



## **Symposium Report**

*American Indian/Alaska Native  
Comprehensive Cancer Control  
Policy and Practice Summit*

**J.W. Marriott Hotel, Denver, CO**

**June 30, 2009**



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## **Executive Summary**

The purpose of the American Indian/Alaska Native (AI/AN) Comprehensive Cancer Control (CCC) Policy and Practice Summit, held June 2009 in Denver, Colorado, was to: (1) engage in a dialogue with elected officials working through the Tribal Consultation Advisory Committee, National Indian Health Board, and CCC Coalitions on identified priority CCC areas and potential policy approaches to address those areas; (2) share and discuss other AI/AN CCC experiences, successful strategies, challenges encountered, and new approaches to affect policy change on identified CCC priority areas; (3) identify the policy approaches that AI/AN Coalition leaders can consider for their own CCC efforts; (4) identify a set of policy-related actions for CCC National Partners to support and assist AI/AN CCC Coalitions to build their capacity affecting policy change; (5) identify a set of policy-related actions for CCC National Partners to address at a national level that support AI/AN CCC Coalitions in their priority policy-related efforts; and (6) provide information on CCC implementation materials that AI/AN CCC Coalitions can use in their implementation efforts of their CCC plans.

Following the opening blessing and overviews of the Summit and the CCC National Partnership, Dr. Jeffrey A. Henderson, President and Chief Executive Officer of the Black Hills Center for American Indian Health, provided the keynote address. His address focused on how to move toward a future of good health and wellness for AI/AN populations. He noted that AI/AN populations experience a number of health inequities, including cancer, and social inequities that have a profound impact on AI/AN health status. Although a significant amount of new data will soon be available, further research is needed to determine effective preventive interventions. Those sanctioned by AI/AN communities then could be replicated in tribal communities via their community health and clinical systems of care. National leadership and governmental financial support are essential to these efforts. Following the keynote address, Summit participants engaged in dynamic policy discussions related to AI/AN populations in the areas of supporting healthy lifestyles, increasing access to screening and follow-up services, and coordinating resources at the tribal, state, and federal levels.

*Discussion Area I: Support Healthy Lifestyles.* Successful examples of how the Cherokee Nation and the South Puget Intertribal Planning Agency (SPIPA) implemented policies to support healthy lifestyles were described. The Cherokee nation focused on creating a smoke-free environment on its reservation using a significant amount of data and research to ensure its program was successful. SPIPA also focused on tobacco use, implementing a media campaign, developing a movie, training clinicians on tobacco intervention skills, and engaged youth to communicate smoke-free messages.

Participants identified a number of possible policy areas to support healthy lifestyles:

- Integrate chronic disease programs to maximize CCC funding.
- Focus on Quitline access and funding.
- Increase and improve communication and collaboration between states and tribes and between tribes.
- Approach public health from a community perspective.
- Develop a broad definition of community that encompasses different tribal meanings (i.e., all tribes are not the same).
- Establish public and community gardens and support farmers markets.
- Create a central AI/AN-based repository for best and promising practices.
- Look to Indian Health Service (IHS) to create and support a CCC tribal advocacy group.
- Advocate for a portion of tobacco settlement funds be provided to the tribes.
- Promote self-determination and advocate for the tribes to create programs appropriate for them.
- Introduce youth to concepts of policy and get them involved.
- Solicit casinos for funding to purchase local gym memberships for tribal members.

*Discussion Area II: Increase Access to Screening and Follow-Up Services.* Successful examples from the Alaska Native Tribal Health Consortium, Northwest Portland Area Indian Health Board, and the Aberdeen Area Tribal Chairmen’s Health Board were highlighted. The Alaska Native Tribal Health Consortium uses collaboration, education, advocacy, legislature, media campaigns, and an itinerant physician program combined with targeted patient navigation to increase access to screening and follow-up services. The Northwest Portland Area Indian Health Board increases access to screening and follow-up services through the initiation of patient navigator programs to break down barriers. The Aberdeen Area Tribal Chairmen’s Health Board has implemented successful specialty screening clinics for men. Some tribes have implemented policies that help their members attend the clinics, such as allowing administrative leave.

Participants identified a number of possible policy areas to increase access to screening and follow-up services:

- Recognize the value of resolutions as a prelude to other actions.
- Provide administrative leave to allow tribal members to attend screening clinics.
- Work with tribal leaders.
- Address data ownership and sharing issues.
- Create a sense of community member traction and ownership for personal efforts to access care (i.e., “Shine their own light.”).
- Advocate for a universal patient navigation system and funding for such a system.
- Increase provider capacity, capability, and usability.
- Increase state and federal funding for home health care and Community Health Representatives.
- Provide specific and universal screening guidelines and guidance and promote their use by tribal health systems, including IHS.
- Examine cancers other than the four major types for data purposes.
- Develop men’s health seminars to increase screening rates for men.
- Develop universal comprehensive cancer screening guidelines.
- Advocate for increased tribal funding for patient navigation programs.
- Address the issue of chronically underfunded programs.
- Advocate for government groups to elevate the status of cancer issues.
- Advocate for additional resources for prevention programs.
- Address accident incidence to increase funding for CCC efforts.
- Advocate for the Reauthorization of the Indian Health Care Improvement Act (H.R. 2708), which includes unfunded mandates.

*Discussion Area III: Coordinate Tribal, State, and Federal Fiscal Resources.* Successful case studies from the Fond du Lac Band of Lake Superior Chippewa Reservation, Cherokee Nation, and Aberdeen Area Tribal Chairmen’s Health Board were illustrated. The Fond du Lac’s cancer team compelled the tribe’s insurance board to fully cover breast, ovarian, and colorectal cancer screening. The Cherokee Nation successfully leverages with other organizations and universities to provide cancer services for its tribal members. The tribe also ensures that its beneficiaries are aware of, applying for, and accessing programs for which they are eligible and ensures that patients access all resources available to them. The Aberdeen Area Tribal Chairmen’s Health Board coordinates resources and partnerships with a number of national stakeholders.

