



Fond du Lac Band
of Lake Superior Chippewa
Wiidookaage Cancer Plan
2025

Fond du Lac Reservation Human Services Division

Mission Statement

The mission of the Fond du Lac Human Services Division is to elevate the health and social well-being of Indian people living in the service area through the provision of services, research, education and employment opportunities.

The photo depicted on the cover is a gift from Jennifer Strickler, Graphic Designer. The photo is of a sunrise over Lake Superior taken in Duluth. The Traditional Flag represents the Fond du Lac Wiidookaage Cancer Program.

Wiidookaage

Wiidookaage is an Ojibwe word meaning, “they help each other.” The concept of *Wiidookaage* guides the Fond du Lac (FDL) Reservation’s Comprehensive Cancer Control Plan revision process and implementation. Through a collaboration of Fond du Lac community members, tribal leaders, healthcare and social services staff, a wealth of information was gathered to provide a foundation for the revision of the plan. Using this information, The FDL Cancer Team developed goals, objectives, and strategies to address many of the issues surrounding cancer in the community. Just as *Wiidookaage* brought the original cancer plan into being, *Wiidookaage* will ensure the cancer plan’s continued success.

The Traditional Staff pictured on the cover of Fond du Lac’s *Wiidookaage* Comprehensive Cancer Plan depicts how the plan was developed. The Traditional Staff is a birch tree sapling. The tip of the Staff is covered with soft, tanned deerskin. These gifts from Mother Earth provide the base for the Traditional Staff. The red, black, yellow and white ribbons that secure the deerskin to the tip of the birch sapling represent the peoples of the world. The many colored ribbon streamers represent many individuals and groups within the Fond du Lac community, and beyond, who contributed to the plan. Tobacco is offered as each new ribbon is tied onto the Staff. Building the Traditional Staff continues throughout the life of the plan. The *Wiidookaage* Traditional Staff presides over the meetings of the FDL *Wiidookaage* Cancer Team and is present at events focused on cancer throughout the Fond du Lac community.

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EXECUTIVE SUMMARY

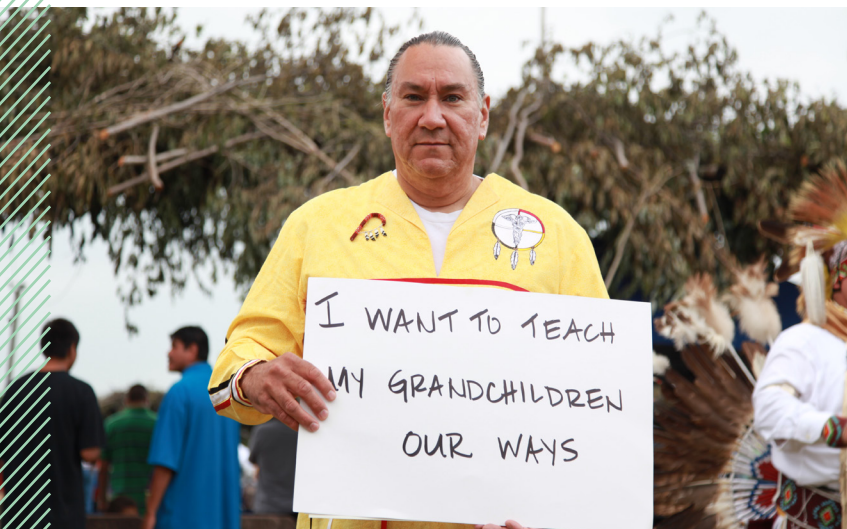
Cancer is the leading cause of death for American Indians in Minnesota, with the highest cancer incidence and mortality rates of any other group in the state. For American Indians, cancer is often diagnosed in advanced stages and many lives are lost because there is limited access to and numerous barriers that exist for prevention and early detection measures.

The Fond du Lac Wiidookaage Comprehensive Cancer Plan defines cancer control activities for the Fond du Lac Reservation through 2025. It was created through a collaboration of Fond du Lac stakeholders including the Reservation Business Committee (Tribal Council), Fond du Lac Human Services Division administration, public health nursing, medical, pharmacy, dental staff and representatives from the Fond du Lac community including cancer survivors and caregivers as well as several other local, regional, national and Indian Country cancer partners. The plan addresses eight components of comprehensive cancer control:

- » **Data and Surveillance:** Utilize cancer data to identify where cancer prevention and control efforts should be targeted for FDL.
- » **Prevention:** Increase community awareness of the need to reduce tobacco use and

exposure to second hand smoke, follow a healthy lifestyle, have regular cancer screenings; and increase provider awareness of the most current information in cancer treatments.

- » **Early Detection:** Increase screening rates among FDL residents through culturally appropriate outreach efforts and elimination of barriers.
- » **Treatment:** Provide culturally appropriate, holistic, coordinated access to treatment; and provide supportive services to Fond du Lac community members with cancer.
- » **Palliative and End-of-Life Care:** Provide palliative care for effective pain management and relief from chronic symptoms. End-of-Life Care to provide physical, mental, and emotional comfort, as well as social support, to people who are living with and dying of the illness.
- » **Cancer Survivorship:** Draw on the strength and wisdom of cancer survivors to help others, and continue to provide services to survivors throughout their lives.
- » **Cancer Caregivers:** Provide readily available information, support and respite to caregivers of people with cancer.
- » **Evaluation:** Regularly evaluate the effectiveness of the Wiidookaage Comprehensive Cancer Plan in order to make modifications needed to advance the plan.



INTRODUCTION

The Fond du Lac Reservation is a sovereign American Indian nation located in northeastern Minnesota. The reservation lies approximately 25 miles west of Duluth, Minnesota, near the city of Cloquet. The Fond du Lac Reservation service population includes over 4,250 individuals enrolled in federally recognized tribes with the majority of the members from the Fond du Lac Band of Lake Superior Chippewa. These individuals primarily reside within or nearby the reservation boundaries. The LaPointe Treaty of September 24, 1854 was the last principle treaty impacting the establishment of the Fond du Lac Indian Reservation. After decades of deterioration within the tribal culture, economic, health, and social status of the tribe, the Reorganization Act in 1934 and the Indian Self-Determination Act of 1976 served to gradually revitalize the reservation community. The impacts of these federal policies are still seen and felt today amongst people living on the Fond du Lac Reservation.

The Reservation Business Committee (RBC) governs the Fond du Lac Reservation. Elected by the enrolled members of the Fond du Lac Band, the RBC governs all aspects of tribal life including, but not limited to: economic ventures; educational opportunities; environmental matters; hunting, fishing and gathering rights; law enforcement; and healthcare. Through the initiative and support of the RBC, the Fond du Lac Human Services Division (FDL HSD) was started in 1974 when the tribe first contracted with the Indian Health Service (IHS) for the Community Health Representatives program. From this small beginning the FDL HSD has grown into a tribal health and social services delivery system including medical, dental, pharmacy, optometry, community health services, assisted living and home care nursing, behavioral health, chemical dependency programming and a wide variety of social services. In 2013, the number of individuals who had utilized the

FDL healthcare services at least once within the past three years (the Indian Health Service User Population) was 7,101.

Comprehensive Cancer Control

Comprehensive Cancer Control is a national program promoting an integrated and coordinated approach to reducing the impact of cancer on the lives of people and communities. It includes monitoring, policy, research, education, programs, services and evaluation. Primary interventions focus on policy, systems and environmental changes that can impact cancer control within a population. A secondary area is community-clinical linkages, which addresses the relationship between a community and a healthcare organization to improve cancer outcomes. Robust evaluation and evidence-based practices are the foundation of quality cancer control.

The Centers for Disease Control (CDC) and Prevention grants funds to states, territories, Pacific Island jurisdictions and American Indian tribes to develop, implement and evaluate plans to address their identified cancer issues. Each plan is unique, yet many of the goals are the same. Almost all plans aim to: reduce the incidence of cancer disease within a population; prevent cancer from developing; detect cancer in its earliest stages when it is most treatable; and assure access to quality cancer treatment and supportive services when cancer is diagnosed. Additional goals are: to seek to establish sound cancer databases; assist people with cancer to achieve the highest possible quality of life; encourage and utilize the expertise of cancer survivors to give hope to people who are newly diagnosed with cancer; educate communities about cancer disease and the resources and services available to address cancer issues; and to support research to find the ultimate cures for all types of cancer. Today, services for cancer survivors have become increasingly important as more people are surviving cancer long term.

Healthcare service provision for American Indians in the United States is a complex process governed by Treaties and Federal Law. To effectively address cancer in a comprehensive manner there must be conscious efforts to develop strong partnerships between the tribal government and community; the tribal healthcare delivery system; local, regional and state healthcare systems; Indian Health Service, Indian Country, Federal healthcare programs and with other organizations addressing cancer issues throughout the United States. Only then can we move forward in the work to reduce and eliminate cancer burden in American Indian communities.

