Reducing the Impact of Cancer

Listening to American Indians in Minnesota

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Background

The Minnesota (MN) state cancer plan is a written framework designed to help partners work together to reduce the impact of cancer. Cancer Plan MN is updated every 5 to 10 years and as part of updating the most recent version the MN Department of Health National Comprehensive Cancer Control Program (MDH NCCCP) along with the MN Cancer Alliance (MCA) hosted face-to-face listening sessions to gather input from MN community members. MCA is a broad partnership of organizations and leaders dedicated to reducing the burden of cancer across the continuum of prevention, detection, treatment, survivorship and end-of-life care. A commitment was made to meet with populations who are typically left out of the conversation and to be intentional about including their feedback in the updated cancer plan. In order to effectively reach the American Indian population in a culturally appropriate way, MDH contracted with the American Indian Cancer Foundation (AICAF) to hold listening sessions in American Indian communities. AICAF held four listening sessions with tribal and urban American Indian groups. A total of 44 people representing several different tribes took part in the sessions and provided input.

Minnesota American Indians suffer from the highest cancer incidence and mortality rates compared to all other racial and ethnic groups in the state. Despite advances in technology, American Indian cancer mortality rates have been on the rise while every other racial and ethnic group has experienced a decrease in mortality rates. Cancer is a sensitive topic in Indian Country. Many tribes cannot translate the word cancer because their Indigenous language does not contain a similar word. In the past and to this day, some consider it bad medicine or taboo to talk about cancer, making it difficult to address the disease.

When reviewing this report, it is important to keep in mind that a combination of factors contribute to the high cancer rates in Indian Country. There are damaging intergenerational impacts of trauma and racism that negatively affect the health and well-being of American Indian people. There is a high burden of known cancer risk factors, such as, commercial tobacco use, alcohol use, obesity and diabetes. Additionally, there are many barriers to prevention and care due to high rates of poverty, lack of access to healthy foods, underfunding for urban and tribal health systems, and limited availability of prevention programs, cancer screening and specialist care.

All of the responses in this report represent the unique challenges and needs that American Indians face regarding cancer prevention, detection, treatment and survivorship. Part 1 of the report summarizes responses gathered in listening sessions facilitated by AICAF with four tribal and urban American Indian groups. Part 2 summarizes the responses from one MDH listening session conducted with a tribal community separate from the sessions convened by AICAF. The data from the group convened by MDH is not included in the AICAF listening session analysis in Part 1 due to differences in how data was summarized.

Summary of Results

Part 1: Summary of responses from American Indian listening sessions

The MDH NCCCP program created a standard three-question form for collecting community input to write Cancer Plan Minnesota 2025. The three-question form was used in all listening sessions across the state. This section summarizes the tribal and urban American Indian communities' responses to the three MDH questions gathered at the four listening sessions convened by AICAF. Participants were instructed to answer each question in regards to their own community. Responses for each question are categorized by prevention, detection, treatment, survivorship and crosscutting issues (Tables 1-3). Table 4 presents a quantitative summary of the themes that emerged across all questions and categories.

Table 1. Summary of responses to Question 1

Question: "Thinking about reducing the burden of cancer in Minnesota, what are some things that are working well?"

Category	Response
Prevention	• Community efforts that address commercial tobacco use • High price of commercial tobacco products • Tribal smoking cessation programs • Secondhand smoke campaigns such as, "Take it Outside" • Traditional tobacco community gardens • Culturally appropriate resources and programs on tobacco • Tribal tobacco policies that ban smoking indoors • ClearWay Minnesota funded tobacco policy work • Nutrition and wellness education programs within the community • Youth prevention education • Cultural revitalization • Community garden programs to increase access to healthy foods • Tribal and work place healthy food and beverage policies • Increasing community awareness on cancer risk factors and its effect on the community
Detection	• Free screening within the community • MDH's breast and cervical cancer screening program (Sage) • Shakopee Mdewakanton mobile mammography • Incentives for screening • Patient cancer screening reminders from clinic

Treatment	• Transportation provided by Community Health Representatives • Home health program • Gas and hotel assistance • Tribal self-insurance plan that improves access to treatment
Survivorship	• Nothing reported
Cross-Cutting	• Inclusion of American Indian people on educational materials • Use of social media for messaging • Diabetes awareness education in community • Education on cancer disparities • Authentic listening • Community engagement, communities know what works for them • Storytelling to share personal cancer journey • Community coalition building • Tribal programs partnering with outside entities • CDC funding tribal communities • Annual breast cancer awareness conference in community

Table 2. Summary of responses to Question 2

Question: "Thinking about reducing the burden of cancer in Minnesota, what are some things that could or should work better?"

