to implement a new Electronic Medical Record (EMR) software that provides more accurate reports on cancer screening data (the implementation started before the summit). They are currently working to implement a reporting system that automatically generates and sends data to investigators. The interviewee reported that the period during which the new EMR was being installed was stressful for the clinics, and there are challenges associated with the reality that the EMR is primarily built for business purposes, and not necessarily to improve screening and patient care. However, the interviewee said there is wide organizational support among health administrators and tribal administrators, and cancer remains a priority topic and people are passionate about the work.

Area of Focus 3: Environmental (Outreach, Communication and Messaging)

The interviewee reported they are getting ready to implement planned activities around environmental change. The data from 2015 showed cancer mortality indicators continuing to rise: "We get a little discouraged with the outcomes data," the interviewee said. They are coming to the realization that this trend stems from health behaviors that are influenced by the mostly rural environment, but "environmental changes and its impacts are slow to materialize in health outcomes." For example, more needs to be done to decrease the sales of soda pop in grocery stores: "We feel like we're spinning our wheels trying to get people into screening."

Partnerships

The interviewee said that the summit provided the first opportunity to meet with the CDC program officer in person, and spending time with Melissa Jim and David Espey "was great." The summit was especially meaningful in learning about the racial re-classifications in data.

Technical Assistance Suggestions and Other Comments

The interviewee suggested that CDC representatives look for opportunities to spend more time on the ground to get to know the community better, especially as the last site-visit was four years ago. The interviewee believes that if CDC were more familiar with the unique circumstances and needs of the program and population, they would be more flexible with funding allocation and understanding of tribal self-determination: "the cancer prevention model they preach does not fit all tribal organizations."

Region H updates

Region H (Cheyenne River Sioux and Great Plains Tribal Chairmen's Health Board) discussed and created their action plans as a group, but planned some activities to be implemented as a group and some individually. There were three interviews with four representatives (one joint interview). Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 4*. Two interviewees were confident and one was very confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Systems

The stage of change for systems change activities varied across the three interviews, from "getting ready" to "maintaining activities."

Cheyenne River Sioux is coordinating with the information technology (IT) department and confirmed that they have capabilities to install customized reminder systems, and will "turn it on" when they are ready. The interviewee was confident that the activities outlined during the summit will be achieved.

The Great Plains Tribal Chairmen's Health Board also worked with the IT systems at the colorectal cancer facility by attending trainings and having discussions about the advantages of using reminder systems. Transitioning to a new system is taking longer than anticipated. The first phase is to get people educated about the system and the second phase is to scale up. The interviewees also spoke about installing provider-assessment feedback to evaluate effectiveness of the intervention in the next couple of years.

Area of Focus 2: Policy: Tobacco

The stage of change for tobacco policy change activities varied across the three interviews, from "not ready" to "implementing activities."

Cheyenne River Sioux is working with the Canli Coalition and the tribal council to introduce cigarette tax compacts and update the policy and ordinance to include e-cigarettes, while also continuing to promote quitlines. One interviewee was confident that that tax compact for e-cigarettes will pass, with the cooperation of Missouri Breaks Industries, an "Indian-owned medical firm." There have also been educational sessions on e-cigarettes—for example, two speakers from universities came to the reservation to present on e-cigarettes.

Interviewees of Great Plains Tribal Chairmen's Health Board report that they are working to raise awareness of the harms of e-cigarettes, but it may take longer than the 1-2 year time frame allotted in the action plan. The timeline may also depend on state-level policy changes: "if [Minnesota] moves in a positive direction, the tribes tend to move that way […] We're not there yet." Current state efforts are focused on raising the age of e-cigarette sales to 21. The Great Plains Tribal Chairmen's Health Board also recently started to incorporate the 5 A's of tobacco cessation in their services and trained approximately 300 people on state quitline and National Indian Network quitlines, which led to an increase in referrals from 19% to 49.5%. The comprehensive cancer control program is coordinating communication and education efforts with a tobacco health educator, who works under the CDC Good Health and Wellness program.

However, interviewees said that "policy change can be hard," pointing to the example that Cheyenne River is the only tribal community in the region to go smoke-free and it took them five to seven years. They attribute Cheyenne River's success to the Canli Coalition with multi-sectoral membership including the elderly, youth and other champions. Interviewees emphasized that tobacco policy is especially hard to pass in a region where there is a high prevalence of smoking, as it has a huge impact on tribal leadership that also often smokes, as well as tribal members.

Area of Focus 3: Environment: Physical Activity and Nutrition

The stage of change for environmental change activities pertaining to physical activity and nutrition varied across the three interviews, from "implementing" to "maintaining and evaluating activities."

