CDC 2016
American Indian/Alaska Native
CANCER SUMMIT
APRIL 26-28, 2016
TRAVERSE CITY, MICHIGAN
REPORT

Looking Back and Looking Ahead: Collaborating to Advance Cancer Control in American Indian/Alaska Native Communities
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CDC 2016 American Indian/Alaska Native Cancer Summit  
TRAVERSE CITY, MICHIGAN

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Summit Objectives

1. Provide a forum for open dialogue about topics of interest to all Centers for Disease Control and Prevention (CDC) Division of Cancer Prevention and Control (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 American Indian and Alaska Native communities over the next ten years, including data; policy, systems and environmental (PSE) changes; tobacco; human papillomavirus (HPV); and colorectal cancer

The CDC 2016 Cancer Summit titled “Looking Back and Looking Ahead: The State of Cancer Control in American Indian and Alaska Native Communities,” convened current and former DCPC tribal grantees from five CDC regions, CDC staff and Comprehensive Cancer Control National Partnership members from April 26 to 28, 2016 at the Grand Traverse Resort in Traverse City, Michigan. This summit followed the September 2005 summit in Tucson, Arizona and the June 2009 summit in Denver, Colorado.

Keynote speakers and panelists provided information and insight at the beginning to set the tone for succeeding discussions among DCPC Tribal grantees by CDC regions. These discussions culminated in the creation of action plans to improve outcomes in cancer control for American Indian and Alaska Native communities over the next ten years.

This report, developed by George Washington University (GW) Cancer Center, summarizes summit proceedings, presentation highlights and key decisions made by attendees, as well as evaluation results completed and generated by attendees.

To view the photo gallery, media release and speaker presentations, visit National Native Network.
Across the lifespan, American Indians and Alaska Natives have higher rates of disease, injury and premature death than other racial and ethnic groups in the United States. However, many chronic diseases, including cancer, can be prevented or mitigated by culturally relevant, community-driven policies, systems, and environmental improvements that support healthy choices and behaviors.

In an effort to address these issues, the Centers for Disease Control and Prevention (CDC) works with American Indian and Alaska Native tribes, tribal organizations and tribal epidemiology centers to promote health, prevent disease, reduce health disparities and strengthen connections to culture and behavior that improve health and wellness. CDC’s National Center for Chronic Disease Prevention and Health Promotion has a significant investment in health and wellness in Indian Country. These investments, in FY 2015, included more than $30 million awarded to tribes and tribal organizations through chronic disease prevention programs including Good Health and Wellness in Indian Country; Partnerships to Improve Community and Health (PICH); Racial and Ethnic Approaches to Community Health (REACH); National Networks – Impact Populations Experiencing Tobacco-Related and Cancer Health Disparities; the National Breast and Cervical Cancer Early Detection Program (NBCCEDP); the National Comprehensive Cancer Control Program (NCCCP), the Colorectal Cancer Control Program (CRCCP); and the Well Integrated Screening and Evaluation for Women Across the Nation (WiseWoman). More specifically, CDC invested nearly $10 million in awards to grantees to prevent and control cancer.

Through the NBCCEDP, CDC provides low-income, uninsured and underserved women access to timely breast and cervical cancer screening and diagnostic services, and referral to treatment programs in all 50 states, the District of Columbia, 5 U.S. territories and 11 American Indian/Alaska Native tribes or tribal organizations to provide screening services for breast and cervical cancer.

The NCCCP helps all 50 states, the District of Columbia, 7 tribes and tribal organizations and 7 U.S. Associated Pacific Islands/Territories to plan and prioritize strategic activities to prevent and control cancer. NCCCP grantees use an integrated and coordinated coalition-based approach to implement activities to reduce the burden of cancer in their communities by maintaining and supporting strong, statewide (or jurisdiction-wide) coalitions of cancer prevention and control stakeholders; and implementing statewide (or jurisdiction-wide) cancer control plans that emphasize the primary prevention of cancer; support people who have been diagnosed with cancer through treatment and beyond; and increase access to quality health care for all people, including those in communities with a higher burden of cancer.

The purpose of CDC’s CRCCP, established in 2009, is to increase colorectal cancer screening rates among people between 50 and 75 years of age by implementing evidence-based interventions and other supporting strategies in partnership with health systems and providing colorectal cancer screening and follow-up services for a limited number of eligible people.

This report summarizes the outcomes and proceedings from the CDC-sponsored 2016 cancer summit, “Looking Back and Looking Ahead: The State of Cancer Control in American Indian and Alaska Native Communities.” This summit was convened at the request of CDC’s current tribal grantees; it provided a forum for open dialogue about topics of interest as well as an opportunity to work together in teams to collaboratively identify priority areas and strategies for cancer prevention and control in Indian Country over the next decade.

Sincere appreciation is extended to meeting co-sponsors including the American College of Surgeons Commission on Cancer; California Rural Indian Health Board, The George Washington University Cancer Center, National Cancer Institute and the National Native Network. In addition, sincere appreciation is extended to the members of the summit planning committee. Special acknowledgment is extended to Ms. Annie Brayboy, whose incredible leadership and commitment to the tribal community has been invaluable.

We hope the American Indian and Alaska Native Cancer Summit report encourages and inspires readers in planning and implementing cancer prevention and control activities in Indian Country.
Day 1: Tuesday, April 26

CDC 2016 American Indian/Alaska Native Cancer Summit
TRAVERSE CITY, MICHIGAN

The Current State of Cancer Control in Indian Country

Day one of the Centers for Disease Control and Prevention’s (CDC) 2016 American Indian/Alaska Native Cancer Summit opened with remarks from the Director of the CDC Division of Cancer Prevention and Control (DCPC), Lisa Richardson, MD, MPH. Dr. Richardson officially welcomed participants and thanked the summit planning committee and sponsors. Then, Ruth Bussey, Grand Traverse Band Health Director, led the opening prayer for the event. Joshua Hudson of the National Native Network (NNN), Margaret Farrell of the National Cancer Institute (NCI) and Nina Miller of the American College of Surgeons (ACOS) welcomed everyone; and Ena Wanliss and Annie Brayboy, Co-Chairs of the Summit from CDC, provided an overview of the summit.

David Espey, MD of CDC was the day’s keynote speaker. Dr. Espey’s presentation on “Cancer Surveillance in American Indian and Alaska Natives: What the Data are Telling Us and Future Directions,” focused on emerging trends in American Indian and Alaska Native cancer data sets. Dr. Espey highlighted regional differences in cancer incidence and demonstrated that making comparisons of cancer rates between American Indian and Alaska Native regions is critical to understanding the cancer patterns for improved program planning and resource allocation. For example, cancer rates in the Plains region and Alaska are much higher than rates in American Indian and Alaska Native populations in the East.
and Southwest regions (White et al., 2014). Dr. Espey also suggested possible future directions for cancer control in American Indian and Alaska Native populations. First, there is a need and opportunity for the cancer control community to focus on liver cancer prevention in American Indian and Alaska Native populations. In contrast to the ranking of liver cancer as the 8th and 10th leading cause of death in the U.S. among non-Hispanic males and females, it is the 4th and 6th leading cause of death among American Indian and Alaska Native males and females, respectively. Risk factors for liver cancer include diabetes and/or obesity, alcohol-related liver disease, hepatitis B and C infection and metabolic disease (Ryerson, et al., 2016).