How The Wiidookaage Cancer Plan Was Created

From 1970 to 2000, the Fond du Lac Reservation (FDL) expanded its healthcare and social services capacity to address acute healthcare needs as well as chronic diseases such as diabetes, cardio-vascular disease, arthritis and asthma. During this same period, several Fond du Lac community members were diagnosed with cancer. Improved data collection techniques have made it clear that the American Indian population in northern Minnesota experiences higher rates of cancer disease and death than other racial/ethnic groups in the United States. Supportive health and social services for these individuals and their families were fragmented, often with no interventions provided by the Fond du Lac Human Services Division (FDL HSD) until the cancer disease had advanced to a terminal stage. Cancer research and treatment have progressed substantially during the last several decades and it has become increasingly apparent that cancer disease is preventable and treatable, especially when detected early. Many types of cancer are preventable through lifestyle choices. Human papillomavirus (HPV) vaccinations can prevent

several types of cancer. Colorectal and cervical cancer screenings improve outcomes through early detection or removing precancerous conditions before the disease can develop. In the case of breast cancer, early detection improves outcomes by finding the disease at its earliest, most treatable stage. Improved data collection techniques have made it clear that the American Indian population in northern Minnesota experiences higher rates of cancer disease and death than other racial/ethnic groups in the United States. The FDL RBC (Tribal Council) is determined to rectify this disparity.

The FDL HSD's healthcare staff became concerned that too many FDL community members were stricken with, and dying from, cancer. In 2002, determined to change this outcome, the FDL RBC applied for a planning grant from the CDC to develop a comprehensive cancer plan for the Band. Funding was received in June 2003 and work began to develop a Comprehensive Cancer Prevention and Control Plan for the FDL community. During the period when the plan was drafted, it was discovered that an average of 1.5 new cancer cases were diagnosed in the community each month. Historically, the word "cancer" was never spoken aloud as it was believed the spirit of cancer would enter one's being. With increased culturally appropriate cancer education provided by the Cancer Outreach Worker and Cancer Educator, the word "cancer" is now freely spoken within the community. Several departments within the FDL HSD have integrated cancer information into their services. Communication has greatly improved between FDL HSD healthcare providers and external healthcare organizations. The FDL medical clinic NextGen Electronic Medical Record (EMR) has had several updates to improve cancer data. Program evaluation has evolved to inform the Cancer Program for planning interventions and evidence-based practices.

CANCER BURDEN OF AMERICAN INDIANS IN MINNESOTA

Previous analyses of cancer incidence and mortality rates among American Indian (AI) populations have determined significant variation in death rates by geographic region (Espey et al., 2007), (Espey, Paisano & Cobb, 2005). Unfortunately, Indian Health Service (IHS) Contract Health Service Delivery Area (CHSDA) counties in the Northern Plains region suffer from some of the highest cancer incidence, late stage diagnoses, and mortality rates when compared to Non-Hispanic Whites (NHW) in the same region (White et al., 2014). In Minnesota, cancer is the leading cause of death for AIs. Cancer incidence and mortality rates for AIs in Minnesota are two times higher than AIs across the United States (Minnesota Cancer Facts & Figures, 2011). AIs have the highest cervical cancer incidence in the state, as well as the highest incidence and mortality rates for colorectal cancer. The five most commonly diagnosed cancers in American Indian men in Minnesota are prostate, lung and bronchial, colorectal, kidney and leukemia while in American Indian women breast, lung and bronchial, colorectal, uterine and kidney cancers are the most commonly diagnosed. The following statistics, from *Minnesota Cancer Facts and Figures 2011*, demonstrate the disproportionate disparity of cancer related morbidity and mortality for the AI population in Minnesota.

- » American Indians when compared to Non-Hispanic Whites in Minnesota were 33 percent more likely to develop cancer and 78 percent more likely to die of cancer.
- » The cancer incidence rate among AI men living in CHSDA counties in Minnesota was 27 percent higher than for NHW men and their cancer mortality rate was 50 percent higher.
- » The cancer incidence rate among AI women living in CHSDA counties in Minnesota was 27 percent higher than that of NHW women and their cancer mortality rate was 86 percent higher.
- » Cancer deaths for American Indian men and women are primarily due to lung and colorectal cancers.
- » The overall cancer mortality and incidence rate for Minnesota's American Indians is more than 2 times higher than the United States average rates as a whole for the geographic areas participating in the SEER program.
- » Lung cancer incidence rates were 2.5 times higher and mortality rates were approximately 3 times higher among American Indians when compared to Non-Hispanic Whites.
- » The colorectal cancer incidence rate is 78 percent higher in American Indians in comparison to NHWs and the colorectal cancer mortality rate is 93 percent higher for AIs.
- » The incidence rate of cervical cancer is approximately 4 times higher in AI women when compared to NHW women.
- » The kidney cancer incidence rate was approximately 3 times higher in American Indians in comparison to NHWs and the cancer mortality rate was 3.5 times higher for AIs.
- » The incidence of cancer of the larynx is almost 4 times higher among AIs compared to NHWs in Minnesota.
- » The oral cancer incidence rate among AIs is almost 2 times higher than that of NHWs.
- » The incidence rate of stomach cancer is 2.5 times higher in AIs and the mortality rate is 4 times higher compared to NHWs.

The FDL Reservation is part of the Bemidji Indian Health Service Area. This area has the highest cancer mortality rate of all the Indian Health Service Areas per the United States Indian Health Services report for the calendar years of 1994-1996 (Indian Health Service, 1999). The Community Health Profile: Minnesota, Wisconsin, & Michigan Tribal Communities 2010, produced by the Great Lakes Inter-Tribal Epidemiology Center, reports that for 2004-2008 the all-cancer age-adjusted mortality for Minnesota American Indians is 220.2 per 100,000 compared to the Minnesota All Races rate of 171.6 per 100,000. The Healthy People 2020 goal for all cancer age-adjusted mortality rates is 160.6 per 100,000. It is important to note the data for this report comes from death certificates and may be impacted by racial misclassification. Racial misclassification is a serious problem in collecting accurate cancer data for American Indian populations and may have artificially

reduced the mortality rate. An investigation by IHS estimated that the AI/AN population in the Bemidji Area was undercounted by 16.1 percent, making it the third highest area for misclassification (Jim, et al., 2014). Due to a variety of shortcomings, tribal specific cancer data is difficult to extrapolate from the larger cancer data sources.

Recent data (July 2015), yet to be formally published by the Minnesota Department of Health Cancer Surveillance System, indicates that the burden of cancer borne by Minnesota American Indians continues to be disproportionately elevated. Death from colorectal cancer is 2.3 times higher (Figure 1.) and lung cancer mortality is 2.6 times higher (Figure 2.). With the exception of breast cancer (Figure 3.), from 2008 to 2012 American Indians have the highest rates of cancer incidence and mortality compared to the all other racial/ethnic groups in Minnesota (Adams, 2015). See Figures 4-9 and Table 1.