Participants identified a number of possible policy areas to coordinate tribal, state, and federal fiscal resources:

- Reaffirm policies regarding federal trust responsibility that enforce the duties of AI/AN agencies.

- Establish AI/AN funding and reimbursement benchmarks based on federal employee rates.
- Advocate for and establish a national AI/AN Medicare plan.
- Advocate for multiple reimbursements (e.g., nonbundled payments) for Medicare services.
- Establish and develop a cancer program specific to AI/AN populations.
- Apply Medicare rates and reimburse for outpatient expenditures.
- Develop a comprehensive approach to address federal policies.
- Develop a white paper regarding AI/AN cancer policies that can be used as a basis for lobbying efforts.
- Develop policy and protocol for how states and tribes work together in the health care arena.
- Strengthen tribal direct health care systems to allow screening to be done in reservation hospitals and clinics.

The ideas from each discussion area were consolidated into a final list so that the participants could vote for the top three items overall that they thought were important to improve AI/AN access to cancer care. The straw poll was intended to provide guidance to the National Partners, not a definitive priority-setting process. The National Partners may act on any of the ideas once they determine how to best use their areas of expertise to advance the ideas identified during the Summit. The items identified as promising areas in which to begin, in order from most votes to least, were to make the case (white paper) for changes to the health care system that will lead to better cancer outcomes for AI/AN populations, better integrate chronic disease programs to maximize CCC funds, advocate for funding for universal patient navigation programs and services, address chronic underfunding of all related AI/AN service programs, particularly CCC programs, and examine an option for federal agencies to hold states more accountable for how they relate to the tribes.

## Summit Proceedings

The following is a summary of the information presented at the American Indian/Alaska Native (AI/AN) Comprehensive Cancer Control (CCC) Policy and Practice Summit, including participant discussion and shared ideas. The purpose of the American Indian/Alaska Native (AI/AN) Policy and Practice Summit, held June 2009 in Denver, Colorado, was to: (1) engage in a dialogue with elected officials working through the Tribal Consultation Advisory Committee, National Indian Health Board (NIHB), and CCC Coalitions on identified priority CCC areas and potential policy approaches to address those areas; (2) share and discuss other AI/AN CCC experiences, successful strategies, challenges encountered, and new approaches to affect policy change on identified CCC priority areas; (3) identify the policy approaches that AI/AN Coalition leaders can consider for their own CCC efforts; (4) identify a set of policy-related actions for CCC National Partners to support and assist AI/AN CCC Coalitions to build their capacity affecting policy change; (5) identify a set of policy-related actions for CCC National Partners to address at a national level that support AI/AN CCC Coalitions in their priority policy-related efforts; and (6) provide information on CCC implementation materials that AI/AN CCC Coalitions can use in their implementation efforts of their CCC plans.



*Welcome Dinner and Reception, June 29, 2009, JW Marriott Outdoor Terrace*



### **Welcome and Introductions**

Mr. Gary Gurian, C-Change Program Director, welcomed participants to the Summit and introduced Ms. Rita Stevens, Committee Chairperson of the Alaska Native Tribal Health Consortium. Ms. Stevens presented Mr. Thompson Williams of the Caddo Nation of Oklahoma with four gifts in honor of his opening blessing.

### **Opening Blessing**

Mr. Thompson expressed his appreciation for being able to provide the blessing for the Summit as he and other members of his tribe have been personally affected by cancer. He performed the blessing, asking for guidance and wisdom, as this Summit has the potential to have a powerful impact on cancer in Indian Country.

### **Overview of Summit**

Mr. Gurian thanked the Summit planning committee, which was comprised of members of the AI/AN community and the CCC National Partnership. The Summit participants include AI/AN coalition chairs, program directors, and/or their designees; representatives from AI/AN stakeholder organizations; and CCC National Partners. The planned discussions will benefit from the variety of participants present. He noted that the Summit will focus on three discussion areas that were identified via survey. Workshops designed for CCC programs will be a part of the 3-day Summit.



### **Overview of the CCC National Partnership**

Ms. Madeline La Porta of the National Cancer Institute (NCI) explained that CCC is a collaboration, and the pooling of resources results in a decreased cancer burden through reduced cancer risk, earlier detection, better treatment of cancer, and increased quality of life. This collaboration of 12 leading cancer organizations works to empower leaders and actively build capacity for cancer control at the state, tribal, territory, and local levels by creating forums. The National Partnership sponsors a number of CCC activities: initiatives, such as CCC leadership institutes, which move specific action items forward; technical/planning assistance team visits, which provide guidance to entities that experience unique challenges in their CCC efforts; policy summits, such as this effort; and budgeting and resources workshops for CCC Coalitions. Two Web-based tools have been developed, Cancer Control P.L.A.N.E.T. (<http://cancercontrolplanet.cancer.gov>) and CancerPlan.org. The tools provide robust methods to connect with national colleagues. The National Partners also provide unique contributions, such as technical assistance, training, resources, advocacy, expertise, and leadership, which have enabled states, tribes, and territories to develop and implement CCC plans. The dramatic increase in the number of states, tribes, and territories with CCC plans is an impressive display of what collaboration can accomplish.

Ms. La Porta described AI/AN-specific initiatives, including leadership institutes in Tucson, Arizona, and Seattle, Washington, in 2005 and 2006, respectively, and this Summit. The ultimate goal is to find synergy between tribal and state CCC plans. The National Partners seek input, and acting accordingly, they established the AI/AN CCC Advisory Group in 2006 to provide input regarding tribal needs. This group has been instrumental in defining issues and providing recommendations to the National Partners for their consideration and provision of action. The AI/AN CCC Advisory Group is moving forward to advance political issues by expanding its membership to include Program Directors from the Tribal CCC programs

and to make recommendations for other stakeholder involvement in the National Partnership CCC movement as collaborating partners.