Category	Response
Prevention	• Improve access to educational materials • Educate the youth on cancer prevention • Increase community education on risk factors and causes of cancer • Use cultural teachings for prevention (food, traditional sports, tobacco and medicines) • Find elders to provide teachings • Use culturally specific tobacco cessation • Address secondhand smoke • Change policy to ban commercial tobacco and raise prices • Improve access to local fresh, affordable, healthy foods • Implement healthy food policies (schools, workplace, community) • Providers should promote active lifestyles • Encourage people in power to lead by example • Make test kits affordable (i.e. radon) • Fund research to find what is wrong with food

Detection	• Providers should promote screenings • Improve reminder system for screening • Provide more incentives for getting screened • Improve reservation screening services • Lower screening age • Use community role models to encourage screening • Increase frequency of screening options (i.e. mobile mammography bus) • Improve colorectal cancer screening education • Provide more self-screening education • Offer CRC screening kits at clinics serving American Indians • Improve cancer identification at tribal clinics, specifically Indian Health Service • Send screening notices, especially among a population with an increased risk, such as American Indians
Treatment	• Offer traditional healers and alternative medicine • Open local/reservation hospice • Identify designated cancer healthcare provider in community • Provide adequate funding for quality healthcare • Improve patient focus in healthcare systems • Research better treatment options • Improve communication and education between provider and patient • Allow caregivers time off from work to care for loved ones • Provide more financial support for cancer patients • Educate cancer patients and caregivers on advocating for themselves
Survivorship	• Educate about the side effects of chemo • Provide long- term support groups • Incorporate culturally based healing activities
Cross-Cutting	• Provide culturally relevant resources • Train providers so they can provide culturally appropriate care • Increase the number of Native providers serving Natives • Ensure providers are giving accurate information • Improve collaboration across Indian health systems • Use care coordinators • Increase access to trainings • Allocate funding based on the increased cancer rates among American Indians • Fund overall wellness programs as opposed to per body part • Research community risk factors within reservations (chemicals, pollutants, waste, etc.) • Engage the community via meetings and talking circles • Recognize unique needs of American Indian population

Table 3. Summary of responses to Question 3

Question: "What would it take to do better in these areas? (Think creatively and be as specific as possible. What resources could be tapped? What new or existing partners need to be involved? Or what kinds of policy changes would support the work?)"

Category	Response
Prevention	• Provide solutions to increase access to healthy, affordable food on reservations • Provide high quality (organic) healthy meals to kids at all schools • Provide food demonstrations to change people's attitudes about healthy food • Create a national tribal commitment to eliminating tobacco exposure and use among youth and infants • Provide culturally appropriate cessation outside of the clinic (i.e. community centers) • Engage youth in cancer education programming • Enact policy to encourage healthy foods at all Indigenous organizations • Provide support programs to encourage talking about cancer within families and communities • Build and sustain tribal economies, specifically in regards to food
Detection	• Increase the frequency of mobile mammography visits • Offer incentives for screenings • Educate young boys and girls on how to perform cancer detection self-examinations • Establish partnership with Uber to get people screened • Perform cancer risk screening at clinics and/or train home health nurse to perform
Treatment	• Integrate traditional healers into healthcare systems • Educate communities about holistic medicine • Prioritize hiring a medicine man as much as an MD or RN • Educate patients and providers on alternative/complimentary methods for treating cancer and healing • Provide transportation for patients to receive treatment • Hire oncologists on reservations rather than forcing cancer patients to travel two hours each way
Survivorship	• Share digital stories of personal cancer journey in clinic lobby • Organize women's and men's education and pampering days for survivors and a separate one for caregivers

Cross-Cutting	• The American Indian Cancer Foundation should make culturally appropriate resources for providers • Have survivors provide cancer education to others • Organize a cancer conference to educate healthcare professionals and community members on data, prevention, detection, treatment and survivorship to be held on a reservation • Create interdepartmental committees within American Indian communities to improve cancer education and coordinated care • Use home health to provide cancer education to patients • Send respected healthcare professionals into schools to educate the youth on cancer prevention • Create culturally tailored resources, strategies and messaging for men • Engage community leaders to educate on cancer prevention and screening • Engage communities in all aspects • Form partnerships between clinics and casinos • Form new partnerships on and off the reservation, partner with other tribes • Fund direct services on reservations • Allocate federal money for American Indian cancer care and prevention • Provide transportation to healthcare • Strengthen national policies to eliminate health disparities for American Indians/Alaska Natives • Encourage tribal leaders to consider health in all decision-making • Test for environmental toxins in American Indian communities (air, land and water)