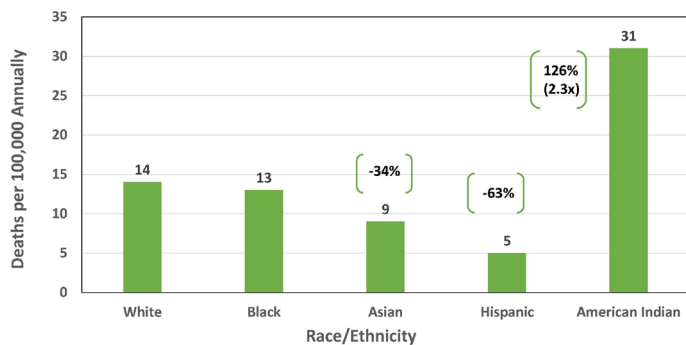


Figure 1. Colorectal Cancer Mortality in MN 2008-2012

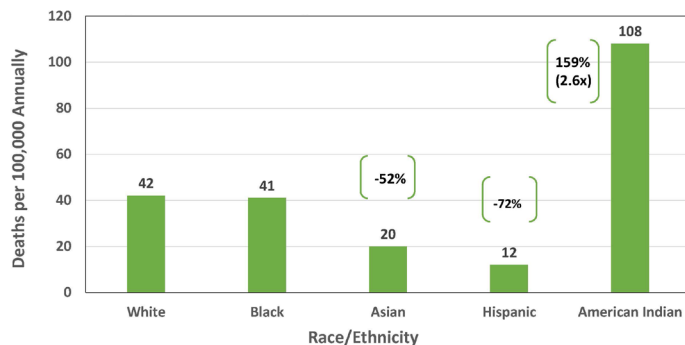


Figure 2. Lung Cancer Mortality in MN 2008-2012

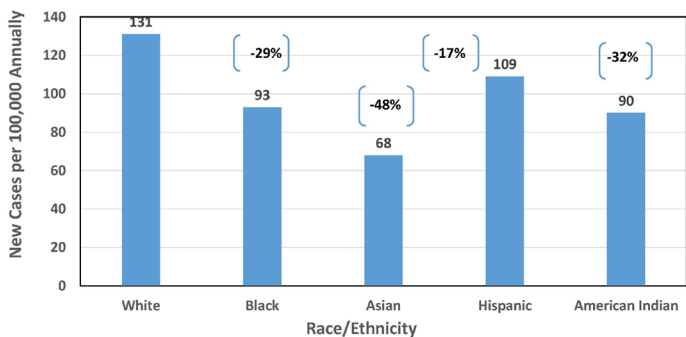


Figure 3. Breast Cancer Incidence in MN 2008-2012

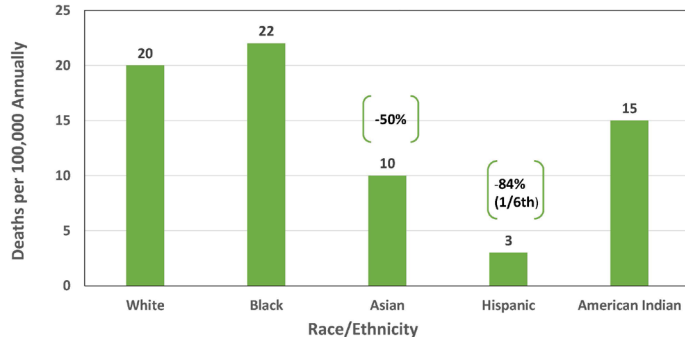


Figure 4. Breast Cancer Mortality in MN 2008-2012

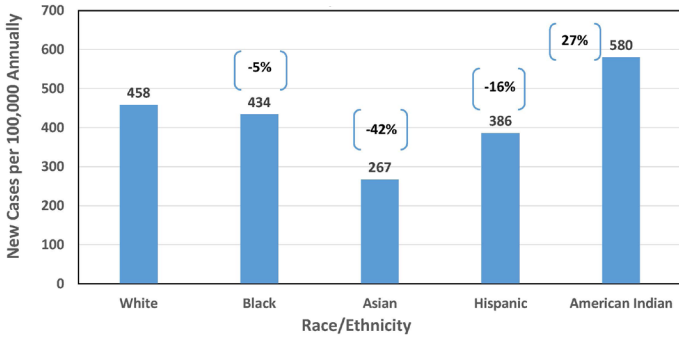


Figure 5. Overall Cancer Incidence in MN 2008-2012

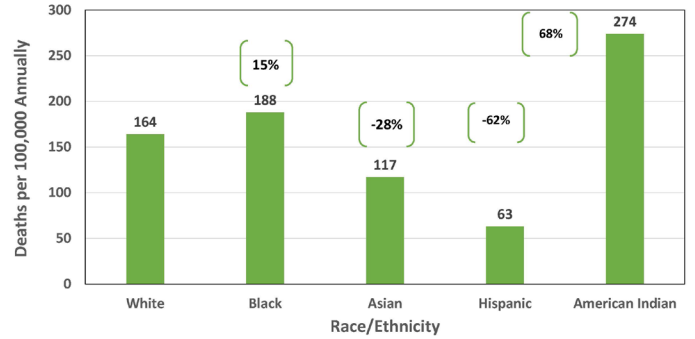


Figure 6. Overall Cancer Mortality in MN 2008-2012

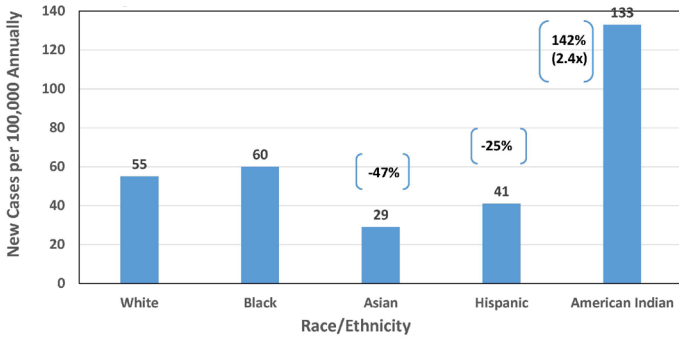


Figure 7. Lung Cancer Incidence in MN 2008-2012

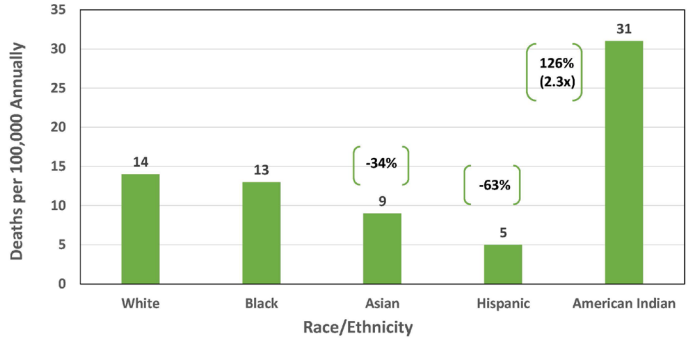


Figure 8. Colorectal Cancer Mortality in MN 2008-2012

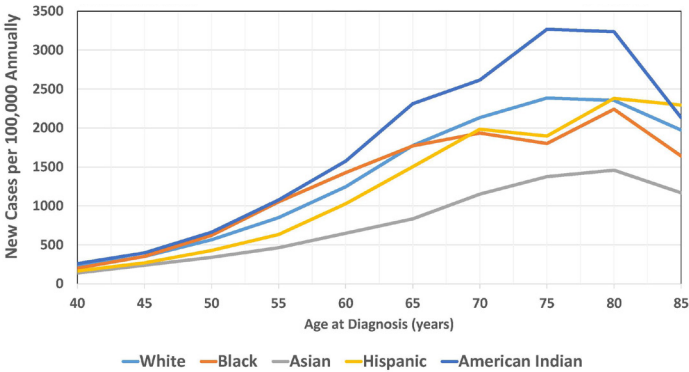


Figure 9. Overall Cancer Incidence by Age at Diagnosis, MN 2003-2012

	Incidence	Mortality
Overall Cancer	1 st American Indian	American Indian
	2 nd White	Black
Colorectal Cancer	1 st American Indian	American Indian
	2 nd White/Black	White/Black
Lung Cancer	1 st American Indian	American Indian
	2 nd White/Black	White/Black
Breast Cancer	1 st White	Black/White
	2 nd Hispanic	American Indian

Table 1. Summary: Cancer Incidence and Mortality according to Race/Ethnicity in MN 2008-2012

These graphs were included in the presentation “Laying the Foundation for Cancer Control with Data” by Kenneth Adams of the Minnesota Cancer Surveillance System, Minnesota Department of Health. The presentation took place at the Cancer Health Equity Network Meeting on July 17, 2015 in St. Paul, MN.

Disparity Issues in Native Communities

The Indian Health Service (IHS) is a federal agency within the U.S. Department of Health and Human Services charged with the responsibility of improving the physical, mental, social, and spiritual health of American Indians and Alaska Natives (AI/ANs). IHS provides comprehensive healthcare services to approximately 1.9 million AI/ANs who are either members or descendants of the 565 federally recognized tribes in 35 states. IHS provides healthcare services to AI/ANs through tribally contracted and operated health programs as well as services attained from private providers (IHS, 2012). FDL is one of the self-compacted tribal healthcare programs that utilize federal funding through IHS along with tribal and other resources to provide healthcare services for tribal members.

The American Indian population is a disparate population with:

- » 14.6 percent unemployment rate, which is second only to the African American population at 15.9 percent and twice that of the Non-Hispanic White population at 7.2 percent (U.S. Department of Labor, 2011).
- » greater than 10 percent more than the national average (14.3) living in poverty. AI/ANs living in Arizona, Maine, Minnesota, South Dakota, North Dakota, Montana, Utah, Nebraska and New Mexico were living with a poverty rate as high as 30 percent or greater (U.S. Census Bureau, 2011).

HEALTHY PEOPLE 2020 PRESIDENTIAL GOAL

To achieve health equity, eliminate disparities, and improve the health of all groups.

HEALTHY PEOPLE 2020 CANCER GOAL

To reduce the number of new cases as well as morbidity, mortality and disability caused by cancer by promoting the use of evidence-based screening tests (breast, cervical, colorectal) and proper cancer management.

- » lower education completion among all public high school students in 2011-2012; AI/AN and African American populations had the lowest percentage rate of completion (68%), compared to Asians/Pacific Islanders (93%), followed by Whites (85%) and Hispanics (76%). The National Center for Education Statistics also shows that for full-time bachelor's degree-seeking students in 2006, only 21.9 percent of AI/ANs completed their degrees, compared to 42.6 percent of White students (National Center for Education Statistics, 2014).
- » 29.2 percent of AI/ANs having no health insurance coverage at all in 2011 (U.S. Department of Health and Human Services Office of Minority Health, 2012).