The goal of the National Partnership is to continue and increase the support to sustain its success and the success of CCC Coalitions by fostering the implementation of CCC plans at the local level, identifying and supporting policy initiatives, facilitating real-time communication with CCC Coalitions, and documenting CCC outcomes. The whole truly is greater than the sum of its parts, and the National Partnership will work together to secure resources, coordinate expertise, and utilize its strengths to change the trajectory of the cancer burden in the United States.

**Keynote Speaker: Dr. Jeffrey A. Henderson**

Dr. Jeffrey A. Henderson, President and CEO of the Black Hills Center for American Indian Health (BHCAIH), noted that the term “inequities” is preferable to “disparities” because its use addresses fairness, justice, and equity. There has been a long history of AI/AN health inequities since the time of first contact, when colonists recognized the lack of immunity to infectious diseases in tribal communities. AI/AN populations continue to experience these inequities even as disease causation has changed from acute to chronic. These continued inequities in underrepresented populations likely are produced by social and political causes. The availability of important new sources of data regarding cancer incidence and mortality in AI/AN populations that will assist with cancer planning and control have the potential to reduce these inequities. One source is the “Annual Report to the Nation on the Status of Cancer, 1975–2004, Featuring Cancer in American Indians and Alaska Natives”, which was published online in October 2007 (<http://www.interscience.wiley.com/cancer/report2007>) and in the journal *Cancer* (November 2007, Volume 110, Issue 10, pp. 2119–2152). The second source is the linked cancer incidence data reported in a special supplement (“An Update on Cancer in American Indians and Alaska Natives, 1999–2004”) to *Cancer* (September 2008, Volume 113, Issue S5, pp. 1113–1273).



It is predicted that by 2015, cancer will overtake cardiovascular disease as the leading cause of death in the United States; by 2020, it will be the leading cause of death globally. Actual causes of death, those that contribute to the leading causes of heart disease, cancer, and stroke, are mostly based on human behavior: tobacco use, poor diet, physical activity, alcohol consumption, and so forth. Poor diet, physical inactivity, and obesity are major factors in the development of cancer and will soon overtake tobacco use as the leading actual cause of death.

Dr. Henderson provided examples of cancer incidence rates for several different types of cancer in males and females of various ethnic groups in each of the Indian Health Service (IHS) regions. Overall, AI/AN individuals are 23 percent less likely to develop cancer than non-Hispanic whites; however, AI/AN populations are at an increased risk to develop certain types of cancer, including kidney, stomach, cervix, liver, and gallbladder. Cancer incidence rates vary 300 to 500 percent between the lowest and highest incidences in AI/AN populations but only 30 percent in non-Hispanic white populations. It is important to ask why certain populations do not develop cancer and what keeps them healthy.

Kaplan’s Multilevel Model of Disease Causation is comprised of a variety of domains (or vectors) that affect individual- and population-level health. Although many different factors effect health (e.g., genetic factors, social relationships, living conditions, social and economic policies), the U.S. political body ensures that third-party payers exhort individuals to change their behavior. The three Summit policy discussion areas can be related to Kaplan’s model. Policy Discussion Area I, to support healthy lifestyles, relates to the individual risk factors domain of the model. Policy Discussion Area II, to increase access to screening and follow-up services, relates to the institutions (including medical care) domain. Policy

Discussion Area III, to coordinate tribal, state, and federal fiscal resources, relates to the social and economic policies domain. It is important to remember that extrinsic thinking is inaccurate; although individual behavior is not the only health-determining factor, external factors are not entirely at fault, either.

Dr. Henderson noted that counties identified as impoverished generally correlate with the presence of reservations. The top 10 poorest U.S. counties in 2000, as identified by several indicators, include eight Native American counties. The U.S. Department of Agriculture commodity foods provided to low-income populations do not include fresh fruits, vegetables, meats, or dairy products. Additionally, more than 70 percent of the U.S. population is estimated to be overweight/obese, and AI/AN numbers are even higher; this is a potential area for intervention. AI/AN populations overwhelmingly report that their source of physical activity is conducting household chores. As lung cancer is the leading cause of death among AI/AN males and females, the BHCAIH has sponsored messages that urge individuals to protect youth and casino workers from the dangerous effects of second-hand smoke. Several cancers are preventable, and people should not be dying of cancers that can be prevented or for which there is effective screening.

Dr. Henderson highlighted new sources of data, including the Education and Research Towards Health (EARTH) Study, an in-person survey conducted from 2003 to 2006. The Centers for Disease Control and Prevention (CDC) Behavioral Risk Factors Surveillance System (BRFSS) utilizes a telephone survey to collect data. As telephone surveys tend to be biased toward higher socioeconomic groups, the EARTH Study attempted to diminish this bias. With the exception of Alaska, cancer screening rates reported in each IHS region for mammography, endoscopy, and Pap tests were significantly lower in the EARTH Study when compared to BRFSS data. When health care expenditures were examined, IHS health expenditures per person fall well below the Federal Employees Health Plan benchmark. Health services for AI/AN populations are grossly underfunded, and more than 50 percent of the low-income, uninsured AI/AN population does not have IHS access for a variety of reasons.



BHCAIH's body of research examines inequities for all diseases and environmental issues. AI/AN populations experience a number of health inequities, and there are many influences on individual- and population-level health that are inextricably linked (e.g., built environments that are not conducive to safe physical activities). Social inequities have a profound impact on health status; improving the socio-economic status of AI/AN populations will improve health better than any other intervention. Tribal, clinical, and national leadership and government financial support are essential to this effort. Further research is needed to determine effective preventive interventions, and identified successful interventions need to be replicated. Ongoing surveillance of behaviors and conditions is essential to gauge progress toward lessening the cancer burden in AI/AN populations. The new cancer incidence data will be beneficial, and the linked cancer mortality data will be available for the workgroup to analyze within the next 6 to 8 months. It is important to make effective use of these data.