Cheyenne River Sioux's Youth Diabetes Program received the John Pipe Voices for Change Award for "outcomes achievement" from the American Diabetes Association in 2016 for the activities that include health fairs and powwows for adults and children, where they take their blood pressure and glucose levels and pass out health information materials. The interviewee said that their success is attributable to the staff that are able to leave their office and go into the communities to work with youth; a policy supported by their leader and funding mechanisms. They are also working with the Special Diabetes Program that organizes challenges: people weigh in at the beginning of the program and are challenged to increase physical activity, eat healthfully and lose weight. If people meet their goals, they have the chance to win mountain bikes. They also plan to organize an activity for mountain bike winners to "hit the trails" this summer. The Tribal Health Department also offers a walking class on Monday, Wednesday and Friday mornings as part of physical activity-leave, which is paid-time off offered to employees to engage in physical activity.

Partnerships in Improving Community Health (PICH), a tribal advisory group, is working on environmental change efforts to improve physical activity levels. PICH adapted and implemented the PSE Community Health Assessment aNd Group Evaluation (CHANGE) tool from CDC and developed a community action plan to work on tobacco, nutrition and physical activity. There are challenges with building walking paths, as outlined in the action plan, due to limited funding.

Partnerships

The stage of change for building partnerships varied across the three interviews, from "implementing" to "maintaining and evaluating activities."

Cheyenne River Sioux and Great Plains Tribal Chairmen's Health Board collaborate often, as they are only 2.5 hours away from each other. For example, after the summit, members of the Cheyenne River Sioux went to Albuquerque to attend a leadership training organized by the Great Plains Tribal Chairmen's Health Board, where they shared summit outcomes with 11 partners.

One interviewee from Cheyenne River Sioux said s/he did not know many other people at the summit, but said that it was "great getting to know various initiatives in the region," CDC representatives and select CCCNP members.

S/he said it was a good opportunity to meet unfamiliar people from Great Plains Tribal Chairmen's Health Board as well.

The interviewees from Great Plains Tribal Chairmen's Health Board attended the meeting for AI/AN Colorectal Cancer Programs the day before the summit, where they met other tribal organizations that were previously funded and learned the keys to their success. The interviewees also said that they "learned a lot" from other comprehensive cancer control programs during the summit: "It was a way to strengthen and build across all tribes that were there—partnership and learning from each other."

Technical Assistance Suggestions and Other Comments

Interviewees requested that CDC not wait another 10 years before convening another summit for AI/AN programs. They also requested that tribal programs receive more dedicated time at national cancer conferences to convene with one another and present their work. Further, they asked for CDC to consider dedicated funding to tribal programs to be earmarked to reduce competition between tribes and with states. One interviewee mentioned that the quarterly CDC tribal grantee updates are more interesting as there is more emphasis on tribal updates compared to CDC updates: "we can do them more frequently, even monthly, because that's how we learn from each other."

Region I updates

Region I (Hopi Tribe, Navajo Nation and Tohono O'Odham Nation) discussed and created their action plans as a group, but planned some activities to be implemented as a group and some individually. There were three interviews. Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 5*. All three interviewees were confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Colorectal Cancer Screening

One interviewee said that they are "getting ready" and another said that they are "currently implementing activities" in this area of focus.

Tohono O'Odham Cancer Partnership is talking to state comprehensive cancer control program staff to talk about the health education efforts promoting Fecal Immunochemical Tests (FIT) for colorectal cancer screening. Tohono O'Odham and comprehensive cancer control program staff met to exchange known best and promising practices and are working together to create an educational PowerPoint intended to be shown to community members.

Navajo Nation identified ownership and provided tribal language for educational materials and public service announcements (PSAs) on local radio stations about colorectal exams.

Hopi Tribe is working with the Indian Health Service (IHS) to provide patient navigation services for clients who need colorectal cancer screening. Patient Navigators speak to clients in their own language to help them overcome barriers to care. Hopi has identified courses that have a good reputation and have sent navigators to attend workshops in-person. One interviewee reported the challenges of dealing with conflicting recommendations for clinical breast exams between various authority organizations is confusing.

Area of Focus 2: Breast Cancer Screening in Navajo Nation

Interviewees said that they are ready for activities in this area of focus.

Navajo Nation clarified the Memorandum of Understanding (MOU) agreement on services that are to be provided from both tribal health services and IHS, and confirmed that the Government Performance and Results (GPRA) standards have been met. However, a potential challenge is that the new medical health facility CEO can change whether the MOU remains or make amendments or revisions.

Barriers to this work include time constraints and limited staff capacity. For example, Tohono O'Odham's procedures and rules and regulations have changed in accordance with changes in their separate health department entity, causing priorities to compete for time.

Area of Focus 3: Breast Cancer Screening for the Hopi Community

Interviewees said that they are ready for activities in this area of focus.

Arizona's comprehensive cancer control program is ready to review the MOU for Hopi's breast cancer screening community and getting ready to share with Navajo Nation. The interviewee also mentioned that many health insurance plans in Arizona found the mortality data among minority populations compelling and agreed to cover mammograms starting at age 40, despite USPSTF recommendations. However, there are challenges with health care coverage and the restriction CDC places on using funds to cover those who have private insurance. As many Hopis are employees of the tribal government that provides self-insurance programs, the breast cancer screening program cannot use CDC funds to pay for such services.