When a tribal health program is unable to provide direct services for an eligible AI/AN person, the IHS Contract Health Service appropriation may cover the cost of referring patients to hospitals and specialists (Purchased/Referred Care (PRC)). However, most AI/AN health programs deplete their funds prior to the end of the fiscal year (IHS fiscal year runs July 1 to June 30). When funds are not available, patients are responsible for the cost of their healthcare services and are often unable to pay for the services themselves (U.S. Senate Committee on Indian Affairs, 2008). These realities impact the provision of timely cancer screening for AI/ANs. Mammography services for breast cancer screening are not available at FDL's tribal healthcare clinics and women needing mammograms must be referred out to other healthcare agencies. This is also true for colonoscopy services that are important for high quality colorectal cancer screening. American Indians in Minnesota have the highest rates of morbidity and mortality due to colorectal cancer compared to all racial/ethnics groups in Minnesota, making screening a continued utmost priority (Minnesota Cancer Facts and Figures, 2011).

WIIDOOKAAGE COMPREHENSIVE CANCER CONTROL PLAN

VISION

The people of the Fond du Lac Community will be cancer free.

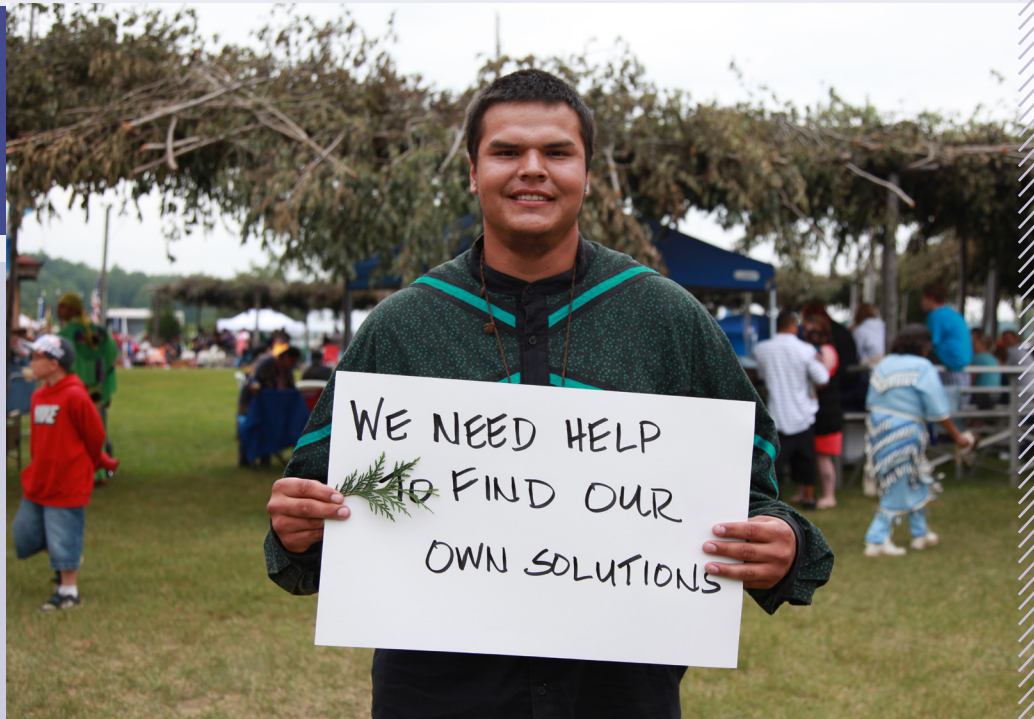
TRIBAL SOVEREIGNTY

TRADITIONAL HEALTH

WELL-BEING

COMMUNITY ENGAGEMENT

CULTURAL COMPETENCY



The Fond du Lac *Wiidookaage* Cancer Team will implement the plan for the Fond du Lac community by:

- » maintaining cancer databases and a Fond du Lac cancer Patient List
- » promoting the practice of lifestyles that will prevent cancer
- » promoting access to regular cancer screening tests to facilitate the early diagnosis of cancer, when it is most treatable
- » providing support to people with a cancer diagnosis and their families immediately upon diagnosis
- » ensuring access to the best possible cancer treatment options
- » maximizing the quality of life for the person with cancer
- » providing comprehensive, compassionate end-of-life care

- » mobilizing cancer survivors to share their collective wisdom
- » providing education about prevention, early detection, treatment, survivorship, palliative support and care
- » creating support systems for caregivers
- » establishing and maintaining the effective evaluation process necessary to track progress and advance the comprehensive cancer program

Tribal sovereignty, traditional health and well-being, community engagement and cultural competency guide the implementation of the plan.

SECTION I:

DATA AND SURVEILLANCE

Access to data is a critical component for any planning process. Data provides the statistical support in establishing the need for programming and services and are necessary to measure progress when a plan is implemented. Ensuring that data collection methods are both culturally appropriate and rigorous is essential for (1) better understanding health disparities and disparities in access to health and human services, and (2) the design and evaluation of evidence-based interventions to eliminate such disparities.

Accurate data for the American Indian/Alaska Native (AI/AN) population has been historically difficult to obtain. Too often, large, nationwide surveys have missing, inaccurate, or misleading data for American Indians and “no data” has been interpreted to mean “no problem” (Burhansstipanov and Satter, 2000). Insufficient and inaccurate health data not only is unreliable for tracking diseases, but also fails to identify the health needs and strengths of AI/AN individuals, families, and communities (Schacht, White, Daugherty, LaPlante, & Menz, 2003). Additionally, Figures 10 and 11 demonstrate that there are dramatic differences in cancer incidence and mortality for American Indians in Minnesota compared to the United States overall, which supports the need for disaggregated, tribal specific data. Such data is needed to enable state and tribal programs to develop and improve local services that will lead to an increased quality of life among AI/AN communities.

Goal 1: Cancer data is utilized to identify where cancer prevention and control efforts should be targeted for the Fond du Lac Reservation.

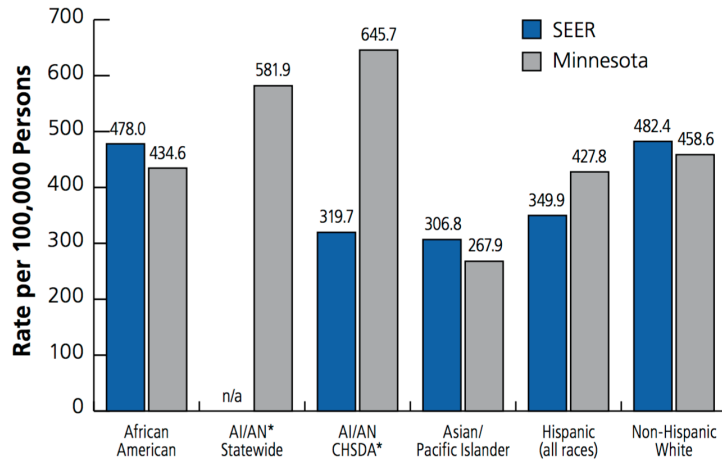
Objective 1.1:

Increase and continuously monitor cancer surveillance data for the American Indian service population of the Fond du Lac Reservation.

1. Accurately document and update patient records within NextGen Electronic Medical Record System to reflect the following cancer data for American Indian persons within the Fond du Lac service population:
 - » Family history of cancer
 - » Personal use of non-ceremonial tobacco
 - » Cancer diagnoses
 - » Source and type of cancer treatment being received
2. Enhance the NextGen Electronic Medical Records System to allow for cueing, entering and extrapolating American Indian service population cancer data.
3. Monitor cancer screening rates and cancer-related vaccine rates for American Indian persons within the Fond du Lac service population.
4. Establish a computerized Fond du Lac Cancer Patient List recording demographic information including family history of cancer; type of cancer; date of diagnosis; stage at diagnosis; treatment and outcome information.
5. Ensure the computerized Fond du Lac Cancer Patient List has the capacity to provide detailed reports as needed for cancer statistics within the population while respecting the privacy and confidentiality of individuals listed in the Patient List.

Objective 1.2:

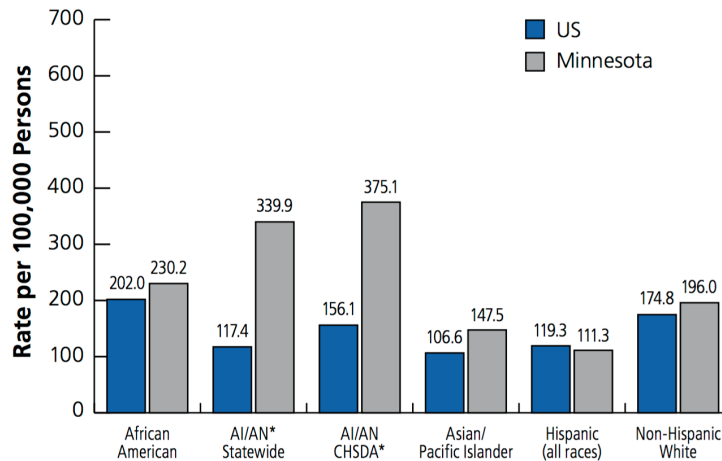
Share results of cancer surveillance data annually with stakeholders to build interest in investing resources to address the cancer burden within the Fond du Lac community.