### ***Policy Discussion Area I***

*Support healthy lifestyles, such as increased physical activity, healthy diet, and prevention and cessation of nonceremonial use of tobacco.*

Mr. Tom Kean, C-Change Executive Director, highlighted the purposes of the Summit and explained that in each policy discussion area, CCC Coalition directors would describe examples of policy issues their Coalitions have experienced and the lessons learned. During each of the three scheduled discussions, par-

Participants will identify policy issues that need to be addressed. During the last scheduled session, participants will have the opportunity to vote for what they consider to be the top three issues; this will help identify key areas on which the National Partnership should focus.



Mr. J.T. Petherick, Cherokee Nation Health Legislative Officer, explained that the Cherokee Nation has implemented several approaches for improving health, including creating a smoke-free environment. In creating this environment, planners found that it is necessary to plan ahead and phase in smoking bans incrementally. Casinos are a separate entity and not required to be smoke-free, but the Cherokee Nation tribal government is emphasizing to the gaming sites the benefits of creating a smoke-free environment. As a result of the smoking ban, demand for smoking cessation classes and usage of nicotine patches and the Oklahoma Quitline have increased; these increases indicate the success of the ban. The Cherokee Nation also

has implemented a “Tobacco Stops With Me” campaign, using Internet, radio, television, and billboard ads that feature prominent Cherokees and individuals to whom the tribal members can relate. Ms. Kym Cravatt, Director of Cancer Programs for the Cherokee Nation, added that the policies were implemented following a great deal of research and data support, including data from cancer registries; this support was responsible for the success of the policies. Mr. Kean asked whether the Cherokee Nation prepared the Quitline for an increase of AI/AN callers. Ms. Cravatt responded that the tribe worked with the state so that Quitline personnel were prepared for the increase. Tribal physicians and smoking cessation classes also promote the Quitline.

Mr. John Simmons, South Puget Intertribal Planning Agency (SPIPA), explained that six tribes comprise his Coalition, so each one was handled individually to address specific issues. One tribe implemented a “Kick Butt” campaign in which volunteers pick up cigarette butts. Currently, 10 pounds of butts have been collected; when 30 pounds have been collected, they will be taken to the tribal council to highlight the need to change policies that still allow public smoking. A movie entitled *Curious Fingers Burn* was inspired by the act of someone throwing a lit cigarette near a little girl who almost picked it up and burnt herself. Another tribe trains clinicians on tobacco intervention skills and has created public service announcements to target casinos, highlighting the fact that it is good business for them to protect their workers and patrons. Young adults are being used to communicate about how to help AI/AN populations stop smoking. Washington State has many initiatives, but some tribes and tribal councils are not taking them seriously, so the youth are communicating as a “revolution” because the older generations are not listening. SPIPA also implemented a policy that requires smoking to occur no closer than 200 feet from its building.

Mr. Kean opened the discussion by asking participants for their responses to the previous presentations. Dr. Nathaniel Cobb, IHS, stated that there has been internal debate within IHS regarding whether Native Americans use Quitlines and whether they work. When IHS was provided data by a Quitline contractor, it was discovered that Native Americans are overrepresented as a percentage of callers, probably as a result of the fact that Native Americans are overrepresented among smokers. Counselors are trained to be sensitive of Native American issues, such as ceremonial use of tobacco, and more formal training is being planned. As a result of these data, IHS will incorporate Quitlines into its cessation policies. A field book that can be used as a clinical guide to evidence-based cessation programs specific to AI/AN populations will begin distribution in the first part of July 2009; it also will be widely available on CD or via Web download.

Ms. Judith Muller of the Alaska Native Tribal Health Consortium noted that states are being impelled to integrate programs; heart, kidney, and tobacco programs can collaborate regarding healthy practices to

maximize CCC funding and present a unified front. She asked whether this type of integration was occurring within the tribes and for examples of any success stories. Ms. Kerri Lopez, Northwest Portland Area Indian Health Board, noted that the tribes also were being impelled to integrate; in Oregon, it is mandatory that those receiving tobacco funds must address integration. The State of Oregon is working with its nine tribes and diabetes and tobacco coordinators to examine wellness in the workplace regarding tobacco and chronic disease; various policies are being explored to determine best practices. Gaps between clinicians and the community were identified; work is being done to reduce these gaps, including educating clinicians regarding to whom patients should be referred. Successful programs and lessons learned from other tribes are being examined; many tribes have programs that promote wellness in the workplace. The Northwest Portland Area Indian Health Board is working with the state to adapt its health questionnaire because the current questionnaire is too long and complicated; many questions were not appropriate for tribal individuals.

Mr. Simmons noted that Washington State is working with the tribes in a close partnership, but tobacco funding has been cut within the state. Ms. Judith Charley, Confederated Tribes of Warm Springs, stated that her tribe has partnered for many years with IHS, the Northwest Portland Area Indian Health Board, and the Northwest Tribal Cancer Coalition, and attendance at CCC meetings has steadily increased. Her tribe received funding for a heart health program, which has included two 10-week courses with specific curricula. Smoking cessation classes are held semiannually, and the tribe participates in the Great American Smokeout. The tribal wellness coordinator holds weekly walking events with Head Start staff and students to encourage exercise at a young age. A diabetes intervention program includes exercise and nutrition components. The long practice of partnering with local agencies has been successful.



Dr. Gloria Grim, Medical Director of the Cherokee Nation, stated agreement with an integrated approach but stated that it is necessary to go beyond to ultimately change the community. Schools seeking tribal grants must complete the CDC School Health Index among other requirements. Policies are in place that determine what can be purchased with tribal funding; food purchases made with tribal funds must adhere to certain guidelines, and dietitians examine all menus. Information is provided regarding healthy restaurant choices, and farmers markets are being provided infrastructure to sustain them within the community. The tribe has constructed a large physical fitness facility that is open to the community and offers competitive sports programs. Focusing on the Cherokee Nation as a whole has been successful.