As part of the program, 12 tribes use community-driven, culturally adapted strategies that make healthy lifestyles easier, such as reducing commercial tobacco use and exposure; improving nutrition and physical activity; increasing support for health literacy; and strengthening team-based care and community-clinical links. The tribes receive leadership, technical assistance, training and resources from 11 tribal organizations in their Indian Health Service (IHS) Administrative Areas.

Panel discussion on “Unique Characteristics of Tribal Communities and the Impact of Cancer Control.”

Kim Marcucci, BFA of the Southcentral Foundation moderated the panel discussion. Individual presentations are summarized below.

Panelist 1: Kris Rhodes, MPH of the American Indian Cancer Foundation presented on the “Role of Tobacco in Healthy Native Communities.” Ms. Rhodes quoted an Anishinabe Elder: “When [tobacco] is used correctly, it has the power to bring good things and, like other medicines, if it is used incorrectly, it has the power to bring great harm” to illustrate the nuance of tobacco control and importance of broad and comprehensive efforts to change norms in American Indian communities.

Dr. Espey also touted the benefits of collaborating around primary prevention to improve health outcomes in American Indian and Alaska Native populations. Good Health and Wellness in Indian Country (GHWIC), a five-year program funded by CDC in 2015, aims to 1) reduce rates of death and disability from tobacco use, 2) reduce prevalence of obesity and 3) reduce rates of death and disability from diabetes, heart disease and stroke.

As part of the program, 12 tribes use community-driven, culturally adapted strategies that make healthy lifestyles easier, such as reducing commercial tobacco use and exposure; improving nutrition and physical activity; increasing support for health literacy; and strengthening team-based care and community-clinical links. The tribes receive leadership, technical assistance, training and resources from 11 tribal organizations in their Indian Health Service (IHS) Administrative Areas.
Ms. Rhodes explained that for many tribes, tobacco is considered a special gift from the creator, and is traditionally used as a communication tool for prayers, medicine and offerings to show respect when asking for help. The tobacco is not always burned, but when it is, it is not inhaled. Traditional tobacco is typically not available in stores and may sometimes be a mixture that does not contain any actual tobacco. In contrast, and of public health concern, is commercial tobacco, or tobacco available for purchase in stores including loose tobacco and cigarettes.

Ms. Rhodes provided some of the historical contexts for the loss of traditional Indian cultural teachings: “In the early 20th century, American Indians were ostracized and traditional ways were devalued due to public policy and procedures within social institutions. As a result, Indian ceremonies, which included the use of Indian tobacco, were conducted in secret and native language was spoken only in homes or private places. Traditional tobacco knowledge was not necessarily passed to the next generation. The generation that was born from parents who attended boarding school were then less likely to be introduced to traditional Indian tobacco and didn’t know the difference between this and harmful commercial tobacco. In recent generations, [some] American Indian people have revitalized ceremonial beliefs and practices [however, there] may be a disconnect with commercial tobacco commonly being used in our ceremonial ways, given the lack of access to traditional tobacco products.”

In addition, historical trauma in American Indian communities is evident and manifest in a variety of ways, notably as violence and addiction that outnumber occurrences in the general population. “We have enormous challenges around healing our spirits from historical trauma and from resulting addictions that often lead to additional trauma. When a person is addicted to a substance, such as commercial tobacco, the substance itself loses all spiritual value.”

Thus, Ms. Rhodes advocated for comprehensive policies, systems and environmental approaches to addressing harmful tobacco use by targeting social determinants of health that underlie disparities in cancer and chronic diseases among American Indian populations. This comprehensive approach includes enacting a “tribal ordinance that disallows harmful tobacco use inside the building and 25 feet outside the building,” growing traditional tobacco in community gardens and providing education for community members.

RESOURCES:
Sacred Traditional Tobacco for Healthy Native Communities: A Balanced Community for Health

Panelist 2: Diana Redwood, PhD, MPH of the Alaska Native Tribal Health Consortium presented on “Colorectal Cancer Prevention in the Alaska Tribal Health System.”

Dr. Redwood reported on the successes of the Alaska Native Tribal Health Consortium’s (ANTHC) Colorectal Cancer Control Program (2009-2015), which aimed to increase colorectal cancer screening among Alaska Native and American Indian people through the provision of direct screening services, provider education, community outreach and education and policy and systems-level improvements. There was a 28% increase in the Alaska Native colorectal cancer screening rate since the initiation of the program compared to the 3% annual increase nationally. Further, although the screening rates among Alaska Native peoples were lower than that of non-Natives before the program, it is now at 64%, which is higher than the non-Native rate of 61%. While this progress is encouraging, Alaska Native screening rates still do not meet Healthy People 2020 or 80% by 2018 goals.
An important strategy for the program has been to hire and train culturally knowledgeable and sensitive Alaska Native and American Indian people who are able to connect with clients and help get them screened. The program held annual trainings on topics including patient navigation, social marketing, motivational interviewing and health literacy; periodic teleconference in-services; and half-day presentations at the statewide Community Health Aide Program (CHAP) annual training.

The ANTHC Colorectal Cancer Program also partnered with Make It Your Own (MIYO), other tribal colorectal cancer control program grantees and cancer education staff at ANTHC to develop Alaska Native culturally-relevant small media, including patient reminder cards, brochures, posters, newsletters, videos and digital stories as part of “The Cancer I Can Prevent” campaign, featuring previously screened Alaskans sharing their screening stories. As a result, ANTHC, along with the Alaska Colorectal Cancer Partnership (ACCP) won Prevent Cancer Foundation’s 2014 National “Screening Saves Lives” Challenge and received a $7,500 grant, which was used to produce video testimonials to further advance the campaign.

Having received feedback from elders and other Alaska Native people that wanted more humor and light-heartedness in cancer prevention messaging, the ANTHC Colorectal Cancer Control Program responded by purchasing Nolan the Colon, a giant inflatable colon with colon screening information. Nolan the Colon travels around the state with staff, some wearing Polypman costumes, to reach and promote colorectal cancer screening to community members. A study on the effects of this effort found that Nolan the Colon significantly increases knowledge of colorectal cancer screening, intention to screen and comfort talking about screening with friends and family (Redwood, Provost, Asay, Ferguson, & Muller, 2013).

**RESOURCE:**
The Cancer I Can Prevent video

Panelist 3: **Delf Schmidt-Grimminger, MD, MBA** of the University of South Dakota presented on “Unique Characteristics of Tribal Communities and the Impact on Cancer Control.” Dr. Grimminger stressed the importance of getting to know the intended audience of any program or study in any community, including the American Indian and Alaska Native populations. This can include talking directly to the intended audience, health board or tribal council; exploring existing cancer programs and infrastructure; and getting to know tribal needs and wants. In particular, Dr. Grimminger recommended forming a Community Advisory Board (CAB) to help understand the uniqueness of the tribe and their history; design the project; answer ethical, religious and social questions; resolve barriers and problems that may arise during the project; and help find local staff and resources. Further, being transparent and visible and providing routine updates in person whenever possible, are vital ways to build and maintain trust.