Further, the 10th annual Tribal Collaborative conference held in November 2016 featured a breast surgeon that spoke on the importance of listening to patients and their family history.

Partnerships

One interviewee mentioned that the summit spurred partnership with the National Native Network that sent their staff to visit the Hopi reservation in September 2016. The summit helped to reinforce the partnership and kinship of Indian Country and "that we can be a resource for one another."

One interviewee said that regional efforts were already well-integrated and partnership and collaboration were strong, so the summit did not spark new partnerships, but "we all loved the conference." The Tribal Collaborative involves every member of the program, including state, San Carlos Apache Tribe, Tohono O'Odham Nation, Hopi, Navajo Nation and other stakeholders such as the American Cancer Society Cancer Action Network. They hold annual meetings to continue the collaborative work.

Technical Assistance Suggestions and Other Comments

One interviewee requested technical assistance on evaluation and assessment of programs to demonstrate effectiveness and secure future funding.

Other Comments

One interviewee mentioned that the federal government needs to provide support to programs and funding opportunities that demonstrate respect for traditional ways and historical trauma, as not every tribe is on the same trajectory for health improvement and systems advancement. Further, s/he suggested that CDC continue to foster and broker partnerships between grantees and CCCNP organizations.

Region J-1 updates

Region J-1 (Southeast Alaska Regional Health Consortium [SEARHC], Alaska Native Tribal Health Consortium, Arctic Slope, Southcentral Foundation and Yukon-Kuskokwim Health Corporation) discussed and created their action plans as a group, but planned some activities to be implemented as a group and some individually. There were two interviews with three representatives (one joint interview). Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 6*. All interviewees were confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Access to Services

One interviewee said they are getting ready and another said they are currently implementing the planned activities in this area of focus.

SEARHC is working on developing a wellness committee that is recognized by the consortium's management and approved the Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMEN) Women's Health Program that allows the 800-900 consortium employees discounts to the swimming pool (45% of SEARHC employees are Alaska Native or Native American). This is a success for increasing access to wellness facilities, as there are not many other options for physical activity, especially during the winter. SEARHC also presented the recommendation for employees to get time off for colonoscopies to the executive management committee, and is currently undergoing review. The response has been slow, as SEARHC already offers a generous paid-time-off policy. Further, due to recent employee turnover, the wellness committee has been inactive; however, the interviewee expected it to revitalize in 2017.

Alaska's comprehensive cancer control program is a statewide organization has offices across Alaska, and some already have employee wellness programs including time-off for cancer screenings, and others are currently discussing and organizing efforts. The interviewee also mentioned that with shrinking resources and high turnover, persuading more offices to invest in employee wellness is challenging.

Area of Focus 2: Recruitment and Retention

One interviewee said they are getting ready and another said they are currently implementing the planned activities in this area of focus.

SEARHC has partnered with the state breast and cervical cancer early detection program to train staff on patient navigation using the University of Alaska's online courses that are currently being developed. SEARHC is also working with medical, nurse practitioner and physician assistant students doing monthly rotations, with the goal of showcasing the region and compelling them to return to provide services. Further, SEARHC leveraged its close partnership with the Alaska Native Medical Center to have an oncologist lead a grand rounds with providers in August 2016. The oncologists presented information to the providers and organized a support group retreat for people living with cancer. The SEARHC population is too small to keep an oncologist on staff and clinicians take on a wider range of responsibilities, which makes such exposure to cancer specialists important for clinicians in the region. Overall, high turnover in rural areas and unique regional geography remain a challenge.

Alaska's comprehensive cancer control program also added increased provider education to their work plan.

Area of Focus 3: Continuity of Services; Linking Prevention to Care

One interviewee said they are currently implementing and another said they are maintaining and evaluating the planned activities in this area of focus.

Alaska's comprehensive cancer control program reported that they have been most successful at identifying and building relationships with unique partners, including Walgreens, community health centers and parish nurses. They conducted key informant interviews with these partners during summer 2016 to collect process evaluation data on what did and did not work, and are currently writing a work plan based on the feedback. For example, they found that two mobile mammography programs were not coordinating with each other, but "that bridge is being built." Further, they found that, according to the Young Women's Christian Association (YWCA), that women are getting screenings locally, which contradicts the assumption that many people go to Anchorage. In response, the comprehensive cancer control program is working to accept local programs and educate local providers to leverage their screening services. The comprehensive cancer control program also partnered with the breast and cervical cancer prevention program and leveraged their partners and funding to conduct outreach to communities, food banks, churches, people with lower health literacy and English as a second language communities.

Partnerships

One interviewee said that the summit "helped solidify the region as a group and helped reconnect some group members that had fallen away… Really great outcome," and that in-person meetings are advantageous for building relationships compared to conference calls and electronic communication.