Char Hewitt, a member of the AI/AN CCC Advisory Group, explained that she lives near a small, reservation-based tribal community located on the shores of Lake Superior in the Upper Peninsula of Michigan. The tribe's health services are accredited for wraparound health care services by the Joint Commission on Accreditation of Healthcare Organizations and the Accreditation Association for Ambulatory Health Care, Inc. Prevention programs have been developed by the tribe, including a colorectal program and other chronic disease prevention programs. The tribe also has a physical fitness center. A physical therapist and nutritionist are available onsite. Additional resources are needed to maintain ongoing efforts in prevention, such as the colorectal program, which was funded with a small grant through the National Call to Action on Cancer Prevention and Survivorship initiative.

Ms. Sally Smith, NIHB, asked whether tribal policies are nationally known. She also noted that a more broad definition or understanding of "community" would be helpful (e.g., Alaskan villages). She noted that a national workgroup is working on accreditation, and national programs are not reaching Alaska.

Alaska programs include community and public gardens and participation in the Just Move It Program (<http://www.justmoveit.org>), a national campaign to promote physical activity in AI/AN populations. She suggested collecting best and promising practices into an AI/AN-based central repository. The SouthEast Alaska Regional Health Consortium is developing a preventive program that allows children to receive check-ups at school before they are ill. Dr. Cobb added that the IHS Health Promotion and Disease Prevention Initiative has started a best practices Web site regarding community health and disease prevention that can be found at <http://www.ihs.gov/NonMedicalPrograms/HPDP>.



Ms. Melissa Candelaria of the American Indian Law Center, Inc. explained that in 2000, the New Mexico legislature established a tobacco settlement fund, 50 percent of which is contributed to health-related programs. In 2004, tribal advocacy groups worked with the New Mexico legislature to provide a set-aside from funds that go to health-related programs. The New Mexico Indian Affairs Department administers this set-aside to the tribes, and the funds are used to promote self-determination. Each tribe determines the health issues on which it will focus and uses the funds accordingly. One important policy area is advocating for self-determination by listening to the

tribes and providing them with opportunities to create programs and activities that are appropriate for them.

Ms. Michele Suina, University of New Mexico Center for Native American Health, noted that youth are a major priority for many tribal communities. She described the Santa Fe Indian School Summer Policy Academy that introduces Native American high school students to a wide spectrum of policy issues, including health. Tribal health includes language, culture, economic development, and traditional practices. It is critical to ensure that young people understand what policy is and their role in it; the program encourages young people to take an interest in traditional activities that are a part of their identity.

Mr. Simmons reminded participants that not all tribes have access to large land areas that promote physical activity; some tribes live in areas that are dangerous for pedestrians and so forth. To address this, SPIPA has solicited for and received funds from casinos to purchase local gym memberships for tribal members.

Mr. Kean reiterated the key points of the discussion:

- Emphasizing a focus on youth, including strategies for engagement and training.
- Examining relationships with states and opportunities for sharing best practices.
- Advocating for self-determination, so that local tribal programs can address by choice their priority cancer and other chronic disease risks.
- Examining IHS leadership and how connections are and can be made.
- Developing an AI/AN-based repository of best practices.
- Creating and implementing policies that promote healthy behaviors.
- Partnering with local organizations to enhance tribal health and promote healthy lifestyles.
- Integrating tobacco policies and how to help people quit smoking.
- Using new, improved data to improve decision-making.

## **Policy Discussion Area II**

*Increase access to cancer screening (especially colorectal) and follow-up services through innovative and evidence-based initiatives, such as providing alternative clinic hours, promoting common screening guidelines among practitioners, and increasing overall capacity to provide screening.*

Ms. Stevens explained that her consortium meets regularly with a statewide steering committee to discuss issues and advise program personnel on key issues, priorities, and areas for coordination; the meetings are very productive. Four main priority areas have been identified: tobacco, palliative care, patient navigation, and colorectal cancer and screening. The cancer program approaches the problem of colorectal cancer and screening by increasing screening capacity, targeting high-risk patients, and educating the public. It is important to target Alaska Natives for early screening. One effort will provide a health fair and screenings at the 2009 Annual Alaska Federation of Natives Convention.

Ms. Muller provided details regarding policy efforts and lessons learned for the Alaska Native Tribal Health Consortium. One successful project has been the Super Colon™, an interactive educational tool that teaches about colorectal cancer. Additionally, the coalition worked with a statewide committee and introduced, passed, and implemented legislation that ensures that insurance companies are responsible for colorectal cancer screening. This had an additional benefit of raising awareness statewide regarding the need for colorectal screening, including increased capacity. Within the state there are six regions, each with a regional hospital, that operate independently and implement their own programs. The consortium does not have authority over the regions but works with them. Initially, a phone survey of each of the regional tribal hospitals was completed to determine baseline information regarding equipment, specialists, and current screening levels. The survey found that there was a shortage of providers able to provide colorectal screenings. The consortium examined policy changes that would address this shortage, and training was initiated so that midlevel providers could perform flexible sigmoidoscopies. Turnover, however, became a problem so the next step was to encourage itinerant physicians to commit to travel to the regions to perform screenings. The challenge with this approach was that the patients did not come despite the availability of the traveling physician and equipment. The third approach now focuses on patient navigation. Advocates contact patients and help them through the screening process, ensuring that the patients are screened. In addition to taking the lead on advocating for legislature, the consortium also initiated a “Love Your Colon” media campaign, developed educational materials, and sponsors fundraisers.



Ms. Lopez described the successful navigator program initiated in the Northwest. A series of panels provided testimony regarding what was happening in Indian Country in terms of cancer; these testimonies resulted in the first patient navigator project in the Northwest. The first project worked to break down barriers, and a second project will focus on an evidence-based component in addition to the other traditional navigator components. Data indicate that the projects have been hugely successful in breaking down barriers but probably will not continue to be funded because of data issues; the NCI maintains that it owns all of the tribal data and has rejected all of the data-sharing plans that the tribes have presented. This is an important policy issue to confront. She noted that cancer survivors are profusely thankful for the program and testify that it made a significant difference in their survival and quality of life. IHS Community Health Representatives (CHRs) are capable of providing patient navigation in communities at least as well as medical personnel. True change will occur only if navigators are available in all communities that help patients navigate every step of the process.