When conducting research with community members, key questions to ask include: Who owns the data? Is it alright to publish? What happens to the remaining samples? How and where should the data and samples be stored?

Further, in light of the fact that there have unfortunately been past abuses in patient protection, researchers need to be aware of and abide by federal regulations to ensure that benefits, risks and purpose of the research are communicated to participants during the informed consent process. Scientific review, Institutional Review Boards (IRBs) and Data and
Safety Monitoring Boards (DSMBs) are also mechanisms to ensure data integrity and minimization of risk.

Panel discussion on “Developing and Accessing Tribal Data at National, Regional, State and Tribal-Specific Levels.”

Noel Pingatore, BS, CPH of the National Native Network and Inter-Tribal Council of Michigan moderated the panel discussion. Individual presentations are summarized below.

Panelist 1: Donald Haverkamp, MPH of CDC presented on “American Indian and Alaska Native Colorectal Cancer Screening Data.” Mr. Haverkamp stressed the importance of colorectal cancer screening surveillance in American Indian and Alaska Native populations, as American Indians and Alaska Natives are more likely to be diagnosed with late stage colorectal cancer and more likely to be diagnosed before age 50 at 16.92% compared to Non-Hispanic Whites at 8.08% (Perdue, Haverkamp, Perkins, Daley, & Provost, 2014). Furthermore, from 1990-2009 there was no decline in the death rate from colorectal cancer among American Indian and Alaska Native men and women.

Donald Haverkamp, CDC

Mr. Haverkamp also provided historical context: colorectal cancer screening was added by IHS as a Government Performance Results Act (GPRA) measure in 2006 and the measure was changed in 2013 to align more with the United States Preventive Services Task Force (USPSTF) recommendations and the Healthcare Effectiveness Data and Information Set (HEDIS) measure. Mr. Haverkamp also reiterated that current colorectal cancer screening among the IHS user population remains below the Healthy People 2020 goal of 70.5%, as well as the 80% by 2018 goal, although screening rates have steadily increased from 35% in 2013 to 38.6% in 2015.

Another colorectal cancer screening data source for the American Indian and Alaska Native populations is Behavioral Risk Factor Surveillance System (BRFSS) surveys, which collects data in all 50 states, the District of Columbia and three U.S. territories. Limitations of BRFSS include the fact that its data include a small number of American Indians and Alaska Natives, leading to unstable estimates; the core module does not collect data on Tribal Affiliation; and American Indians and Alaska Natives in general have lower rates of household phone coverage than the general U.S. population, which makes them harder to survey. However, when BRFSS survey data analyses are restricted to Contract Health Service Delivery Area (CHSDA) counties, they can provide more accurate estimates of colorectal cancer screening among American Indians and Alaska Natives. The CHSDA counties are counties that contain federally recognized tribal lands or those that are adjacent to tribal lands, which provide more accurate race classifications for American Indians and Alaska Natives: 64% of the American Indian and Alaska Native population resides in the 637 CHSDA counties.

Conducting Tribe-specific BRFSS surveys is a way to provide an estimate for colorectal cancer screening that is very specific to the community surveyed, and estimates can be quite different than state or regional BRFSS estimates. Tribal BRFSS can also have higher participation and survey response when conducted by a local entity such as a Tribal Health System or Tribal Epidemiology Center that are known to the community. Tribes want tribal-specific cancer data, and would like to conduct their own tribal BRFSS surveys.
Panelist 2: Melissa Jim, MPH of CDC presented on “Developing and Accessing Data at the National, Regional and Tribal Specific Levels.” Ms. Jim highlighted complications associated with data collection among the American Indian and Alaska Native population such as race misclassifications in cancer surveillance and vital statistics databases and variances by state. Thus, decreasing misclassification can improve accuracy of health indicators, program planning and resource allocation.

Ms. Jim gave an overview of the history of data collection in the U.S. Prior to 1992, the Surveillance, Epidemiology and End Results Program (SEER) covered 14% of the U.S. population. However, in 1992, the Cancer Registry Amendment Act authorized CDC to establish the National Program of Cancer Registries (NPCR). With SEER and NPCR combined, the entire U.S. population is covered, which allows epidemiologists to obtain national cancer incidence data; monitor cancer trends over time nationally and regionally; describe cancer patterns in special populations; describe and investigate rare cancers; guide planning and evaluation of cancer control programs; provide data for prioritization of health resources; and advance clinical, epidemiologic and health services research.

Administrative records from IHS were linked with central cancer registries, including SEER and NPCR. The process included identifying American Indian and Alaska Native cases that were misclassified as non-Native. As a result of the IHS linkage, the number of individuals identified as American Indians and Alaska Native increased in all IHS regions and cancer rates among American Indians and Alaska Natives increased for all IHS regions compared to U.S. non-Hispanic Whites between 1999 and 2004 (Espey et al., 2007). The rates after the linkage are considered to be more accurate.

State death records are also in the process of being linked with IHS records. Preliminary data show that death rates among American Indians and Alaska Natives increased in each state, albeit at varying levels, after the linkage.

Ms. Jim also introduced the Mortality to Incidence Ratio (MIR) as an indicator of survival that compares fatality between groups. It is calculated as the age-adjusted death rate divided by the age-adjusted incidence rate. It is thought to be more accurate than “relative survival,” and is easy to calculate from existing cancer incidence and mortality data. MIR is also thought to be a potentially useful proxy for estimating cancer survival; however, it is not a widely used indicator and there are currently few publications using it.

Mary C. White and colleagues compared MIR for all cancer sites combined by region for American Indians and Alaska Natives compared with non-Hispanic Whites in CHSDA counties, and showed that “greater progress in cancer control was achieved for White populations” compared with American Indian and Alaska Native populations over the last two decades (White et al., 2014). These disparities are likely related to lower socioeconomic status and lack of health care access among American Indians and Alaska Natives. This population is also consistently diagnosed at later stages, particularly for cancers that can be prevented with screening.

Ms. Jim also provided tribe and state-specific data sources. For example, in Oklahoma, the American Indian population does not reside within reservation boundaries, so is more heterogeneously distributed throughout the state. Therefore, the standard method of classifying race does not reliably document American Indian births and deaths and special
organized with tribal health coalition staff in September 2006 in Traverse City, with CDC assignees to IHS, Great Lakes Inter-Tribal Council, Inter-Tribal Council of Michigan, and various tribal health representatives in attendance.

Meeting attendees discussed issues of misclassification and examples of how linkages could improve data quality. Attendees decided to focus on providing each tribal organization with analytical files and improving statewide data by developing a framework to address confidentiality at the patient and tribal-levels and to maintain tribal control. The Inter-Tribal Council of Michigan agreed to work with tribes on logistics and provide analytical support.