Table 4. Quantitative summary of emerging themes for all three questions			
Theme	Q1. What is working well? (# of responses = 68)	Q2. What could work better? (# of responses = 130)	Q3. Strategies for improving (# of responses = 81)
Education (prevention, cancer awareness)	14	31	22
Screening (awareness, access, reminders)	11	20	5
Culture	3	11	4
Healthcare quality	0	10	1
Healthy food	6	9	7
Access to healthcare	4	8	6
Tobacco (cessation and prevention)	11	7	2
Research	0	7	1
Policy	5	6	3
Patient resources/support	0	6	2
Program resources (people, funding)	2	4	7
Holistic, traditional care	0	4	3
Community-driven programs/solutions	6	2	1
Healthcare workforce	0	2	0
Community leadership	0	2	1
Engagement	3	1	6
Partnership	3	0	10

Part 2: Summary of MDH-facilitated American Indian listening session

One tribal community participated in a listening session facilitated by MDH. This information is presented separate from the AICAF listening sessions results due to differences in how data was collected and analyzed. The results summary is included below in the format in which it was

reported by MDH. Despite differences in reporting methodology, this data is important to include as it adds to the overall picture of what the American Indian population needs and wants regarding cancer prevention, detection, treatment and survivorship.

Table 5. Results summary of Minnesota Department of Health American Indian community listening session categorized by question

1. **Thinking about reducing the burden of cancer in Minnesota, what are some of the things that are working well?**
    - Screening services (CRC and Breast)
    - Cancer awareness
    - Increasing access to fruits and vegetables
2. **Still thinking about reducing the burden of cancer in Minnesota, what are some of the things that could or should work better?**
    - Transportation to and from care
    - Not enough support for case managers and navigators
    - Not enough emphasis on prevention starting with our youths
    - Not enough education to employers about cancer survivors
3. **What would it take to do better in these areas? (Think creatively and be as specific as possible. What resources could be tapped? What new or existing partners need to be involved? What kinds of policy changes could support the work? Etc.)**
    - More coverage under emergency medical assistance, so that the poor aren't limited and have a comparable range of medical options
    - Transportation needs to be a recognized covered cost
    - Need better data and policies that require the data to be considered in policy and decision making, particularly where rural MN is concerned
    - Federal funding requirements are not sensitive to minority cultures and beliefs -thus increasing inequity
    - MDH needs to create a "goal" calendar (one year out) to help providers focus on the same thing at the same time
    - We need more culturally competent navigators

Conclusion

It is important to note the themes that emerged across the questions in the listening sessions (summarized in Table 4). Often, themes could point to both community strengths as well as areas that could use more focus. For example, participants mentioned several prevention programs, including those focused on tobacco and healthy foods in their communities, as assets, but also saw areas for improvement, such as the need for improved access to healthy foods in poor and rural communities, and incorporating culture and traditional teachings into programs. Similarly, participants listed cancer screening programs and reminders from clinics as positives. However, they identified many ways to improve screening access and care, including several comments to improve the quality of care around early detection provided for American Indians. Participants saw some progress with community engagement and community-driven solutions, but also identified that community engagement, community leadership, and partnerships between tribes and outside organizations, are needed in the development of key strategies for improvement.

Healthcare issues, including improved healthcare quality and access, improved patient resources, improved support for those undergoing treatment, and the integration of traditional healing emerged as important areas in need of change in American Indian communities. As a theme, healthcare was mentioned less as an asset and more as an area for improvement and opportunity compared to other topics. Bright spots of the healthcare theme that were mentioned by participants included home health nursing programs, programs that helped support cancer patients with assistance in the form of gas money for travel to doctor appointments, and screening programs like the mobile mammography unit that travels to some communities annually.

Education was the most prevalent theme across each question for all four listening sessions held by AICAF. Participants indicated that education about cancer risk and prevention is improving, but identified a need for more programs that can bring cancer education and awareness to communities. A few of the education topics requested were cancer risk factors, screening for different cancer types, Native traditions, and natural medicines.

The summary of results from the listening session held by MDH aligned with the results from listening sessions held by AICAF in that cancer awareness, prevention education for the community, and cancer screening services were viewed as areas of strength and as areas for improvement. Results also aligned on healthcare needs including funding specifically for case managers and navigators, improved cultural competence of staff, improved access to care, and increased funding overall. The MDH listening session differed in listing food access as a strength, and it included the following additional feedback not mentioned in any of the AICAF sessions: collect more/better data to support decision making, include transportation to and from care as a covered cost, and provide culturally sensitive funding requirements.

Listening sessions were held with the intent of gathering community input across the broad spectrum of cancer for Cancer Plan Minnesota 2025. The American Indian communities provided candid and rich feedback that has been submitted to MDH and MCA to help guide workgroups writing the new state cancer plan. The results in this report are more than just data to use for the next state cancer plan, they can be used to guide the work of tribes, county and state health departments, Native and non-Native organizations, and clinics serving the American Indian population. The work is not limited to cancer specific programs. The community input provides insight on actionable items from healthcare to education to food access issues and others that will affect health outcomes. The wisdom for finding solutions to health inequities is held within each community. We have listened to what they have to say, and now it is time to take action.