* AI/AN=American Indian/Alaska Native; CHSDA=Contract Health Service Delivery Area; n/a=not available, not published in SEER CSR. Rates are age-adjusted to the 2000 US population. SEER incidence data are from the SEER 18 Areas; rates for Hispanics and non-Hispanic whites exclude cases from the Alaska Native Registry.

Source: MCSS (Feb 2015) and *SEER Cancer Statistics Review, 1975-2012*.

Figure 10. Cancer Incidence by Race/Ethnicity, Minnesota and SEER, 2008-2012



* AI/AN=American Indian/Alaska Native; CHSDA=Contract Health Service Delivery Area. Rates are age-adjusted to the 2000 US population. Mortality data are for the entire US; rates for Hispanics and non-Hispanic whites exclude deaths from New Hampshire and Oklahoma.

Source: Minnesota Center for Health Statistics and *SEER Cancer Statistics Review, 1975-2012*.

Figure 11. Cancer Mortality by Race/Ethnicity, Minnesota and the US, 2008-2012

The Contract Health Service Delivery Area (CHSDA) is determined as the geographic area within which health care services are available by the Indian Health Service to American Indian community members belonging to a federally recognized tribe (IHS, 2015). According to the 2015 report from the American Cancer Society, cancer rates for American Indians in Minnesota are twice that of the national average.

Strategies:

1. Provide annual reports of cancer surveillance data to administrators, department coordinators and the Fond du Lac Human Service Division (FDL HSD) Continuous Quality Improvement Committee.
2. Publish cancer surveillance findings in the tribal newspaper and tribal web site on an annual basis.
3. Present cancer surveillance findings to the Reservation Business Committee (Tribal Council) and FDL HSD Advisory Board on an annual basis.
4. Distribute findings to the Fond du Lac *Wiidookaage* Cancer Team.

SECTION II: PREVENTION

According to the World Health Organization, at least one-third of all cancer cases are preventable (2015). Behavior patterns and lifestyle choices clearly impact cancer risk, yet many people do not recognize the power they have to alter their risk of disease. To successfully reduce the burden of cancer in our society, we must increase the awareness of prevention strategies in our patients and our communities (Colditz & Stein, 2004). Prevention is the most powerful factor in decreasing cancer morbidity

and mortality (Robert Hiatt, 2006) and is the most cost-effective long-term strategy for the overall control of cancer (WHO, 2015).

The American Cancer Society estimated that there would be approximately 1,658,370 new cancer cases diagnosed and 589,430 cancer deaths in 2015 (American Cancer Society Cancer Facts & Figures 2015). Tobacco use is responsible for nearly 1 in 5 deaths. More so, according to Centers for Disease Control and Prevention, more than 480,000 deaths annually in the United States are due to cigarette smoking and exposure to secondhand smoke (Office on Smoking and Health, 2014). Scientific evidence suggests that an additional one third of cancer deaths will be related to nutrition, physical inactivity and overweight and obesity (American Cancer Society Cancer Action Network, 2012). Community education on healthy lifestyles and behaviors is an essential component of cancer prevention for communities. It is especially relevant being that 78 percent of all cancers are diagnosed in persons age 55 and older (American Cancer Society Cancer Facts & Figures 2015). Preventive education must include intensive outreach to community elders.

Over the course of the past three decades, the Fond du Lac Reservation has implemented programs through its FDL Human Services Division to address diabetes and cardiovascular disease. One of the major focuses of these programs is prevention of these diseases through healthy lifestyle choices. Incorporating cancer prevention into these established programs is part of the FDL *Wiidookaage* Cancer Plan. Non-ceremonial tobacco use is the single most important challenge for Fond du Lac in decreasing cancer morbidity and mortality. With smoking rates over 54 percent within the Fond du Lac population; tobacco cessation, education, and policy to deter use of tobacco in non-ceremonial ways is critical to changing the pattern of cancer within the Fond du Lac population (Minnesota American Indian Adult Tobacco Survey, 2010).



Roberta Marie's Story

Boozhoo, my name is Roberta Marie and I am a health educator, my focus is on Secondhand Smoke Policy Change and Education. Being it is winter I am going to use a storytelling format.

Once when I was a teenager I started working as a waitress and also started smoking cigarettes like the other waitresses did. I joined the Army right after high school and could purchase a pack of cigarettes on the PX for only 35 cents. Like many others I said to myself, I will quit when I am 21, when I am 25, when I am 30 when I am 35. I finally quit when I was 41 years old, after a total of seven attempts. Unfortunately my one and only child, my son Joshua became a smoker. He has quit before but is has relapsed and is still smoking today. That is my biggest heartache, that is what he learned by example from his father, his step-father and me.

When I moved back to the reservation I worked with the elders, worked at the school and then became a smoking cessation educator. Helping others quit smoking was truly a passion of mine, having been a pack and a half day smoker I know how hard it is, and what they are going through. I was enjoying my work as a cessation educator when I was asked by a tribal official to become the manager of the FDL Cloquet Community Center. That experience helped me build relationships and really get to know the members of my community. After four years I saw that there was an opening at the MNAW in the same department I had worked as a smoking cessation educator. I applied for the opening in Community Health Services as a Health Educator in Secondhand Smoke Policy Change and Education.

I started in this new position on October 27th of 2014, knowing I had a big task in front of me. I ordered a jacket with the smoke free zone message and worn that most days. I ordered cell phone stands that can also hold business cards, you received them in your bag. That kept the "breathe smoke free" message on their desk. I started educating the community and talking to the tribal council, and anytime I received a complaint I went right to the RBC Representative of the area where the complaint was filed. The tribal attorney was great and in December we drafted a letter to propose a date of May 1, 2015 for the reservation to go smoke free. While I was talking to him, I found that there was a policy already in place in the Fond du Lac Employee Policy Book, it stated that the rights of the non-smoker came before the person smoking. That if you were in a smoking area at work, you could ask the person to stop smoking. I made copies of this and handed it out to RBC members, to refresh their memory or to educate them that this was a policy. I also handed it out to anyone who was suffering from secondhand smoke in their work

area. It was also put on the information tables that the health educators: Emily Smith, Katie Gokee, Rozanne Hink, Bonnie Lafromboise (Public Health Nurse), and myself had placed at all three FDL Centers. This information helped educate persons of their rights, being a non-smoker.

There was an elder, who worked at the Sawyer Center and was a former RBC member who had suffered from major health problems in the past and present. I had talked to him at length during my first visit to the Sawyer Center in November 2014. He was employed at the Sawyer Center and was suffering daily, having to breathe in smoke. I went to the Sawyer Center Representative and informed him about the band member's employee troubles. When I found out about the non-smoker rights policy, he immediately faxed it to the center manager. From that, the dining area went smoke free and did the sewing room. But, according to this elder the rule was not always followed. This was also reported to the Sawyer district representative. Emily Smith and Rozanne Hink kept me up date about how it was going for this elder during their visits to this center. Rozanne and I wrote memos to the District Representative every time we had news about the trouble that smoking was causing for this elder. Being surrounded by smokers, this gentleman was feeling that he was targeted but he persisted, I continued to go to David Tiessen, Sawyer Representative, Chuck Walt, executive director, along with regular visits to the other members of the RBC spreading the message of going smoke free. David then said he had made the decision to go smoke free at that center, that went into effect and the smokers were not happy, even starting a petition with 40 signatures and giving David a hard time at his monthly meeting in January. The RBC next meeting was held and they decided to go smoke free on the reservation, also including smoke free Fond du Lac Vehicles.

Nate Sandman and I met with Chuck Walt and drafted a policy that was polished by the tribal attorneys. This policy was approved and went into effect on February 15, 2015.

My next step is to get the casino's smoke free, foster homes smoke free, and to educate smokers not to smoke in their homes and cars. I will GET IT DONE!

Miigwech for your time today,

Respectfully Roberta Marie, Health Educator, Secondhand Smoke Policy Change and Education.

Goal 2: Promote the prevention of cancer disease through healthy lifestyles, physical environments and healthcare interventions that reduce cancer risk for the Fond du Lac Reservation.

Objective 2.1:

Increase the knowledge and awareness of cancer prevention behaviors among Fond du Lac community members through culturally specific education interventions.

Strategies:

1. Establish and maintain community education events, such as the Men's Health Brunch, Women's Health Brunch and Survivor's Celebration, featuring interactive, community-based cancer disease prevention information.
2. Identify individuals, cancer survivors and health and social services providers from within the Fond du Lac community willing to serve on a Speakers Bureau and speak publicly on cancer topics for Fond du Lac community health related events.
3. Provide cancer prevention education through evidence-based small media displays for the community at healthcare clinics, community-gathering places, Powwows, community health related events and tribal programs in schools and work sites.
4. Disseminate evidence-based cancer prevention information through large media, such as tribal newspaper articles and other mass communication venues to promote cancer risk reduction behaviors.
5. Provide web links to appropriate cancer information resources through the Community Health Services Department web page for the Fond du Lac Web Site.