This work is organized so that it is initiated by the tribes; agreements are written; linkage to cancer, mortality and live birth data are jointly monitored by tribe, state and inter-tribal council staff; and analytical files are developed thereafter. The resulting de-identified files are sent to the tribes and all identifiable files are shredded. The result is an agreed-upon analytical data set for tribal use, which is de-identified with selected variables that can produce tribal data reports and help shape tribal health initiatives. At the same time, the state is able to develop linkage-adjusted data to significantly improve the accuracy of race and ethnicity classifications within statewide data files.

Future directions for the initiative include continuing the service and expanding linkages to better incorporate mortality and natality data; finding alternatives to census data on American Indian and Alaska Native populations by working toward tribal denominators; identifying resources

RESOURCES:
- American Journal of Public Health issue on American Indian and Alaska Native Mortality
- An Update on Cancer in American Indians and Alaska Natives, 1999-2004
- Supplement to Cancer: Cancer Incidence in American Indians and Alaska Natives

Panelist 3: Glenn Copeland, BBA, MBA of the State of Michigan presented on “Developing Useful Data on American Indian Health: Addressing the Problem of Misreporting—The Michigan Approach.” Mr. Copeland gave background information on Michigan’s efforts to improve available data, including establishing a cancer epidemiology collaboration with the University of Michigan and Inter-Tribal Council of Michigan to explore possibilities for analyses and student interns to help with the work. At around the same time, an exploratory meeting was

Glenn Copeland, Michigan Department of Community Health
Tribe members had lower rates of death due to accidents, stroke, and influenza and pneumonia.

The results of the Sault Tribe linkage project demonstrate that the community is impacted by significant health disparities, such as high rates of deadly lung cancer and low survival rates for breast cancer patients. Ms. Culfa gave recommendations for improvement focusing on clinical treatment and prevention of various cancers and risk factors, particularly commercial tobacco abuse: 1) Implement and maintain a comprehensive commercial tobacco control program and 2) Screen, treat, and prevent breast, colorectal and lung cancers.

Panelist 4: Bonnie Culfa, RN, MSN of the Sault Ste. Marie Tribe of Chippewa Indians Health Division presented on “The Cancer Report: 1998-2012.” Ms. Culfa provided background information on Michigan’s Vital Records, which underestimates the burden of death from specific preventable diseases among American Indians, as American Indian people are often reported as White on their death certificates or medical records. In 2015, a linkage was conducted as a partnership between the Sault Ste. Marie Tribe of Chippewa Indians, the Michigan Department of Health and Human Services, the Michigan Public Health Institute, and the Inter-Tribal Council of Michigan. The process allowed the tribe to correctly label its own members within the state vital records by directly linking tribal enrollment data with state records. The linkage showed a total of 1,254 mortality cases among Sault Tribe members from 2004-2013.

Between 2004-2013, cancer was the leading cause of death among Sault Tribe members living in Michigan. Compared to the state as a whole, Sault Tribe members had higher rates of death due to cancer, chronic lower respiratory diseases, diabetes, suicide and kidney disease. Compared to the state as a whole, Sault

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The working session was followed by a recap and evaluation of the day’s activities along with a preview of the following day with Jen Olson, MS of the South Puget Intertribal Planning agency, Ena Wanliss, and Annie Brayboy of CDC.
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<thead>
<tr>
<th>Regions</th>
<th>Opportunity 1</th>
<th>Opportunity 2</th>
<th>Opportunity 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region E</td>
<td>Improve data systems, reporting systems and sharing of our data</td>
<td>Build on past successes with the cancer program to keep the momentum moving forward with the development of a leadership team</td>
<td>Continue to advance the work on the non-ceremonial tobacco policy</td>
</tr>
<tr>
<td>Region F</td>
<td>Communication and messaging: develop a process to test messaging prior to spending the funds on it</td>
<td>Tobacco research: Need the data and research to determine what makes an individual start using tobacco. Expand current programs to be more accessible to the community</td>
<td>Investigate no-show rates</td>
</tr>
<tr>
<td>Region H</td>
<td>Reduce structural barriers using evidence-based practices and interventions</td>
<td>Increase awareness of fecal occult blood test (FOBT) and fecal immunochemical test (FIT) kits</td>
<td>Increase navigation program through coordination and partnerships</td>
</tr>
<tr>
<td>Region I</td>
<td>Data: Obtain tribal-specific data. Sources available include ACR, Navajo Epidemiology Center, Hopi Center, Tohono O’Odham Nation BRFSS</td>
<td>Community: Address prevention areas (HPV, Hepatitis, exercise, smoking, healthy eating, screening). Tailor the messaging specific to the community. Look at and leverage current resources if possible</td>
<td>Systems: Identify health plans who serve American Indians and Alaska Natives and educate them on systems change and evidence-based interventions</td>
</tr>
<tr>
<td>Region J-1</td>
<td>Access to services/treatment</td>
<td>Manpower shortages and retention of employees (especially in rural communities)</td>
<td>Continuity of services and linking care to primary prevention</td>
</tr>
<tr>
<td>Region J-2</td>
<td>Share best practices to increase tribal enrollment linkages: utilize web-based portals, increase meetings and share with repositories for literature searches; identify successes and messaging</td>
<td>Resources and education: navigating resources such as Tribal Epidemiology Centers, Make It Your Own (MIYO) and new cancer topics</td>
<td>Environmental impacts and emerging cancer that are not currently screenable. Fort Lewis Army Base/Lewis McChord Airforce Base</td>
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As part of efforts to evaluate the summit, participants were asked a different question each day of the summit and asked to provide qualitative feedback by writing on large sticky notes to put up on display. On Day 1, the question was: “In your own words, what is the current state of cancer control in Indian Country?” (Figures 1 and 2). Responses reflected participants’ attitudes and recognition of progress that has been made in cancer control with some writing that there are “pockets of good work” and that efforts are headed “in the right direction.”

The responses also hinted at challenges and areas for improvement, such as a renewing focus on primary and secondary prevention and increasing access to tribal-specific data, collaboration and funding.

Evaluation results from surveys administered at the end of the summit are also available beginning on page 31.
The final event of the first day was an nDigi Fest, sponsored by the California Rural Indian Health Board and the National Native Network.

The cultural exchange through “digital storytelling,” featured stories that cover the many aspects of cancer prevention, education, care and treatment. The program celebrated and honored cancer-related, Native-focused digital stories that were culturally unique and powerfully healing. The presentation was moderated by Brenda K. Manuelito and Carmella Rodriguez of nDigiDreams.

The event opened with a prayer from Daisy Kostus of the Cree First Nation of Waswanipi, and an Eagle Staff presentation that was conducted by Linda Woods from the Grand Traverse Band of Ottawa and Chippewa Indians.