Another interviewee said that the summit was useful to know future areas of priority and available resources for Alaska Natives: "I remember taking notes during presentations and thinking: 'I'm going to follow up with them.' Liver cancer, for example. I appreciate the ability to network with these experts." The interviewee reported being mostly familiar with everyone in attendance, "which is not a bad thing. It's good to see some continuity," but would have liked to have seen more people from IHS.

Technical Assistance Suggestions and Other Comments

Both interviewees mentioned that resources on employee wellness would be helpful to make the quick and convincing case to employers by presenting the costs and benefits. This resource might include how to encourage employees to support needed paid-time off to support the 80% by 2018 colorectal cancer screening goal. It might also include newsletters and templates that the human resources department or the wellness committees could reuse for their employees.

Another suggestion was for more success stories for health care professional retention and increased access to services, as well as examples of successful workplace health policies.

Region J-2 updates

Region J-2 (Native American Rehabilitation Association, South Puget Intertribal Planning Agency, Northwest Portland Area Indian Health Board and California Rural Indian Health Board) discussed and created their action plans as a group, but planned some activities to be implemented as a group and some individually. There was one interview. Areas of focus, planned action steps, stages of change, successes and challenges are summarized in *Table 7*. The interviewee was confident that the activities outlined during the summit will be achieved.

Area of Focus 1: Tobacco Cessation for Survivors

The interviewee reported they are not ready to implement the planned activities in this area of focus, but mentioned that they are working on developing smoking cessation resources in general. Tobacco cessation specifically for cancer survivors is not their first priority, given the high rates of tobacco use in the community in general (approximately 40%) and relatively low numbers of cancer survivors (approximately 300 new diagnoses in the whole region). Additionally, it is difficult to plan programs and evaluate changes, as cancer centers do not collect data on smoking among cancer survivors and the data that Centers for Medicare and Medicaid services collect with the lung cancer screening registry is not publicly available.

Area of Focus 2: Survivor Groups

The interviewee reported they are getting ready to implement the planned activities in this area of focus and have been connecting tribal programs to resources and survivorship programs in cancer centers.

Area of Focus 3: HPV Vaccinations

The interviewee mentioned that they have worked on mini-projects funded by the Cancer Prevention and Control Research Network to conduct focus groups with community members on HPV vaccination interventions at pharmacies. Staffing changes at partner organizations and pharmacies and limited time have been a challenge to administer the vaccines.

Partnerships

The interviewee said that the summit allowed for in-depth conversations with some attendees, especially CCCNP members. For example, a conversation initiated about a paper from the National Academy of Medicine that reported data on the impact of insurance outcomes among native patients, which conflicted with other data sources, spurred further dialogue.

Technical Assistance Suggestions and Other Comments

The interviewee said that additional funding for tobacco cessation resources for tribes would be beneficial and for CDC to promote clinical cessation interventions and not quitlines to reach cancer survivors, pregnant women and tribal members.

Other Stakeholder updates

Intertribal Council of Michigan and State of Michigan Partner

Two stakeholders who attended the summit also provided updates and comments during their interviews.

Updates:

- Formed cancer screening and prevention workgroup, which has been successful with addressing infant health, and are seeking to extend the success to cancer and maternal health issues.
- Created an action plan to provide training and education to non-traditional providers such as home-visitors for mothers to talk about cancer screening. This included a session on colorectal, breast and cervical cancer screenings.
- Organized dance shawl workshop in November 2016, where women wear shawls that represent meaning and serve as a catalyst for community members to start talking about health topics and disparities. They will promote breastfeeding, screening and mammograms as methods of prevention.
- Planning to host the first-ever Smoking Cessation and Reduction in Pregnancy Training (SCRIPT) in February 2017 in Michigan for health care providers and educators who provide direct services with families, especially pre- and post -natal smoking cessation. SCRIPT is a train-the-trainer model with a focus on sustaining smoking cessation postpartum.

Comments:

- It is important to include breastfeeding as a cancer prevention method in technical assistance materials and resources.
- More resources and capacity to talk about LGBTQ and two-spirit health would be meaningful.
- The summit was a good way to promote efforts in cancer data linkages to correct misclassifications for AI/AN populations.