Ms. Tinka Duran of the Aberdeen Area Tribal Chairmen’s Health Board described successful specialty screening clinics for men and noted that efforts for screening began with tribal dialogue. A great deal was learned from the tribes, and in the 1990s the Standing Rock Sioux Tribe began working with women’s cancers, implementing specialty clinics that eventually included men’s cancers, and now a strong partnership with IHS and a local public health unit is in place that allows the men’s specialty clinics to occur four times per year. The Pine Ridge Indian Reservation also implemented similar clinics and successfully advocated for clinicians to be available on Saturdays. Standing Rock implemented a policy to allow administrative leave to be taken to attend the screening clinics, and the tribes have passed resolutions in support of the screening programs; it is important that IHS provides its support as well. The health board is working with the tribes to increase awareness regarding the need for early screening.

Before opening the discussion to all participants, Mr. Kean highlighted the key points from the policy case studies:

- The value of resolutions as a prelude to beginning other efforts.
- The benefit of allowing administrative leave to obtain screening.
- The importance of engaging leadership in policy work.
- The importance of advocating for navigators in all communities.
- The challenge of data sharing and ownership.
- The importance of creating a sense of traction and ownership (i.e., “Shine the light.”).
- The benefit of examining provider capability and usability.

Ms. Deborah Broken Rope of Broken Rope Associates stated that CHRs are key for a number of health care services; a lot is expected from them, but the programs are not well funded, and home health care programs are nonexistent. More federal financial support is needed. Dr. Cobb noted that colorectal cancer screening often is considered low priority because it is not immediately life threatening, but this approach is short-sighted because the costs of treating colorectal cancer are much higher than preventive screening. Mr. Kean noted that the National Breast and Cervical Cancer Early Detection Program is worthy, but it only serves 15 percent of the need in the United States and has been chronically underfunded for many years; the parallel colorectal cancer screening program that has been launched also will be chronically underfunded. This chronic underfunding is critical for this group to discuss. Ms. Hewitt noted that when funding is not made available for preventive services, treatment funds are not enough to cover all individuals that need to be treated. It is necessary to advocate for additional funding for CCC breast, cervical, and colorectal early screening programs to detect cancer before it enters the secondary and tertiary processes. Many tribal contract health service programs run out of funding early, leaving no treatment funds available. Dr. Henderson stated that contract funding is expended so quickly as a result of accidents and unintended deaths, which are the leading causes of morbidity, disability, and mortality in AI/AN populations from birth to age 64. Decreasing accidents and injuries would allow for more funds to screen for and treat cancer.



Dr. Cobb stated that patient navigation is beneficial, but this is a funding issue rather than a policy issue. Funding for patient navigators is not available from the NCI because its grants must be used for research. Ms. La Porta commented that the National Cancer Act mandates that the NCI disseminate the results of its research to the public; this can be accomplished via a number of methods, including dissemination to CHRs. This issue should be brought to the National Cancer Advisory Board, the NCI Board of Scientific Advisors, and the President’s Cancer Panel to remind them that bench science is not the only concern; it is critical that the public receives the benefit of the research. Dr. Adam Clark of the Lance Armstrong

Foundation explained that the President's Cancer Panel has stressed that the National Cancer Program, which operates at a higher level than the NCI, is responsible for action and dissemination. As such, policy changes should be at the Secretary or Department level, and there are avenues to accomplish this, even across agencies. The President's Cancer Panel is looking for cancer groups and organizations to stress this need. Mr. Kean noted that revisions to the National Cancer Act currently are in bill form.

Dr. Armin Weinberg, Intercultural Cancer Council, suggested that special screening guidelines for cancers considered uncommon may need to be investigated, especially in determining the different risks in various communities. To implement this, however, significant amounts of data and more person-years of followup would be needed. Even with the influx of new data on the horizon, there is not enough to justify early screening for uncommon cancers, but clinicians and researchers should think beyond major cancers and consider rare cancers. Dr. Cobb warned that developing special screening guidelines may add confusion, with the exception of the case of gall bladder cancer.

Dr. Weinberg stated that there are 18 new grantees, including four tribal groups, for colorectal cancer screening programs, and the major issue is persuading men to get screened; to encourage more men to get screened, men should lead the programs. Programs that aim to increase screening in men and women should have men and women co-leads. Dr. Weinberg described a monthly community meal that encouraged men to bring multiple generations of their family. The community would discuss general health issues, but after the women and girls left, the men had very frank health discussions that could not have occurred in mixed company. During the 8 months that this community meal took place, the number of men bringing their sons and grandsons increased dramatically. This model could be replicated and partnered with screening interviews.

In terms of the data sharing issue, Dr. Weinberg explained that the National Institutes of Health has data sharing requirements for grants greater than \$500,000. Dr. Cobb added that IHS is working with the Office of General Counsel to develop standard language to share federal data with tribal organizations. The discussion includes an exploration of what data ownership means. Federal and tribal organizations often view data ownership differently, and these discrepancies must be addressed. IHS is looking for ideas on how to approach this issue. Broad guidelines can be developed, even though individual cases still can be negotiated. Ms. Smith stated that the U.S. Department of Health and Human Services (HHS) AI/AN Health Research Advisory Council is working closely with several agencies within HHS in regard to data sharing and ownership to make funding agencies understand that the tribes own the data. The goal is to foster Native American research.



A participant noted that federal help with and increased funding for the Reauthorization of the Indian Health Care Improvement Act (H.R. 2708) would be beneficial; it has not been reauthorized since 1999. Reauthorization would provide for retention and recruitment of health care providers, expand women's health programs to include men, and increase cancer screenings. Mr. Gurian added that many tribes are engaged in the health care reform debate in Washington, DC, and C-Change has materials and reports that can be used in these efforts to illustrate that there is a significant return on investment for evidence-based screening.