Stories included titles “Zaagidiwin (Love)” told by Punkin Shananaquet of the Lac Courte Oreilles/Match-e-be-nash-she-wish Band of Potawatomi; “Stage 2...Stage 3” by Rita McDonald, Cancer Navigator for Northern Cheyenne Tribe, “Lessons Learned” told by Donald Sumners of the Pokagon Band of Potawatomi Indians, “Yuuluqaucirkaq (Healthy

Way of Living)” told by Agnes Roland of the Yupik, “My Mother Prayed Cancer Away” told by Ophelia Spencer of the Navajo, “Nikaanag (My brothers, my friends)” told by Dr. Erich Longie of the Spirit Lake Sioux, “Gift of Another Day” told by Dr. Suzanne Cross of the Saginaw Chippewa Indian Tribe, and “Calling on the Great Spirit” by Daisy Kostus.
Embracing Policy, Systems and Environmental Approaches to Address Cancer Disparities Among American Indian and Alaska Native Communities

The second day of the American Indian/Alaska Native Cancer Summit opened with Sharon Johnson of Fond du Lac Wiidookaage Cancer Team Chairwoman, offering an opening prayer. Ena Wanliss and Annie Brayboy from CDC and Noel Pingatore from National Native Network and Inter-Tribal Council of Michigan summarized the accomplishments of Day 1 and objectives of Day 2.

Jeffrey Henderson, MD, MPH of Black Hills Center for American Indian Health was the day’s keynote speaker. Dr. Henderson’s presentation on “The Curious Case of Cancer in American Indians and Alaska Natives: Using Policy to Influence Change,” began by echoing Day 1 presentations on barriers to getting a complete picture of the impact of cancer in American Indians and Alaska Natives, from racial misclassification and incomplete coverage of the population by surveillance efforts.

Dr. Henderson outlined the Multilevel Model of Disease Causation (also known as the Ecosocial Model of Population Health,) as shown in Figure 3, where individual and population health influence the physical environment, and the physical environment influences the individual and population health (Kaplan, Everson, & Lynch, 2000). Due to these intersections of ecosocial factors that impact health outcomes, Dr. Henderson

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**Figure 3: Multilevel Model of Disease Causation**
Reproduced with permission from Dr. George Kaplan (Kaplan, Everson, & Lynch, 2000)
Henderson emphasized the importance of using policy strategies to influence change.

Tobacco and smoking-related policy is key to improving outcomes in American Indian and Alaska Native populations. Smoke-free policies are not the only strategy to affect change. For example, Navajo Nation is working to increase cigarette tax rates, which is currently at 40 cents per pack. There are clear health and economic benefits to increasing cigarette taxes in Navajo Nation: Increasing taxes to 75 cents per pack is predicted to lead to approximately $480,000 in additional state tax revenues per year, a 6.5% decline in youth smoking, 500 fewer youth and 200 fewer adult smokers and $10.7 million in health savings. Increasing taxes to $1.50 per pack is expected to lead to approximately $890,000 in additional state tax revenues per year, a 13% decline in youth smoking, 1,000 fewer youth and 400 fewer adult smokers and $21.3 million in health savings.

Policy change is not easy. A major barrier is commercial tobacco companies selling cigarettes in casinos. Additionally, passing legislation to protect populations from secondhand smoke has proven to be challenging.

Through health education, communication and advocacy, there have been notable successes, such as the passage of the Azeé Bee Nahaghá of Diné Nation Commercial Tobacco-Free Resolution in 2014, which banned commercial and smokeless tobacco from being used during prayer service. President Shelly of Navajo Nation also issued an Executive Order in 2014 to make workplaces smoke-free. Such policy-level efforts also extended to the casino industry: Ho-Chunk Gaming became the first tribal casino in Wisconsin to be tobacco-free in 2015.

Dr. Henderson also highlighted the food environment as an area where policy can be used to influence change, such as implementing taxes on junk food. The clinical environment is another key area for policy change, as evidenced by the Affordable Care Act’s support for preventive measures. Policy change can also be effective in protecting populations from environmental exposures and increasing workplace safety.

Dr. Henderson concluded his presentation by recommending increased community, tribal,
clinical and national leadership and government financial support; further research to determine effective preventive interventions; replication of proven interventions; ongoing behavioral surveillance to gauge progress; and greater participation of tribes and communities in the efforts to improve health.

Panel discussion on “Embracing Policy, Systems and Environmental Approaches to Address Cancer Disparities in American Indian and Alaska Native Communities.”

Richard Mousseau, MS of the Great Plains Tribal Chairmen’s Health Board and Linda Burhansstipanov, MSPH, DrPH of Native American Cancer Research Corporation moderated the panel discussion. Individual presentations are summarized below.

Panelist 1: Margie Burkhart, BA of Cherokee Nation Health Services presented on “Cherokee Nation Comprehensive Cancer Control.” Cancer is the second leading cause of death in Cherokee Nation, with lung, breast, prostate, colorectal and cervical cancers having the biggest impact. Native Americans in the Cherokee Nation Tribal Jurisdictional Service Area continue to experience higher incidence rates than the rest of the Oklahoma population for some of the most common types of cancer. Further, a 2011 survey conducted by Cherokee National Public Health

Panelist 2: Eric Vinson of Northwest Portland Area Indian Health Board presented on “Health

Programs found that only 40% of Cherokee adults reported exercising vigorously for at least 150 minutes per week and less than 2% reported eating five or more fruits and vegetables every day.

The Learn to Grow garden project was created in response to community needs, and provides hands-on learning experiences in the garden and kitchen to young children in family child care homes, centers and Head Starts in eight counties in Northeast Oklahoma. Children learn about fresh fruits and vegetables and are encouraged to start a garden at home with their parents. Trained child care providers also incorporate the harvested vegetables into children’s lunch and snacks, and children set up stands at farmers markets where “veggie bucks” are used to buy and sell vegetables such as cucumbers, squash, bell peppers, tomatoes and onions.

Approximately 4,000 children enrolled in Learn to Grow in 2016, and since the average size of household families in child care is 3.5, the estimated reach is approximately 14,000 children and family members. Learn to Grow also received recognition from First Lady, Michelle Obama, for its contribution to promoting healthy eating and weight in the community.

Margie Burkhart, Cherokee Nation
Policy in the Northwest: Past, Present and Future.” Mr. Vinson began by providing historical context to tobacco control policy efforts in the Northwest Portland Area. In response to survey findings showing 50% smoking rates among American Indians in the Northwest region and high rates of smokeless tobacco use among youth, the Northwest Portland Area Indian Health Board launched the Tribal Tobacco Policy Project in 1987. As part of the project, staff members created and piloted a workbook with a policy template for tribal resolution; made site visits with tribal health directors, health educators, clinic nurses, prevention counselors, human resources coordinators, youth coordinators and tribal health committees; and gave formal presentations to the tribal council with a tribal advocate. As a result, 32 of the 36 tribal programs developed a Tribal Tobacco Policy.

As part of the Western Tribal Tobacco Prevention Project in 1996, the Northwest Portland Area Indian Health Board worked with tribes and states to discuss methods to increase tobacco taxes, engage tribal programs and secure funding for tribal programs. Stemming from these efforts, the Tribal Comprehensive Cancer Control plan was written in 1998; the National Tobacco Network was created in 2000; the Northwest Portland Indian Health Board was funded in 2003; and CDC provided national funding in 2006.

Presently, Northwest tribes are addressing public health policy issues through the Special Diabetes Program for Indians (SDPI) in Community and Competitive Grants focusing on primary prevention and cardiovascular disease; the Child safety seat study; tribal tobacco policy and prevention by providing state funding to Idaho and Oregon; and the Northwest Portland Area Indian Health Board tribal resolution supporting the tribal comprehensive cancer plan. Priority topics for policy change include safe walking trails, seatbelt survey and law, healthy food, immunizations, childhood obesity prevention and tobacco control.