6. Design and produce a culturally specific brochure promoting the Fond du Lac Wiidookaage Comprehensive Cancer Plan to the community.
7. Collaborate with tribal, local, state and national cancer partners to develop or acquire culturally appropriate educational and information resources.
8. Use the Guide to Community Preventive Services: The Community Guide from the Community Preventive Services Task Force to assist in planning interventions.

Objective 2.2:

Improve professional knowledge, understanding of cancer prevention and provision of services that prevent cancer, through ongoing education and training for Fond du Lac Health and Social Services healthcare providers.

Strategies:

1. Provide continuing education opportunities for FDL Health and Social Services healthcare providers on cancer prevention topics, including but not limited to:
 - » Cancer Screenings: colon, breast, cervical, lung
 - » Human Papillomavirus (HPV) vaccinations
 - » Healthy Life Styles: Wellness
 - » Diabetes and Cancer
 - » Obesity and Cancer
 - » Tobacco Use and Cancer
 - » Nutrition and Cancer
 - » Skin Cancers
2. Identify and disseminate credible cancer information and culturally specific resources for cancer prevention to all FDL Health and Social Services healthcare providers.

Objective 2.3:

Increase appropriate cancer information integration into Fond du Lac Human Services

Division Health and Social Services programs to promote behaviors that reduce cancer risk among Fond du Lac community members.

Strategies:

1. Collaborate with the *On the Move* exercise program to include information on the benefits of exercise in preventing cancer.
2. Collaborate with FDL HSD's Nutrition Programs (dietitians, Diabetes program, Cardiovascular program, Community Health Services Nutrition program, Women, Infants and Children (WIC) program, etc.) to include information on the impact of healthy diet and healthy weight on cancer prevention.
3. Increase awareness of Health in All Policies approaches by working with other FDL Reservation Tribal organizations to increase easy access to exercise: increase safe walking trails; allow time for exercise within the work hours; establish employee wellness programs; and encourage the FDL Health Insurance Board to adopt programs to promote healthy lifestyles.

Objective 2.4:

Decrease the Fond du Lac Reservation adult (age 18 and above) non-ceremonial tobacco use from 54 to 45 percent (FDL Human Services Division Biennial Needs Assessment, 2014) by June 29, 2025.

Strategies:

1. Support collaboration between all FDL HSD departments in addressing non-ceremonial tobacco use by establishing an evidence-based protocol to address non-ceremonial tobacco dependence, using the Five A Model, recommended by the United States Preventative Services Task Force (USPSTF) and the U.S. Public Health Service.
2. Support culturally specific Tobacco Abuse education within the tribal school curriculum.

3. Utilize age-specific, culturally appropriate tobacco use education materials in health programs and community education programs within the Fond du Lac community.

Objective 2.5:

Provide education to stakeholders focused on reducing second and thirdhand smoke exposure within the Fond du Lac community.

Strategies:

1. Provide culturally tailored trainings and information for Fond du Lac community members, tribal leadership, and Health/Social Services staff regarding the dangers secondhand smoke presents to unborn babies, children/youth, non-smokers, elderly and others with chronic health conditions.
2. Work with the Reservation Business Committee to expand smoke-free environments throughout the Reservation: work sites; tribal businesses; community gathering areas; and service providing sites.
3. Encourage smoke-free community events.
4. Advocate for a Tribal Resolution to have all Fond du Lac Reservation public places and events smoke-free.
5. Support smoke-free homes within the Fond du Lac Reservation community through a smoke-free homes campaign rewarding families who designate their homes as smoke-free.

Objective 2.6:

Decrease potential exposure to environmental carcinogens for Fond du Lac Reservation community members.

Strategies:

1. Collaborate with the FDL Environmental Program and Community Health Services to assess, identify, and develop interventions to address potential carcinogens within the Fond du Lac community properties.

SECTION III:

EARLY DETECTION

Early detection is key to reducing mortality for many types of cancer (oral cavity, larynx, colon, rectum, skin, breast, cervix, urinary bladder and prostate). Early detection of cancer includes two core components: education and screening. Education efforts must promote public awareness of the early signs of certain cancers and proper follow-up procedures with healthcare providers if cancer symptoms are found to be present. Early detection may help reduce cancer mortality, however it is dependent on proper diagnostic and treatment follow-up, the health service infrastructure and target population compliance (Mackey, Jemal, Lee and Parkin, 2006). Screening tests for cervical and colorectal cancers may prevent these cancers from developing by detecting pre-cancerous conditions (CDC, 2014).

Cancers that can be prevented or detected earlier by screening account for at least half of all new cancer cases (CDC, 2014), yet the Fond du Lac Reservation faces many challenges in establishing an effective cancer screening program. Fear of cancer diagnosis, access barriers, financial issues and lack of knowledge about the benefits of cancer screening hinder cancer screening efforts. Cultural aspects, such as modesty, keep individuals from submitting to cancer screening tests. Mammography and colonoscopy screenings are not available at Fond du Lac's tribal healthcare clinics. Tribal clinic clients must be referred out to other healthcare agencies.

With regular recommended screening examinations, a healthcare professional can prevent cervical and colorectal cancers through the discovery and removal of precursor lesions. Screening can detect cancers of the breast, colon, rectum, cervix, prostate, oral cavity and skin at early stages. Between 5 and 10 percent of all cancers are strongly hereditary,

so that knowledge of cancer patterns within families is necessary for timely screenings (American Cancer Society, 2015). Because the recommendation of their provider is the major reason people have screenings, adherence to a consistent set of screening guidelines and ongoing provider education regarding the benefits of cancer screenings is vital.

Goal 3: Fond du Lac community members will have access to and utilize age and risk appropriate cancer screening services.

Objective 3.1:

Increase culturally specific outreach activities conducted within the FDL community to improve cancer screening rates.

Strategies:

1. Develop culturally specific, evidence-based "best practice" outreach programs to increase participation in cancer screening tests.
2. Focus on increasing cancer screening for:
 - » Breast: mammograms (FDL baseline 2013: 37%) (goal Healthy People 2020: 81%).
 - » Colorectal: colonoscopy, FIT, FOBT (FDL baseline 2013: 46%) (FDL Medical Clinic goal: 60%).
 - » Cervical: pap test (FDL baseline 2014: 65%) (goal Healthy People 2020: 93%).
 - » Skin: visual exam
 - » Oral tissue: manual oral tissue exam, VelScope exam
 - » Prostate: PSA test with informed consent
 - » Lung: low-dose computed tomography (LDCT)
3. Develop cancer outreach programs for male Fond du Lac community members that are culturally specific and focused on men's cancer issues.

4. Increase community awareness of cancer burden within the American Indian population in Minnesota and Fond du Lac through community education activities.
5. Provide web links to appropriate cancer information resources through the Community Health Services Department's web page for the Fond du Lac Reservation Web Site.
6. Provide opportunities for Fond du Lac HSD staff to access cancer education with a focus on cancer navigation and cancer outreach to inform development of culturally tailored community cancer screening education.
7. Partner with American Cancer Society to implement cancer screening outreach programs utilizing Community Health Representatives and/or a Community Outreach Worker.

Objective 3.2:

Partner with the Fond du Lac Human Services Division healthcare leadership to promote the use of consistent cancer screening standards and evidence-based interventions based on current cancer research to establish systems and policy changes.

Strategies:

1. Collaborate with FDL HSD Clinical Systems Improvement team, consisting of leadership representation from Medical Clinic, Administrative and Administrative Support Services, Continuous Quality Improvement and the Cancer Program to develop the policy and systems changes that assures the use of consistent cancer screening standards.
2. Provide professional continuing education opportunities for Fond du Lac Human Services Division healthcare providers related to current cancer screening standards and evidence-based cancer

screening interventions.

3. Develop a Client Reminder System, utilizing The Guide to Community Preventative Services evidence-based recommendations, tailored to the Fond du Lac population for Fond du Lac Clinics to remind clients of cancer screenings: mammograms, pap tests and colorectal cancer screening.
4. Assure all clients age 12 years and above receive routine screening for oral cancer during dental examinations as determined by FDL HSD Dental Department leadership.
5. Eliminate financial barriers to accessing regular cancer screening by 1) Increased collaboration between FDL HSD healthcare and social service providers to increase access to financial support for off-site cancer screening costs and 2) Partner with the Minnesota Department of Health SAGE program and the Shakopee Mdewakanton Mobile Mammography Services to provide low cost and free mammograms for American Indian women in the Fond du Lac service area.



Objective 3.3:

Fond du Lac Human Services Division healthcare providers will assess all clients for familial cancer history.

Strategies:

1. Enhance NextGen Computerized Medical Record to provide cueing for healthcare providers to obtain and review familial cancer history with clients.
2. Initial focus on colorectal, breast and ovarian cancers.
3. Utilize cancer partnerships to identify experts in the field of genetics and cancer to provide education for Fond du Lac Human Services Division healthcare providers.
4. Educate Fond du Lac community members about genetics and cancer risk through a variety of community outreach activities.

Objective 3.4:

Increase awareness of the importance of familial cancer history among Fond du Lac community members and healthcare providers.