### **Policy Discussion Area III**

*Coordinate tribal, state, and federal fiscal resources and reimbursement systems to support increased access to cancer screening and treatment services for American Indians and Alaska Natives.*

Ms. DeAnna Finnifroc, Fond du Lac Band of Lake Superior Chippewa Reservation, explained that the service population for the reservation is approximately 12,000 individuals; the reservation is the largest employer in the area. Fond du Lac has its own insurance company, and employees that work at least 30 hours per week and their spouses and children are eligible for coverage. Because of the number of people insured, an insurance board was instituted. Some of the members of the reservation's cancer team also sit on the insurance board, and when the team set out to develop a cancer program, the members did not realize how significant a role the insurance board would play. The cancer team realized that insured women were not getting their annual mammograms or Pap tests because the out-of-pocket expenses were too great. Additionally, despite the fact that the reservation has the highest rates of colorectal cancer incidence and mortality in the state compared to all other ethnic groups and colonoscopies are highly encouraged, colorectal screenings were not covered by insurance. When the cancer team made the insurance board aware of this, the board decided to take a wellness-focused approach; there now is no deductible or co-pay for annual mammograms and Pap tests. The insurance board, however, was not willing to cover colonoscopies, but it was willing to cover flexible sigmoidoscopies. When the cancer team argued that colonoscopies are considered the gold standard for colorectal cancer screening, particularly in the case of the reservation's at-risk population, the insurance board decided to cover cancer screening along American Cancer Society guidelines, including colonoscopies. The current challenge is convincing the insurance board to cover colonoscopies and annual mammograms for those patients that have previously had polyps removed or been diagnosed with breast cancer, respectively.

Mr. Petherick described the Cherokee Nation's use of tribal resources to leverage for cancer control and prevention. What can be accomplished depends on how elected officials earmark funds; it is valuable to know what needs to be accomplished with the funding. The Cherokee Nation has been able to supplement health care services, and it had the foresight to negotiate with hospitals; health care is managed better than with Medicare. The tribes can do a great deal for their communities, so it is important to identify and pursue opportunities. The tribe is working with the University of Oklahoma–Tulsa to build a cancer center in Tulsa with funds from the Cherokee Nation tobacco tax. The tribe also works with Oklahoma State University and the Oklahoma State Department of Health for cancer screening. Because there is a long waiting list for screening at Cherokee facilities, the tribe is working with local hospitals outside of the reservation system to increase access to screening. The Cherokee Nation makes an effort to ensure that its beneficiaries are aware of, applying for, and accessing programs for which they are eligible and ensures that patients access all resources available to them. The tribe also supports families of patients, especially in terms of allowing them to be near their family members who must undergo treatment away from home.



Dr. Donald Warne, Aberdeen Area Tribal Chairmen's Health Board, described policy advocacy efforts to coordinate resources and partnerships with national stakeholders. He noted that it would be helpful to develop a white paper regarding AI/AN cancer policies that can be used as a basis for lobbying efforts. Additionally, the federal government has a trust responsibility to provide health care to AI/AN individuals; because of treaties, the AI/AN population is the only population born in the United States with a

right to health care. This trust responsibility should be policy; the IHS is underfunded, particularly when compared to other agencies. The benchmark for health care expenditures for AI/AN individuals should be that of the federal employees health fund. Because one-third of all senators do not have any tribes in their constituency, it is necessary for national stakeholders to lobby on the tribes' behalf. In terms of the Reauthorization of the Indian Health Care Improvement Act, without additional funding it cannot be implemented even if it is passed; the Act has no value unless funding is attached. In examining the role of Medicare/Medicaid and states, despite the fact that the health care is federally funded, the states are the gatekeepers of the tribes' access to health care, which is unconstitutional. A national AI/AN Medicare plan and national standardized reimbursement should be instituted for AI/AN populations. A cancer program specific for AI/AN individuals—similar to the federally funded, community-based National Diabetes Education Program—needs to be implemented, because even in areas with low cancer rates, the mortality rates are high as a result of late diagnosis. Most cancer treatments occur off reservation and are outpatient, but patients are only reimbursed for inpatient procedures. Medicare rates for reimbursement of outpatient treatments are needed. A comprehensive approach to cancer policy should be developed, and the National Partners and other national stakeholders should be used to lobby for the policy.

Mr. Kean opened the discussion for comments. Dr. Cobb stated that, in terms of a special fund or program for cancer similar to that of diabetes, there is a need to adopt a broad approach that focuses on chronic illnesses, as each affects the others. IHS launched a clinical quality improvement effort with a broad focus and coordinated funding so that many health issues could be addressed simultaneously. Because funding decisions often are made by directors of silos, attention is needed at higher levels to highlight the fact that there are a number of health inequities that must be addressed. Mr. Kean expressed his concern that some content-specific items may disappear with current broad health reform efforts. Dr. Warne stated that one centrally operated system of care may not work with cancer, and it may not be as effective in reaching tribal members as community-based initiatives. Dr. Cobb commented that dealing with health issues separately can be ineffective; there are ponderous mechanisms to transfer funding into the field.

Dr. Clark stated that the Lance Armstrong Foundation is attempting to identify situations in which the research has been done and clear evidence exists but no action is being taken; once identified, the foundation provides funding in these areas. Finding mechanisms to provide access should be examined at a higher level than NCI, and appropriate public health officials (i.e., the experts) need to communicate to Congress what needs to be done and how. What works is what should be driving policy. Ms. Lopez added that the CDC Tribal Consultation Advisory Committee should be involved in policy issues.



Ms. Cravatt explained that the Cherokee Nation funded a linkage study with mortality and other data. It is important to gather data and make the case to Congress regarding cancer needs in Indian Country. Although cancer care is contracted out, the federal government still must uphold its trust responsibility. Many tribal members feel comfortable only at reservation hospitals; patients need to be comfortable while receiving treatments and not worry about the challenges of navigating the system. Ms. Broken Rope added that the direct health care system should be strengthened so that screening occurs within the tribal health care system for all of the tribes. This will include many changes, including training health care providers. The tribes also need to build on existing authority to collect from third party insurance companies. IHS has mandated that tribal self-insurance plans must be wholly funded by the tribe, which may cause problems for large tribes. Tribal authority needs to be refined. Dr. Henderson added that his tribe, to afford the self-insurance plan and keep rates artificially low, created a loophole so that visits to the reservation hospital, which is where the majority of beneficiaries will be treated, will not be reimbursed.