Tobacco control remains a priority, as tribal BRFSS reports show high rates of current smoking in tribes in Northwest Portland Area, ranging from 23.1% in one tribe to 33.5% in another.

Panelist 3: Evelyn Watchman of Navajo Nation presented on the “Navajo Nation Breast and Cervical Cancer Prevention Program (NNBCCPP),” a CDC cooperative agreement that first started in 1996. Its purpose is to increase screening rates and decrease morbidity and mortality rates of breast and cervical cancer. The program provides clinical navigation, including mammography screenings, Pap tests, ultrasounds, colonoscopies and referrals, as well as community navigation, including individual and group education, chapter meetings, school health and tribal fairs.
There are cultural barriers, such as traditional diagnoses that may confuse patients and stigma or taboo that may lead patients to refuse to acknowledge cancer symptoms. Mammograms can also be painful and lead to missed appointments. Environmental and transportation barriers to care exist in Navajo Nation, from unpaved roads to infrastructure erosion due to national disasters.

To lower these barriers and increase screening, NNBCCPP advocated for implementing a two-hour administrative leave for Western Navajo Nation employees so they can attend the annual fair. The Navajo Nation President and Vice-President’s office approved the memorandum.

NNBCCPP also succeeded in getting the Mobile Mammogram unit parked outside a grocery store parking lot. To incentivize screening, patients were given roses and were entered into a drawing for a chance to win a designer purse. The winner of the drawing was announced after the Cancer Awareness Walk. The program also partnered with Bashas Corporation, who provided refreshments.

Ms. Watchman reported that NNBCCPP served 329 women during October Breast Cancer Awareness Month in 2015 through mobile mammography and a mini conference organized during Cervical Cancer Awareness Month in 2016. Strong partnerships with Tsehootsooi Medical Center Mobile Health Program and Hopi Breast and Cervical Cancer Program were key to their success. NNBCCPP is currently working to expand trainings with the Kayenta Public Health Nursing Program and Uranium Program to Hozho, which means to “promote quality of life.”

Panelist 4: Richard Mousseau, MS of the Great Plains Tribal Chairmen’s Health Board presented on “Using Policy, Systems and Environmental Change Approach to Increase Colorectal Cancer Screening.” As part of a CDC cooperative agreement, the Great Plains Tribal Chairmen’s Health Board aims to increase colorectal cancer screening rates in 18 tribes in four states: South Dakota, North Dakota, Nebraska and Iowa. There is great need for screening, as only 27% of American Indian adults between 50 and 75 years of age in the Great Plains region have been screened for colorectal cancer, according to 2015 GPRA measures.
Mr. Mousseau asserted that health programs must shift focus from changing individual behavior to changing policies, systems and environments to help communities make healthier choices to lower the burden of diseases such as obesity, diabetes and cancer. In addition, policy, systems and environmental change can make a positive impact across the cancer continuum: from prevention, early detection, diagnosis, treatment, quality of life, survivorship to end of life care.

Mr. Mousseau also made the connection between policy, systems and environmental approaches and many Great Plains tribes’ cultural beliefs of creating healthy habits and knowledge for future generations, which is encapsulated in the sacred hoop of life and interdependent relationships of the tribal environment.

Mr. Mousseau unpacked what policy, systems and environmental approaches mean in the context of American Indian communities. First, policy interventions aim to change laws, ordinances, tribal resolutions and regulations. For example, policies allowing flex time can be useful in creating opportunities for employees to schedule a screening for colorectal cancer screening during the day and maintain their expected number of work hours.

Second, systems interventions aim to change interconnected elements of a tribe or tribal organization or community. For example, reminder intervention systems can be implemented to prompt colorectal cancer screening in IHS clinics, hospitals and tribal health programs.

Third, environmental interventions aim to bring physical or material changes to the economic, social or physical environment. For example, communities can be designed with safe walkways to encourage physical activity.

**RESOURCES:**

- Advocacy Toolkit: Guide to Grassroots Leadership Advocating for Policy, Systems and Environmental Change Through Creation of Community Coalitions
- Evaluating Policy, Systems and Environmental Change Interventions: Lessons Learned from CDC’s Prevention Research Centers
- Healthy Communities, Healthy Behaviors: Using Policy, Systems and Environmental Change to Combat Chronic Disease
- Policy, Systems and Environmental Change Resource Guide
- Use of Evidence-Based Interventions to Address Disparities in Colorectal Cancer Screening

Summit participants gathered by CDC regions to discuss Policy, Systems and Environmental Approaches to Address Cancer Disparities in American Indian and Alaska Native Communities to inform their action plans (Table 2).

Groups by CDC regions reported on their action plans to the rest of the participants.

The working session was followed by a recap and evaluation of the day’s activities along with a preview of the following day with Ena Wanliss and Annie Brayboy of CDC.
Table 2: Summary of top three policy, systems and environmental approaches to decrease cancer disparities in American Indian and Alaska Native communities reported by regional working sessions

<table>
<thead>
<tr>
<th>Regions</th>
<th>Opportunity 1</th>
<th>Opportunity 2</th>
<th>Opportunity 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Region E</strong></td>
<td>Imbed systems change around data and cancer screening rates. Improve quality measurements around data at Fond du Lac.</td>
<td>Build on past successes by forming a leadership team for strategic planning and fostering collaboration around cancer.</td>
<td>Continue tobacco policy work.</td>
</tr>
<tr>
<td><strong>Region F</strong></td>
<td>Health systems: clinic-based case managers and medical case managers for Women’s Health Breast and Cervical Program to take better care of patients.</td>
<td>More health systems assessments</td>
<td>Public health communication and messages to encourage screenings and prevention. Outreach and education for human papillomavirus (HPV) vaccines. Special diabetes program and community health program. Partnerships with other programs and cancer programs.</td>
</tr>
<tr>
<td><strong>Region I</strong></td>
<td>Time off for Navajo Nation employees to get their breast cancer screenings.</td>
<td>Navajo clinic systems change at service unit levels: linking mobile mammovan with clinics for nutrition services and Pap tests.</td>
<td>Time to walk at lunch for Hopi and Tohono O’Odham employees.</td>
</tr>
<tr>
<td><strong>Region J-1</strong></td>
<td>Encourage employees (many of whom are Alaska Natives) to allocate time for employee wellness and cancer screenings. Smoke free facilities. Same-day access, extended hours and Saturday clinics.</td>
<td>Trauma-informed care: help local providers deal with stress in their home communities. Tailor and reframe provider recruitment strategy to ensure that the right people are hired. Hire and train recent graduates and rely less on itinerant providers.</td>
<td>Acknowledge common goals and work in partnership with projects such as mobile mammography where diverse partners are involved. Bundle services so that a patient coming in for a colonoscopy also gets a mammogram and diabetes check.</td>
</tr>
<tr>
<td><strong>Region J-2</strong></td>
<td>Reminder systems are being used but not smoothly. Remind contractors to refer women back to the program. Remind public and staff of our services.</td>
<td>Partnership: TANF, WIC, Teen Advisory groups to meet with leadership and get surveys completed. Utilize Behavioral Health staff for motivational interviewing and cessation services.</td>
<td>Tobacco reduction and cessation policy. Use ex-smokers to promote tobacco-free policies. Oral policies lead to traditional “decisions”.</td>
</tr>
</tbody>
</table>
In a similar fashion to Day 1, attendees were asked to provide qualitative feedback by writing on large sticky notes to put up on display. On Day 2, the question was: “What is the most significant and unique challenge or barrier that remains in cancer control in Indian Country?” (Figures 4 and 5).