***Table 2**:* Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region E

Area of Focus	Planned Action Steps	Stages of Change and Successes	Challenges
Systems	• Improve data reporting systems and internal sharing of data between departments at Fond du Lac • Work with Fond du Lac administrative services and the medical clinic to make sure any referral forms sent to outside agencies have correct information regarding race. This leads to truer percentages regarding Native American information at the state level • Human Services Advisory board will bring forth a plan to the tribal council to direct Human Services Division administration and upper management to increase data sharing among Fond du Lac and also with outside agencies	Stage of change: Getting ready • Established baseline data and quality measures for AICAF's "I Quits" program tailored to Fond du Lac, which will help demonstrate program effectiveness. One program activity is to increase referrals to smoking cessation counselors	• Uncertainty with and timing of funding with next CDC FOA
Collaboration	• Have initial discussions with primary department leaders in medical, community health services and administrative services to develop a cancer leadership team • Develop a plan to present to upper level management such as the human services division associates and directors regarding the importance of forming a leadership team • Form a leadership team with staff from specific Fond du Lac Human Services Division departments to continue the successes with the cancer program	Stage of change: Not ready • Communicated with department leaders in medical, community health services and administrative services to develop a cancer leadership team	• Several advisory members retiring • Uncertainty with and timing of funding with next CDC FOA
Policy	• Hire a smoking cessation counselor • Support the Clearway program and the smoking cessation program by integrating it into MCH and Social Services programs such as moving forward with smoke free foster homes and increasing referrals to smoking cessation • Increase cooperation and partnerships between the clinic and the tobacco programs	Stage of change: Maintaining and evaluating activities • Hired one smoking cessation counselor, who is working closely on cancer program outreach and smoke-free and second-hand smoke initiatives with ClearWay • Passed tribal ordinance, which mandates that foster care homes and transportation vehicles for children must be smoke-free • Increased tobacco-free ordinances around tribal offices except for casinos. One casino has become 100% smoke-free • Organized a smoke-free community gathering sponsored by law enforcement	• Continuing to promote smoke-free policies

***Table 3**:* Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region F

Area of Focus	Planned Action Steps	Time Frame	Stage of Change and Successes	Challenges
Policy and health system	• Review policies and procedures that are in place for patient care to increase screenings and decrease the no-show rate	Quarterly and annually	Stage of change: Maintaining activities • Implemented new patient care policies and procedures to increase screenings and decrease no-show rates for colposcopies • Currently maintaining activities	None specified
Systems	• Pull reports of number of screened patients, education, diagnosis code, etc.	Quarterly and annually	Stage of change: Currently implementing activities • Implemented a new EMR software that provides more accurate reports on cancer screening data • Currently working to create a report that automatically generates and sends data to investigators	• Took 11 months to transition to the new EMR system. The clinical environment has therefore been stressful • The EMR is primarily built for business purposes, and not necessarily to improve screening and patient care
Environmental (Outreach, communication and messaging)	• Contact program managers developing a plan • Conduct trainings • Develop messages and use evidence-based interventions	Oct. 2017 Annually	Stage of change: Getting ready • Currently getting ready to implement planned activities	None specified

***Table 4**:* Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region H

Area of Focus	Planned Action Steps	Time Frame	Stages of Change and Successes	Challenges
Systems	• Investigate various software systems • As the IHS IT system does not help with reminder and billing issues, customize and implement new software that does	1-2 years	Stages of change: Getting ready / maintaining activities • Cheyenne River initiated conversation with IT department and are getting ready to turn on the customized reminder system • Great Plains Tribal Chairmen's Health Board worked with IT systems and reminder systems at the colorectal cancer facility	• It can take time to transition to a new IT system and train staff. Scaling up is the next challenge
Policy: Tobacco	• Tax compact with state to include e-cigarettes • Update policy to include e-cigarettes • Increase awareness of e-cigarettes • Communicate with CDC's Office of Smoking and Health • Partner with Food and Drug Administration (FDA) representatives	1-2 years	Stages of change: Not ready / currently implementing activities" • Cheyenne River worked with the Canli Coalition to introduce cigarette tax compacts and update policy and ordinance to include e-cigarettes • Efforts to increase awareness e-cigarettes underway • Incorporated the 5 A's of tobacco cessation in services • Trained 300 people on state quitline and National Indian Network quitlines, which increased referrals from 19% to 49.5% • Tobacco Health Educator working on communication and education efforts under the CDC Good Health and Wellness program	• Policies restricting e-cigarettes may not happen in the 1-2 year timeframe. Waiting on the state to set precedence of increasing age of sales of e-cigarettes to 21 • Policy change is hard and takes time
Environ-ment: Physical activity and nutrition	• Increase the number of walking paths • Build funding opportunities • Create awareness for a lifestyle of healthy exercise and nutrition in schools • Youth diabetes management • Special diabetes management • Walking class	1-2 years	Stages of change: Currently implementing / maintaining and evaluating activities • Youth Diabetes Program at Cheyenne River has been given an award • Conducted health fairs and powwows with adults and children, where they measure blood pressure and glucose levels and pass out health information • Adapted and implemented CDC's PSE Change Tool and developed a community action plan to tackle tobacco, nutrition and physical activity • Reached about 500 youths though community events, where they educated youths on the importance of physical activity (funded by PICH grant) • Created media consent forms to promote physical activity using social media and newspapers • Planned the creation of a video of students being physically active • Working with Special Diabetes Program that organizes physical activity and healthy eating challenges • Instituted physical activity-leave, a type of administrative leave at the Tribal Health Department	• Funding is needed to organize a survivorship support group • Funding to create walking paths is limited