A participant noted that the CDC leverages partnerships to increase efforts to address public health issues. Chronic diseases in AI/AN populations are a significant problem. The CDC has reached out to NIHB, local health boards, and the tribes to address the major concerns. Leveraging cooperative agreements with state partners can help to hold states accountable for how they engage the tribes, especially in terms of integrating chronic disease models. CDC's National Center for Chronic Disease Prevention and Health Promotion is the largest funded center within the CDC, but there is no coordinated approach to how the CDC works with the tribes to leverage use of available resources. All agencies need to be involved in an advisory group to advocate for the federal government to honor its trust responsibilities to the AI/AN constituency. Additionally, other cancer partners should be involved in CDC and tribal discussions.

### **Group Discussion**

Mr. Kean asked participants to consider all of the summarized concepts that had been discussed during the three discussion sessions and vote for the top three items overall that they thought were important to improve AI/AN access to cancer care. He noted that this was a straw poll that would provide guidance; it was not a definitive priority-setting process. The National Partners may act on any of the concepts once they determine how to best use their areas of expertise to advance the ideas identified during the Summit, but the poll provides an indication of where to begin.

The results of the voting were as follows:

#### *Discussion Area I: Support Healthy Lifestyles*

- **Better integrate chronic disease programs to maximize CCC funds—11 votes.**
- Create a repository of AI/AN best and promising practices—5 votes.
- Establish public and private partnerships to further community goals—2 votes.
- Improve communication and collaboration between states and tribes and tribes and tribes—2 votes.
- Engage/involve youth in policy—1 vote.
- Establish environmental policies to create safer/health-friendly indoor and outdoor places and spaces—1 vote.
- Advocate for use of tobacco revenue to further CCC efforts—0 votes.

#### *Discussion Area II: Increase Access to Screening and Follow-Up Services*

- **Advocate for funding for universal patient navigation programs and services—11 votes.**
- **Address chronic underfunding of service programs—9 votes.**
- Address data ownership issues—3 votes.
- Advocate for expansion of resources for prevention programs—2 votes.
- Build and/or increase allocation resources for provider capacity, capability, and utilization—2 votes.

- Advocate for the Reauthorization of the Indian Health Care Improvement Act (H.R. 2708)—*1 vote*.
- Address the issue of reducing accident incidence rates as a method to increase funding for CCC programs—*0 votes*.
- Develop guidelines for tribal leaders to establish policies that further CCC efforts—*0 votes*.
- Foster ongoing AI/AN research programs—*0 votes*.
- Recognize the value of resolution as a prelude to other actions—*0 votes*.

*Discussion Area III: Coordinate Tribal, State, and Federal Fiscal Resources*

- **Make the case (white paper) for changes to the health care system that will lead to better cancer outcomes for AI/AN populations—17 votes.**
- **Examine an option for federal agencies to hold states more accountable for how they relate to the tribes—8 votes.**
- Promote adequate funding for IHS and other federal agencies working with AI/AN communities and individuals—*5 votes*.
- Advocate for the federal government to fulfill its treaty responsibility for health care to Native Americans—*2 votes*.
- Address the role of states in allocating Medicaid—*0 votes*.

Mr. Kean explained that in June 2010, the National Partnership will sponsor a “mega institute” that will bring tribal, state, and federal organizations and agencies together. He explained that the National Partners have played a role in planning, organizing, and implementing other leadership institutes. He asked whether there were any other actions that the National Partners could take to the next institute that have not been discussed.

A participant stated the National Partners are in a position to advocate for the Reauthorization of the Indian Health Care Improvement Act. Mr. Kean noted that the National Partners could take action despite the fact that this concept did not receive many votes. The National Partners can work together to support the bill, and each partner can examine how its individual expertise can be best put to use.

In response to a question regarding the similarities between the previous CCC Policy and Practice Summit for states and this Summit, Mr. Kean answered that there were several similarities, which indicates that there may be many opportunities for leveraging.

Mr. Simmons asked how the National Partners would communicate to the tribes not present at the Summit. Mr. Kean responded that many national AI/AN stakeholders were present at this Summit, and will communicate with other national stakeholder organizations, which will expand the capacity to reach others. A participant added that by including tribal coalition members that represent several tribes, communication to the tribes will be increased.

A participant noted that the collaborating relationships of stakeholders present could be strengthened via a planned, identified, and implemented process. In addition, stakeholders can and should examine the policies and protocols of states that have been successful in working very closely with the tribes; these

states should be included in the mega institute to describe and define their success with tribal groups and educate other states how to reach out to their tribal organizations. Mr. Kean agreed that this would be powerful, and it would be beneficial to hear the imperfections and lessons learned from these states as well. Ms. Broken Rope added that intertribal groups also should be included. Mr. Kean asked the participants to identify all of the groups with which the National Partners should be communicating and provide the suggestions to C-Change staff. C-Change is committed to working with AI/AN groups, but sometimes the hierarchy and nation-to-nation status can be confusing, and there has been conflicting feedback as to which groups C-Change should contact for leveraging enhanced collaboration. The more feedback and ideas C-Change receives, the more successful it can be in addressing AI/AN needs.

### **Wrap Up and Adjourn**

Mr. Gurian thanked Mr. Kean for facilitating the meeting, those who helped with survey information and identifying best practices, and his C-Change colleagues for handling the logistics of the meeting. In terms of next steps, the National Partners will review the issues identified during the Summit and determine opportunities to address the ideas individually and as a group. He encouraged participants to attend the post-Summit reception and the Marketplace of Ideas, which was designed to provide examples of CCC program strategies to assist tribal CCC Coalitions in enhancing their cancer control program efforts.

Ms. Cravatt provided the closing prayer.



**Market Place of Ideas and Reception, June 30, 2009, JW Marriott Bluebell Ballroom**

# **Appendix**