Barriers to access to health services, including lack of transportation, health care facilities and providers as well as long distances to facilities dominated the responses. A lack of patient navigation services was also mentioned as a barrier, and could help mitigate other access barriers.

Programmatic barriers include limited funding, resources and commitment from IHS for cooperation and partnership. Lack of culturally-tailored and tribal-specific program designs is also a barrier for cancer control in Indian Country. There were calls for increased focus on community-driven programs, prevention strategies and integration of cancer and chronic disease efforts. Challenges associated with data collection and dissemination to demonstrate the need for further resources were also mentioned. Evaluation results from surveys administered at the end of the summit are also available beginning on page 31.
The third and last day of the American Indian/Alaska Native Cancer Summit opened with a prayer offered by Karen Morgan of the Alaska Native Tribal Health Consortium. Ena Wanliss and Annie Brayboy from CDC summarized the accomplishments of first two days and objectives of Day 3.

Participants also shared their “take-home points” from the summit, including:

- Data is important to inform program activities and funding opportunities.
- Solutions are built within the American Indian and Alaska Native communities. Learning from communities’ successes and challenges is important.
- nDigi Fest was moving and increased understanding of cultural nuances.
- Commitments from CDC and the Comprehensive Cancer Control National Partnership to build stronger and healthier communities were demonstrated.
- Collaboration is important to address the challenges American Indian and Alaska Native communities face.
- Continued communication is paramount. There is a need for tribal leaders, or potentially CDC, to facilitate bimonthly calls to maintain momentum.
- Data presented during the summit reinforced the unique challenges experienced by American Indian and Alaska Native populations, which CDC will keep in mind.
- Feel empowered to go home and address cancer disparities and advocate for cancer programs.
- Thankful for the opportunity to gather for the summit and engage in open discussion.

Summit participants gathered by CDC regions to discuss and report back with summaries of their action plans and recommendations for cancer prevention and control in Indian Country over the next decade (Tables 3-8).

Judith Muller, MHA of Alaska Native Tribal Health Consortium and DeAnna Finifrock, MSN, PHN of the Fond Du Lac Reservation Cancer Program moderated the discussion.
### Table 3: Summary of overarching policy, systems and environmental priorities and action steps reported by Region E

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
</tr>
</thead>
</table>
| 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 | Not provided       |
| 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 | Not provided       |
| 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 | Not provided       |

### Table 4: Summary of overarching policy, systems and environmental priorities and action steps reported by Region F

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy and health system</td>
<td>• Review policies and procedures that are in place for patient care to increase screenings and decrease the no-show rate</td>
<td>Quarterly and annually</td>
</tr>
<tr>
<td>Systems</td>
<td>• Pull reports of number of screened patients, education, diagnosis code, etc.</td>
<td>Quarterly and annually</td>
</tr>
</tbody>
</table>
| Environmental (Outreach, communication and messaging) | • Contact program managers developing a plan  
• Conduct trainings  
• Develop messages and use evidence-based interventions                                                                                           | Oct. 2017 Annually   |
### Table 5: Summary of overarching policy, systems and environmental priorities and action steps reported by Region H

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
</tr>
</thead>
</table>
| 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    |
| Policy: Tobacco                   | • Tax compact with state to include electronic cigarettes (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    |
| Environment: 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 |

### Table 6: Summary of overarching policy, systems and environmental priorities and action steps reported by Region I

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
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</thead>
</table>
| 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 |
| 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 |
| 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 |
### Table 7: Summary of overarching policy, systems and environmental priorities and action steps reported by Region J1

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
</tr>
</thead>
</table>
| Access to services                | • Develop employee wellness opportunities  
• Offer employee time off for screenings  
• Develop a Wellness Committee recognized by management                                                                                       | Aug./Sep. 2016   |
| 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   |
| 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   |

### Table 8: Summary of overarching policy, systems and environmental priorities and action steps reported by Region J2

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Action Steps</th>
<th>Time frame</th>
</tr>
</thead>
</table>
| 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     |
| Survivor groups                   | • Convene groups covering women’s issues  
• Cancer survivor group  
• Collaborate with local tribes                                                                                                                  | Not provided     |
| HPV vaccinations                  | • Male immunizations  
• Develop HPV education with tribal input                                                                                                         | Not provided     |
Lisa Richardson, MD, MPH of CDC gave the closing call to action on “Continuing the Momentum Beyond the Summit.” Dr. Richardson reviewed CDC’s related programs, including the National Breast and Cervical Cancer Early Detection Program, Colorectal Cancer Control Program, Comprehensive Cancer Control Program and National Program of Cancer Registries. In addition, the CDC-funded National Native Network is administered by the Inter-Tribal Council of Michigan and directed by a board composed of three other partner organizations.

Dr. Richardson echoed the importance of interventions focused on changing policies, systems and the environment to make individuals’ default decisions healthy. Dr. Richardson also reiterated CDC’s commitment to continued support for cooperative agreement awardees and activities and seeking and investing in new and innovative opportunities.

In similar fashion to Days 1 and 2, attendees were asked to provide qualitative feedback by writing on large sticky notes to put up on display. On Day 3, the question was: “What technical assistance can help you meet American Indian and Alaska Native (AI/AN) programmatic and community needs?” (Figures 6 and 7).

Figure 6: Word cloud of summit participants’ responses to the question: “What technical assistance can help you meet AI/AN programmatic and community needs?” (n=26)
Many participants want more technical assistance on culturally-appropriate and tribal-specific evaluation, communication/messaging and education materials to promote screening and other health services. Similarly, participants want assistance adapting and translating evidence-based interventions (EBIs) to their communities. There is also a need for technical assistance for writing compelling grants and success stories with tribe and community-specific data. Some participants asked for CDC and other organizations to bridge the gap between tribal programs and IHS.

Evaluation results from surveys administered at the end of the summit with further information on technical assistance needs are also available beginning on page 31.

To close the summit, participants held hands in a circle around the perimeter of the conference room, as Eldon Kalemsa of the Hopi Tribe led the prayer.
After the summit, participants were asked to complete a survey, made available in paper and electronic format, to assess satisfaction with and outcomes of the summit and ways to improve similar meetings in the future. Of the 53 attendees who completed the survey, 23 (43%) represented the American Indian and Alaska Native (AI/AN) National Breast and Cervical Cancer Early Detection Programs (NBCCEDP); 11 (21%) represented AI/AN Comprehensive Cancer Control Programs (NCCCP); 8 (15%) represented CDC staff; 4 (8%) represented other National Partnership staff; 2 (4%) represented AI/AN Coalition Members; 2 (4%) represented AI/AN Colorectal Cancer Control Programs; 2 (4%) represented State NBCCEDP; and 1 represented State NCCCP (2%) (Figure 8). The vast majority of attendees were program coordinators, managers and directors, as well as American Indian and Alaska Native coalition members and data managers (Figure 9), and have held their roles for over two years (Figure 10).