Table 5: Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region I

Area of Focus	Planned Action Steps	Time Frame	Stages of Change and Successes	Challenges
Colorectal cancer screening	• Educate Chief Medical Officers, Chief Executive Officers (CEOs), clinics and lab directors • Educate providers on FIT • Educate IHS administration and clinic staff • Educate Tohono O'Odham Nation health department management	1 week 4 weeks 8 weeks Ongoing	Stages of change: Getting ready / currently implementing activities • Identified ownership and provided tribal language for education materials and PSAs on local radio stations about colorectal exams • Worked with IHS to assist clients who may need colorectal cancer screening using patient navigation • Created sub-committee of Tohono O'Odham Cancer Partnership to educate the population on FIT tests	• Time constraints and limited staff capacity • Changes in health department structure at Tohono O'Odham
Breast cancer screening in Navajo Nation	• Meet with the Breast and Cervical Cancer Prevention Program acting Director and create a road map • Solicit CEO approval and educate • Train medical providers • Follow-up service unit by service unit	3-4 weeks 8-12 weeks Sep. 2016 6 months	Stage of change: Ready • Clarified MOU agreement for breast cancer screening • Confirmed GIPRA standards have been met	• The CEO of the medical facility is new, which can affect whether the MOU remains or amendments or revisions will be made
Breast cancer screening for the Hopi community	• Review the Memorandum of Understanding agreement • Educate on program and program requirements • Talk with the CEO and Medical Director • Include clinical breast examination trainings at the November Tribal Collaborative	1 week 4-6 weeks 6 weeks Nov. 2016	Stage of change: Ready • Ready to review MOU for breast cancer screening • Breast surgeon spoke at the November Tribal Collaborative conference	• Conflicting recommendations from various organizations regarding clinical breast examinations • Limitations with CDC funding being used to screen IHS employees

***Table 6**:* Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region J-1

Area of Focus	Planned Action Steps	Time Frame	Stages of Change and Successes	Challenges
Access to services	• Develop employee wellness opportunities • Offer employee time off for screenings • Develop a Wellness Committee recognized by management	Aug./Sep. 2016	Stage of change: Getting ready to currently implementing activities • Working on developing a Wellness Committee recognized by management • Approved Wise Women in Women's Health program that gives discounts to the swimming pool to consortium members and women • Presented recommendation for employee time off for colonoscopies to executive management committee	• Hard to get organizations to allocate funding towards employee wellness with limited budgets and high turnover
Recruitment and retention	• Partner with schools: high schools, colleges and professional schools • Offer focused trainings for providers • Identify opportunities for cross-training	Aug./Sep. 2016	Stage of change: Getting ready to currently implementing activities • Partnering with University of Alaska that has a program to provide in-home support and looking to create online courses on patient navigation as a framework for "peer navigators" or "home navigators" • Working with medical, nurse practitioner and physician assistant students to do monthly rotations in Alaska • Identified behavioral health as an opportunity for cross-training • Working on educating local providers to leverage their screening services • Looking to replicate the process with colorectal cancer resources, so Dr. Brooks visited to inform that effort	• High turnover in rural areas • Unique service area and geography
Continuity of services; linking prevention to care	• Utilize unique partners • Use updated technologies (mapping) • Strengthen comprehensive cancer control, breast and cervical cancer and colorectal cancer partnerships statewide	Aug./Sep. 2016	Stage of change: Currently implementing activities to maintaining or evaluating activities • Identified and built relationships with unique partners • Mapped breast and cervical cancer screening resources • Built unique partnerships such as the Young Women's Christian Association	• Partnership can be difficult to build because they don't have the same focus • Unique service area and geography

***Table 7**:* Summary of overarching policy, systems and environmental priorities and planned action steps during the summit and reported stages of change, successes and challenges six months later by Region J-2

Area of Focus	Planned Action Steps	Time Frame	Stages of Change and Successes	Challenges
Tobacco cessation for survivors	• Improve community messages for survivors to quit smoking • Talk with clinic providers to gain support • Create a one-page cheat sheet regarding smoking cessation for survivors • Contact the American Society of Clinical Oncology about adapting provider and patient materials • Support cancer plans • Identify survivors and increase referrals to diabetes, MIC and other programs • Reach out to tribes about cancer survivors who smoke • Identify survivors that smoke	Not provided	Stage of change: Not ready • Worked on smoking cessation resources in general	• High rates of tobacco • Focusing on smoking cessation specifically among survivors is not a priority, given the high prevalence and need among the general population • Cancer centers do not have surveillance systems on survivors and smoking • Cancer centers and clinics do not have community-based cessation resources
Survivor groups	• Convene groups covering women's issues • Cancer survivor group • Collaborate with local tribes	Not provided	Stage of change: Getting ready • Planned a big women's health event and training for providers and community health representatives and nurses for spring 2017 • Connected tribal programs to survivorship programs, cancer centers and resources	• None reported
HPV vaccinations	• Male immunizations • Develop HPV education with tribal input	Not provided	Stage of change: Getting ready • Funded to conduct focus groups with community members for HPV immunization interventions at pharmacies	• Staffing changes with partner organizations such as pharmacies • Limited time