Strategies:

1. Develop culturally specific education materials for the community focused on family cancer history and cancer prevention.
2. Establish a system to routinely gather familial cancer history during healthcare appointments.

SECTION IV:

TREATMENT

Cancer treatment has evolved and developed slowly over the course of time, with treatment today typically involving medical interventions that include: surgery, chemotherapy, radiation, hormonal treatments and immunotherapy. The best possible treatment plan for each individual is dependent upon the type, site and stage of the cancer. Cancer treatment for a Fond du Lac community member is further complicated,

because cancer is often diagnosed at a later stage when treatment is much more extensive and risk of death is greater. The plan must also be developed with consideration of the personal preferences of the individual with the diagnosis. The care is delivered by a team of healthcare providers and involves complex coordination of appointments, medications, services and other supportive resources for the person with cancer and her or his caregivers. Diagnosis of cancer for a Fond du Lac community member takes place at off-reservation healthcare organizations, often far removed from the person's home and community.

Care coordination barriers faced by Fond du Lac community members with cancer include access to timely treatment, financial concerns, lack of support and supportive resources, lack of knowledge about cancer treatments and clinical trials, lack of communication between providers, the person with cancer and caregivers, and challenges in navigating the cancer care system. Another challenge is the lack of ready access to a traditional healer. Appropriate and beneficial treatment for American Indians requires cultural tailoring to be most effective (Resnicow, 2012). The integration of culturally meaningful healing traditions and practices provided by a traditional healer would benefit the Fond du Lac member suffering with cancer diagnosis. In addition to these barriers, American Indians have a greater mistrust of the healthcare system, which leads to late stage diagnosis. According to a study assessing cancer care barriers; American Indians tend to also express lower levels of satisfaction with healthcare (Guadagnolo, 2009).

The partnership of the person with cancer, the healthcare providers, the caregivers and an integrated cancer care system can change the outcome from one of despair to compassion and support. The 5-year relative survival rate for all cancers diagnosed between 2002 and 2008 was 68 percent, which is an improvement from 50 percent recorded in 1975-1977 (National

Institutes of Health, 2013). Such advancement in survival rates is due to improvement in the diagnosis and treatment of cancer as well as successful initiatives to increase screening rates. Designing interventions to overcome the identified barriers is the major focus of this portion of the plan.

Goal 4: Fond du Lac community members diagnosed with cancer will receive quality clinical cancer care, follow-up treatment and services.

Objective 4.1:

Increase programs and protocols provided through FDL Health and Human Services to assure timely access to coordinated, high quality cancer care and supportive services for community members with cancer.

Strategies:

1. Assess and identify gaps in supportive services for individuals diagnosed with cancer.
2. Arrange continuing professional education opportunities to ensure Fond du Lac healthcare providers have access and are aware of the most current clinical guidelines for cancer treatment and care.
3. Establish best-practice cancer standards of care for the Fond du Lac healthcare system.
4. Establish ready access to current professional cancer treatment and care resources.
5. Educate Fond du Lac community members and healthcare providers on cancer clinical trials and the importance of these clinical trials to advancing cancer treatments and survival.
6. Partner with local healthcare organizations to address barrier issues for Fond du Lac community members diagnosed with cancer.

7. Improve linkages and communication between Fond du Lac healthcare providers and cancer treatment centers.

Objective 4.2:

Increase awareness among Fond du Lac healthcare providers about the protocols for effectively managing side effects of cancer treatment for their patients.

Strategies:

1. Provide continuing education for Fond du Lac healthcare staff in recognizing and managing cancer treatment related side effects including physical, cognitive and psychological changes.
2. Develop clinic policies and procedures related to managing side effects of cancer treatment for their patients.
3. Improve the availability of medications through the Fond du Lac Pharmacy formulary that assist in managing cancer treatment side effects.
4. Offer additional complementary and alternative medical services through the Fond du Lac Human Services Division for Fond du Lac community members with cancer.

Objective 4.3:

Increase access to culturally specific, traditional healing and spiritual services for Fond du Lac community members who are experiencing cancer.

Strategies:

1. Provide education to increase awareness among Fond du Lac healthcare staff of cultural traditions that may be practiced by Fond du Lac community members and how these practices may impact western medicine interventions when treating and managing cancer.
2. Actively engage traditional healers in

provision of healthcare and spiritual support services for Fond du Lac community members with cancer.

3. Develop a system to facilitate easy access to traditional healers when a Fond du Lac community member with cancer requests this service.

Objective 4.4:

Increase direct support services through the Fond du Lac Human Services Division programs for Fond du Lac community members with cancer.

Strategies:

1. Engage FDL Human Services Departments (Home Health, Community Health, Medical Clinic and Social Services) in case management, financial support and connections to resources for individuals with cancer.
2. Promote opportunities for cancer education for the FDL Human Service Department's support staff.
3. Develop comprehensive, culturally appropriate, supportive cancer counseling services within the Fond du Lac Human Services Division Behavioral Health Department
4. Improve FDL Human Service Division's internal Client Referral System to ensure all Fond du Lac community members with cancer have supportive services offered to them.
5. Expand utilization of the FDL HSD Electronic Medical Record System to improve communication and continuity of care for cancer patients.
6. Advocate for broadening the Fond du Lac Human Services Division's clinic staff to include a Registered Nurse, specializing in cancer case management.
7. Establish capacity to bill for Community

Health Worker (CHW)/Community Health Representative (CHR) cancer navigation services.

SECTION V:

WIIDOOKAAGE CARE FROM DIAGNOSIS AND BEYOND:

Palliative and End-of-Life Care

The Fond du Lac Comprehensive Cancer Team defines palliative care as “supportive interventions that begin at the moment a person receives the diagnosis of cancer.” This concept is embodied in the Ojibwe word, “Wiidookaage,” meaning “they help each other.” Even in the best situation, when the person has a plan for treatment, cancer is still an enormous burden with treatments that prolong life sometimes causing substantial strain and problems for the person (Institute of Medicine, 2008). However, when knowledgeable and compassionate healthcare providers, supportive services, and a caring community surround the cancer patient and his or her caregivers, the journey through cancer can feel lighter. Healthcare providers today face the challenge of treating the whole person and not just the disease. They must both apply the most effective biomedical treatment, and meet the patient's psychosocial needs. Ignoring the latter can compromise the effectiveness of the care and create adverse experiences for the person receiving treatment (Journal of Clinical Oncology, 2012).

Dr. Judith Salmon Kaur, a Choctaw/Cherokee who is the medical director for the Mayo Clinic Hospice and the Native American Programs of the Mayo Comprehensive Cancer Center states, “Palliative care and end-of-life services are poorly available, yet critically needed,” (National Cancer Institute, 2011).

Palliative care represents an issue of emerging importance in Indian Country. This is a direct result of demographic changes, including an ever-expanding elder population, increasing numbers of individuals afflicted with chronic disease, and advances in chronic disease management. Palliative care issues have rarely been addressed in American Indian communities for reasons unknown. Programs for American Indians must be culturally sensitive and readily available within the individual's community. Foremost is the need to develop effective pain management programs, as well as those directed towards advanced care planning, staff support, and respite care. Building infrastructure to meet this need is most important and includes training for clinicians, caregivers, and patients in methods currently available to relieve human suffering (Michalek, Mahoney, Gilbert, Kaur, 2005).

The Fond du Lac Wiidookaage Cancer Plan contains several strategies addressing the needs for palliative care whether the care supports the person with cancer into his/her Spirit Journey or leads to long-term survivorship. The palliative care for Fond du Lac begins immediately upon diagnosis of cancer. The palliative care is meant to help the individual maximize his/her health and well-being along the cancer journey. End of life care is the care that is provided when it becomes apparent that the individual will not survive the cancer disease.

Goal 5: Fond du Lac community members diagnosed with cancer will have culturally specific, comprehensive, supportive health and social services for palliative and end-of-life care.

Objective 5.1:

Increase capacity of the Fond du Lac Fond du Lac Human Services Division (HSD) to identify

and track all Fond du Lac community members diagnosed with cancer.

Strategies:

1. Develop a collaborative tracking system between the departments of the Fond du Lac HSD focused on clients with a cancer diagnosis.
2. Clarify current Fond du Lac Human Services interdepartmental referral system to assist in tracking of Fond du Lac community members with cancer diagnosis.
3. Define documentation procedures for all Fond du Lac Human Services departments providing services for Fond du Lac community members with cancer diagnosis.

Objective 5.2:

Increase capacity of the Fond du Lac HSD to provide culturally specific, integrated, family-orientated cancer care and education supporting medical and socio-emotional needs of Fond du Lac community members with cancer and their caregivers.

Strategies:

1. Enhance Fond du Lac HSD staff to provide supportive palliative care for Fond du Lac community members with cancer and their caregivers including, but not limited to:
 - » Registered Nurse Cancer Case Manager
 - » Community Health Worker Cancer Navigator
 - » Medical Social Worker with cancer services focus
 - » Behavioral Health Clinic Counselor with cancer counseling focus
2. Provide specialized educational opportunities for Fond du Lac Human Services staff involved with Fond du Lac community members with cancer and their caregivers.
3. Form a Task Force to assess current

supportive services and develop culturally specific support services for Fond du Lac community members with cancer and their caregivers.