Attendees were also asked in the survey to rate their satisfaction and the process of the summit from 1 (strongly disagree) to 5 (strongly agree). On average, summit attendees agreed that they met their personal and professional goals; the location, timing and content of the summit were appropriate; and their knowledge about cancer control and challenges and opportunities relating to policy, systems and environmental approaches in Indian Country increased (Table 9).
Table 9: Average ratings for process and satisfaction evaluation questions (1=strongly disagree, 5=strongly agree) (n=53)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>I met my team/professional goals attending the summit</td>
<td>4.1</td>
</tr>
<tr>
<td>The summit objectives were clearly stated</td>
<td>4.2</td>
</tr>
<tr>
<td>The summit agenda aligned with the objectives</td>
<td>4.3</td>
</tr>
<tr>
<td>Time allotted to each agenda item was appropriate</td>
<td>4.1</td>
</tr>
<tr>
<td>Issues being discussed during breakout sessions were pertinent to my interests</td>
<td>4.3</td>
</tr>
<tr>
<td>The days of the week chosen for the summit were appropriate</td>
<td>4.3</td>
</tr>
<tr>
<td>The location, Traverse City, Michigan, selected for the summit was appropriate</td>
<td>3.8</td>
</tr>
<tr>
<td>The facility selected for the summit was appropriate</td>
<td>4.2</td>
</tr>
<tr>
<td>The summit improved my understanding of the state of cancer control in Indian Country</td>
<td>4.3</td>
</tr>
<tr>
<td>The summit increased my understanding of the most significant challenges and barriers that have been overcome in cancer control in Indian Country</td>
<td>4.1</td>
</tr>
<tr>
<td>The summit increased my understanding of the most significant unique challenges and barriers that remain in cancer control in Indian Country</td>
<td>4.3</td>
</tr>
<tr>
<td>The summit improved my understanding of policy, systems and environmental change opportunities, needs and approaches to address cancer disparities in AI/AN communities</td>
<td>4.2</td>
</tr>
<tr>
<td>I intend to implement the policy, systems and environmental change approaches to address cancer disparities in AI/AN communities</td>
<td>4.1</td>
</tr>
<tr>
<td>The priorities established during the summit are satisfactory and actionable</td>
<td>4.1</td>
</tr>
<tr>
<td>The summit increased collaboration between AI/AN and state programs and stakeholders</td>
<td>4.1</td>
</tr>
</tbody>
</table>
The most valuable components of the summit reported in freeform by attendees included:

- Networking not only between different tribes, but also with CDC consultants and Comprehensive Cancer Control National Partnership members (n=23);
- Working sessions, with some specifying the value of discussing goals and creating action plans (n=16); and
- Presentations, particularly those on data, policy, systems and environmental approaches and other programs’ successes (n=12).

Areas for improvement for future summits include:

- Increased coordination of presentations, as some survey respondents thought there were too many presentations with overlapping content, especially on data, which some felt were too didactic (n=9);
- Increased opportunity to network, such as including ice breakers at the beginning of the summit, time to talk specifically to CDC program consultants and work with attendees from regions other than their own (n=4);
- More central location for meetings, as travel times were strenuous for some. Some also suggested starting the day later to help attendees adjust to the time difference (n=3);
- Conduct a pre-conference survey to aid agenda setting (n=1);
- Have an American Indian and Alaska Native attendee lead the working sessions instead of CDC program consultants (n=1);
- Organize the cultural exchange around lunch time to increase attendance (n=1);
- More stretch breaks (n=1); and
- Offer healthier meal options (n=1).

Missing stakeholders survey respondents indicated they would like to see at the next summit are:

- IHS representatives (n=26);
- Tribal council members and leaders (n=7);
- More National Comprehensive Cancer Control Programs, including Susan G. Komen, Leukemia and Lymphoma Society and National Association of Chronic Disease Directors (NACDD) (n=4);
- State cancer programs (n=3);
- Centers for Medicare and Medicaid Services (CMS) (n=2);
- Policymakers (n=2);
- Chikasaw Nation representatives (n=1);
- Data managers (n=1); and
- Other non-funded tribes (n=1).

Future topics of interest to be potentially covered in future summits include:

- Updates and successes on regional or program progress (n=5);
- Culture and traditions (n=3);
- Grant writing and capacity building (n=3);
- IHS plans and partnership development (n=3);
- Program evaluation (n=3);
- Communication and media campaigns (n=2);
- Success stories and models (n=2);
- Cancer and chronic disease integration (n=1);
- Cancer care plans (n=1); and
- Inter-tribal mentorship (n=1).

Technical assistance needed as identified by survey respondents are:

- Data collection and sharing (including Electronic Health Records) (n=7);
- Evaluation (n=7);
- Communication, dissemination and promotion (n=6);
- Grant writing (n=2);
- Testing evidence-based and culturally-tailored interventions (n=2);
- Mentorship (n=1);
- Coalition building (n=1); and
- Momentum-building after the summit (n=1).

As the evaluation results show, the summit provided an opportunity for American Indian and Alaska Native cancer programs, coalitions, CDC staff and stakeholders to network, share ideas and plan activities to reduce cancer disparities. American Indian and Alaska Native programs and coalitions seek support with data collection, evaluation and communication, among others, as well as increased and sustainable funding to continue their work reducing barriers to care in their communities.
Selected Additional Resources

For more 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 (AICF) 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.

National Native Network Resource Library and 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:

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.”

EVIDENCE-BASED INTERVENTIONS:

Best Practices in American Indian and Alaska Native Public Health addresses some successes and challenges of Tribal Epidemiology Centers.

Joint Jurisdiction Courts: A Manual for Developing Tribal, Local, State and Federal Justice Collaborations is a “roadmap for tribal and community leaders who want to develop joint jurisdiction courts or initiatives in their own communities.”

Understanding the Issues: How to Use Community Assessment, Evidence and Theory to Inform Your Cancer Control Approaches is a summary of the Ask-the-Expert session with speakers from Cancer Prevention and Control Research Network (CPCRN).

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.”

MEDIA AND COMMUNICATION:

80% by 2018 Communications Guidebook: Effective Messaging to Reach the Unscreened is designed to help educate, empower and mobilize audiences
who are not getting screened for colorectal cancer.

**Communication Training for Comprehensive Cancer Control Professionals 101: Media Planning and Media Relations** “is an on-demand online training that walks participants through the process of media planning, creating media-friendly materials and building relationships with journalists.”

**The Media Planning and Media Relations Guide** “provides an overview of important content for planning and writing CDC-required media plans.”

**References**


Sponsors

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Wiidookaage: Ojibwe word meaning “they help each other”

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