Methods

In response to feedback from AI/AN Summit Planning Committee members that it would be beneficial to also conduct follow-up evaluation with CCCNP stakeholders, GW Cancer Center created a short survey, which was open for over two weeks in November and December 2016. The demographic information of six respondents are summarized in *Table 7*. The six respondents participated in most of the workgroups, whether actively or passively, and were from CDC, National Cancer Institute, GW Cancer Center and the American College of Surgeons on Cancer. The survey respondents identified technical assistance providers as well as representatives of the AI/AN National Breast and Cervical Cancer Early Detection Programs, AI/AN Colorectal Cancer Control Programs and/or State Comprehensive Cancer Control Programs. Three were program officers, two were program coordinators, managers or directors and one was an epidemiologist, and all had held their positions for more than two years.

Updates

Increased Knowledge

Of the six respondents, five indicated that they learned something new about the tribes from the summit, including about the uniqueness of the AI/AN community as a whole, issues most important to the tribes and AI/AN community and important differences from the rest of the U.S. population (one strongly disagreed). These takeaways highlight the need to focus research, programming, technical assistance and funding that are tailored to the community. Respondents specified their key takeaways as follows:

- "Highest risks in Indian Country are so different from what CDC funds."
- "I learned more about how they operationalize colorectal cancer screening, particularly in the Northern Plains and the Southwest."
- "The importance of advocacy to gain important and relevant data for cancer control planning and surveillance."
- "The critical importance of issues [such as] tobacco cessation [and] availability of healthy food."

Intention to Use Newly Acquired Knowledge

Four survey respondents indicated that knowledge gained during the summit had improved his/her relationship with the tribes as follows:

- The summit "increased awareness of the importance of inclusion of the tribes in the provision of [technical assistance] from a national perspective."
- Since the summit, "I have taken an active role in brokering the relationship between [my organization] and tribal representatives to get useful data into the hands of tribes and make sure tribal concerns are included in strategic planning. [I have] been working to increase research training funding for AI/AN researchers."
- The summit helped them understand "the context" in which they work.
- The summit has prompted an effort to look "at cancer from a primary prevention level: what preventative measures can prevent multiple cancer types?"

Successes of the Summit

Four respondents said that the collaborative workgroup activities were the keys to the summit's success, and opportunities for attendees to interact, provide input, form relationships and build trust. Two respondents attributed the summit's success to the authentic speakers and attendees, and one pointed to the "packed" agenda and wealth of relevant and interesting information provided.

Table 7: Demographic Data of Survey Participants (N=6)		
	n	%
Workgroup Participation*		
Region E	1	16.7
Region F	1	16.7
Region H	0	0.0
Region I	1	16.7
Region J-1	1	16.7
Region J-2	2	33.3
Did not participate	1	16.7
Organization Represented		
CDC	3	50.0
National Cancer Institute	1	16.7
GW Cancer Center	1	16.7
American College of Surgeons Commission on Cancer	1	16.7
Program Representation*		
Technical Assistance Provider	3	50.0
AI/AN National Breast and Cervical Cancer Early Detection Programs	2	33.3
AI/AN Colorectal Cancer Control Programs	1	16.7
State Comprehensive Cancer Control Programs	1	16.7
Job Title		
Program Officer	3	50.0
Program Coordinator/Manager/Director	2	33.3
Epidemiologist	1	16.7
Length in Role		
>2 Years	6	100.0

*totals may not add up to 100% because multiple responses were selected

Improvements for Future Summits

Four respondents strongly agreed that the summit should be repeated again in the future. One agreed and another strongly disagreed. Three survey respondents suggested that follow-up technical assistance or scheduled meetings may be ways to ensure the delivery of specific, measurable, achievable, realistic and time-bound (SMARTer) action plans from future summits. One respondent also suggested that there be discussion about baseline targets for objectives and assistance finding the appropriate data.

Summit Evaluation

Three respondents strongly agreed and three agreed that the evaluation of the summit was useful, mostly because it simply provided documentation and data on inputs, comments and feedback from summit attendees. One specified that having participants “write comments on large sheets of paper” for qualitative feedback was particularly helpful, and another appreciated that specific time was allocated to evaluation during the summit, rather than at the end of the summit.

Planned Technical Assistance or Support for AI/AN Tribes and Grantees

Two respondents specified their current efforts to acquire more funding for tribal programs: one specified that a small CDC team has developed funding to create a tribal clinic assessment tool for 2017/2018 and are convening regularly to discuss the plan. Further, one respondent specified that there are ongoing efforts to connect tribal programs to CCCNP contacts that can share experiences and best practices. Finally, one respondent is planning for more tribal involvement in the Cancer Moonshot initiative.

Conclusion

The 2016 CDC Cancer Summit provided a much-needed opportunity for AI/AN grantees and stakeholders to gather. The first objective of the summit to "provide a forum for open dialogue about topics of interest to all CDC DCPC tribal grantees" was met: whether attendees renewed existing relationships or formed new partnerships, attendees overwhelmingly reported that they learned from each other. The second objective of the summit, to "provide an opportunity… to work together in teams to collaboratively identify priority areas and strategies for American Indian and Alaska Native communities," was also met with the creation of action plans during the summit in April 2016. Six months later, this report reveals steady progress and some key early successes. Although notable barriers to action plan implementation persist, from program and health care workforce retention and funding sustainability to the time-consuming nature of implementing policy, systems and environmental strategies, programs have continued to work on priority cancer topics including tobacco cessation, HPV vaccination and colorectal cancer screening.

AI/AN grantees and stakeholders continue to request technical assistance with program evaluation. Topics of interest include workforce retention; workplace wellness frameworks and policies; and LGBTQ and two spirit health. Those interviewed also frequently cited the need for funding mechanisms to be sensitive to the needs, circumstances, traditions and settings of AI/AN communities. They further emphasized the uniqueness of each tribe and the need to adjust funding opportunities and program expectations accordingly.

The summit also proved beneficial to CCCNP organizations. Many reported having learned something new and become more aware of and sensitive to the needs of tribal grantees and the communities they serve. CCCNP attendees reported that they have already started to work within their respective organizations to improve opportunities and resources made available to AI/AN grantees.

Selected Additional Resources

The CDC provides information on disparities in **"Cancer Among American Indians and Alaska Natives."** For additional resources, visit GW Cancer Center's Cancer Control Technical Assistance Portal's (TAP) searchable **Resource Repository** of tools and resources, including reports, toolkits, fact sheets, infographics and trainings. New resources are added regularly, and readers are also encouraged to submit resources to be added to the repository.

GENERAL:

American Indian Cancer Foundation (AICAF) lists resources derived from the Tribal Health Equity and Healthy Native Foods project, among others.

Comprehensive Cancer Control TAP "is a centralized website the pulls together existing and new technical assistance."

Intercultural Cancer Council and Caucus (ICC) Library lists fact sheets, publications and reports on cancer disparities.

Northwest Portland Area Indian Health Board (NPAIHB) Resource Library collate resources on tribal comprehensive cancer control efforts.

National Association of Chronic Disease Directors (NACDD) Cancer Council "connects together all cancer program staff for knowledge sharing, brainstorming, problem solving and best practice dissemination pertaining to cancer control and prevention."

Native American Cancer Research Corporation (NACR) lists NACR-developed resources including booklets, videos and fact sheets.

EVALUATION:

CDC's Comprehensive Cancer Control Branch Program Evaluation Toolkit "is a 'how to' guide for planning and implementing evaluation activities in cancer prevention and control programs."

Gateway to Health Communication & Social Marketing Practice: Research & Evaluation **"**provides resources to help build your health communication or social marketing campaigns and programs."

Implementing, Evaluating and Improving Your Communication Campaigns is a summary of the Ask-the-Expert session with Dr. Shawnika Hull from George Washington University's Milken Institute School of Public Health, who shared tips and directions for evaluating communication programs.

National Colorectal Cancer Roundtable (NCCRT) Evaluation Toolkit provides "information and tools to help organizations or groups evaluate their efforts, measure outcomes, report their results and improve their programs over time."

GRANTS AND FUNDING:

Grants and Funding: Diversifying and Securing Resources for Cancer Control is a webinar recording featuring experts from comprehensive cancer control consortiums and coalitions.

Tribal Grant Writing Training: Enhancement, Evaluation and Promotion is "designed, specifically for tribes and tribal organizations, to increase knowledge on grant proposal development, writing a good abstract and grant evaluation."

LGBT & TWO-SPIRIT HEALTH:

Center for American Progress provides an overview of Two-Spirit health and actions to support Two-Spirit/Native American LGBT people.

Tribal Equity Toolkit Tribal Resolutions and Codes to Support Two Spirit & LGBT Justice in Indian Country facilitates the development of tribal laws that ensure that Two Spirit/LGBT people have the same access and opportunities as other community members.

SMOKING CESSATION FOR SURVIVORS:

National Native Network Resource Library features resources that "serves to decrease commercial tobacco use and cancer health disparities among members of American Indian and Alaska Native Tribes across North America."

Tobacco Cessation and Control Resources includes "effective resources for oncology care providers and patients."

WORKPLACE WELLNESS:

Engaging Businesses in Comprehensive Cancer Control Coalitions: The Value Proposition for Comprehensive Cancer Control supports coalitions in analyzing their current membership and identifying and engaging new members from the business community

Making the Business Case: How Engaging Employees in Preventing Care Can Reduce Healthcare Costs illustrates to employers how cancer costs burden businesses and how companies can start offering preventive and cancer-screening services.

Sponsors

- Centers for Disease Control and Prevention's Division of Cancer Control and Prevention
- American College of Surgeons Commission on Cancer
- California Rural Indian Health Board
- The George Washington University Cancer Center
- National Cancer Institute
- National Native Network

Wiidookaage: Ojibwe word meaning "they help each other"

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