4. Collaborate with local, regional and national cancer partners to provide supportive resources for Fond du Lac community members with cancer and their caregivers.
5. Provide culturally specific education to Fond du Lac community members with cancer and their caregivers about cancer support services available through Fond du Lac Human Services Division.
6. Ensure that Fond du Lac community members with cancer and their caregivers have access to Traditional Healers and Spiritual Guides.

Objective 5.3:

Increase end-of-life services available to Fond du Lac community members and their caregivers through the Fond du Lac HSD.

Strategies:

1. Educate Fond du Lac Healthcare providers and the Fond du Lac community about the need for and the benefits of end-of-life care.
2. Partner with local Hospice Services to augment their services when a Fond du Lac community member is receiving Hospice Services.
3. Provide comprehensive case management services for Fond du Lac community members.
4. Eliminate financial barriers to accessing quality end-of-life care for Fond du Lac community members with cancer.
5. Inform the Fond du Lac community of services and resources available to support a Fond du Lac community member with cancer in need of end-of-life care.
6. Ensure the Fond du Lac Pharmacy has

appropriate pain management medications readily available when pain medications are prescribed for a Fond du Lac community member with cancer.

SECTION VI:

CANCER SURVIVORSHIP

Recent advances in the prevention, early detection, diagnosis and treatment of cancer help cancer patients live longer. As a result, the number of cancer survivors is increasing. As of January 2014, there were nearly 14.5 million cancer survivors in the United States (American Cancer Society, 2014). However, “American Indian cancer survivors are an underserved and understudied group” (Johnson et al., 2010).

Several sources attribute underrepresented cancer rates in American Indian/Alaska Native survivors “due to data limitations, such as racial misclassification, condensing of categories to ‘other’ and a lack of a comprehensive database for AI/AN cancer” (Burhansstipanov, 2000; Lance Armstrong Foundation, 2002). Racial misclassification can occur when race is assigned, rather than by self-identification, or due to changing racial definitions.

There is recognition of the complications of both cancer and its treatments. This includes physical, social and mental challenges over the near and long terms following a cancer diagnosis. Individuals living with cancer also encounter many practical daily living issues. According to Johnson et al. (2010), all survivors have health issues, such as fatigue resulting from cancer treatments, but flexible and supportive work environments appear to be helpful. “Why Me, Why Anybody”, a chapter in *Surviving Cancer as a Family and Helping Co-Survivors Thrive* (2010) authored by Sharon R. Johnson, Fond du Lac enrollee and Elder, provides a valuable resource of culturally-significant questions and answers for the Fond du Lac population. They

can receive answers to questions regarding everything from initial diagnosis through long-term cancer survivorship. An initial step in improving the care of cancer survivors is to raise awareness and provide information in the healthcare community, among cancer survivors and the general public. As individuals make the transition from cancer patient to cancer survivor, they need to be informed about the long-term effects, so they can be active partners in their own long-term care (Lewis, 2006).

Goal 6: Fond du Lac community cancer survivors will achieve maximum quality of life.

Objective 6.1:

Increase the FDL HSD capacity to develop and administer assessments to determine the needs of Fond du Lac community cancer survivors.

Strategies:

1. Conduct assessment with Fond du Lac cancer survivors to determine their needs.
2. Form a Task Force including Fond du Lac community members and Fond du Lac Health and Social Services staff to develop programs based on results of assessment.
3. Assist Fond du Lac community cancer survivors to communicate their needs to health and social services care providers within Fond du Lac and to off-site agencies and resource providers.
4. Provide education opportunities for Fond du Lac Human Services Division staff about cancer survivorship issues.

Objective 6.2:

Increase FDL HSD capacity to provide services and supportive interventions for Fond du Lac community cancer survivors.

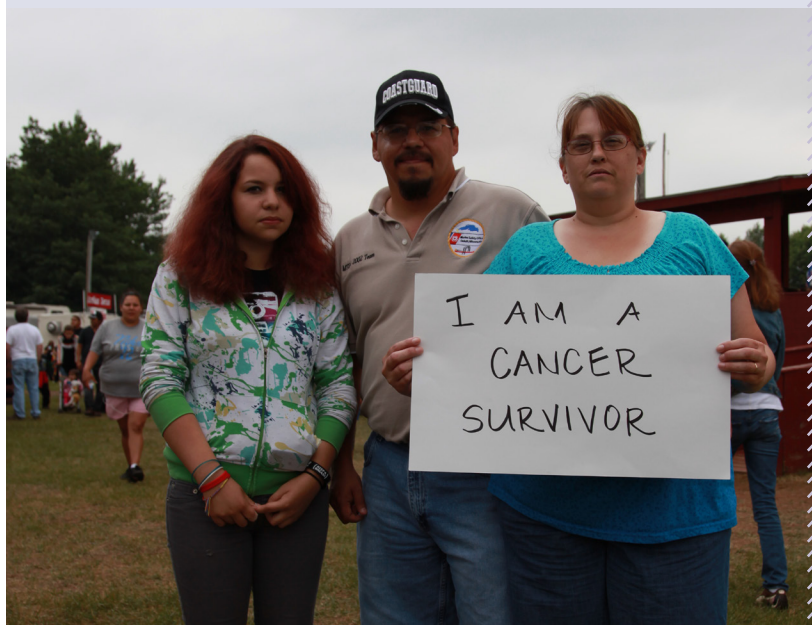
Strategies:

1. Organize and facilitate cancer survivor

COMPONENTS OF AN EFFECTIVE PROGRAM FOR LONG-TERM CANCER SURVIVORS

- » Consideration of long-term issues and survivorship from the time of diagnosis
- » A multidisciplinary approach, including participation by a nurse who can synthesize medical information, target education, and create a health promotion focus
- » A treatment plan that
 - » documents treatment received (including dosages) and future health risks from treatment
 - » has a wellness focus (including exercise and nutrition), which patients can take with them and share with whomever is following them, whether an oncologist or primary care provider
- » A comprehensive database, for use in both research and in identifying survivor issues
- » Education of nurses, other health care providers, and program staff about survivorship issues and resources available within the community
- » Education of survivors and their families about long-term issues
- » Involvement of survivors in planning initiatives of the program
- » Creation of a community of survivors, including a virtual or Web-based community, where they can share information
- » Involvement of the local community, both for support services and for financial backing

(Lewis, 2006)



- support groups for Fond du Lac community cancer survivors.
2. Provide counseling services for cancer survivors through the Fond du Lac Human Services Behavioral Health Department.
 3. Provide community outreach/cancer navigator services to assist Fond du Lac community cancer survivors in locating and accessing supportive resources.
 4. Enhance Fond du Lac Social Services programs to include services and counseling to assist Fond du Lac community cancer survivors with financial and post-cancer diagnosis supply issues related to cancer (example: breast prosthesis).
 5. Advocate for policy and procedures to assist community cancer survivors who are employed within Fond du Lac Reservation enterprises to maintain employability.

Objective 6.3:

Increase involvement of Fond du Lac cancer survivors in cancer programming.

Strategies:

1. Develop opportunities for Fond du Lac community cancer survivors to employ their collective experience and wisdom to enhance the quality of life for all cancer survivors within the Fond du Lac community.
2. Encourage and support Fond du Lac community cancer survivors in sharing their stories through a variety of venues both locally and throughout Indian Country.
3. Ensure representation by community cancer survivors on the Fond du Lac Cancer Team.
4. Provide education within the Fond du Lac community about issues and resources available for Fond du Lac community cancer survivors.

SECTION VII:

CANCER CAREGIVERS

While the impact of a cancer diagnosis on the lives of family members is recognized, there remains a need for family-based intervention. The role of the family in providing support/caregiving to a relative with cancer is recognized as a biopsychosocial process. According to the study *Cancer, Employment, and American Indians*, while going through cancer treatment, around one third of survivors report needing psychosocial supports (Johnson et al., 2010). It is also important to note that family members serving supportive and instrumental roles may also face significant stress as co-survivors (Marshall 2010).

According to Ell and Northen (1990), the family serves a “vital role” in “health promotion, health maintenance, and in the management of illness” (p. 13). A number of researchers have pointed out that family support is not only multifaceted, but also sustained across the lifespan of the person with chronic illness/disability, and thus must be included in research regarding disability-related issues. The family’s committed lifespan role contrasts with the role played by most health professionals and service providers, including rehabilitation counselors, who typically offer focused attention on a time-limited basis. Speice, et al. reported “family members serve as a resource for patients making critical decisions about treatment. They may affirm or challenge decisions about a treatment protocol. Sometimes they even have to prompt the patient to get treatment” (p. 106). There is still much work remaining “in developing systematic and sustainable community-based and community-appropriate intervention for families affected by cancer.” (Marshall 2010)

Goal 7: Fond du Lac community members who are caregivers for people with cancer will have comprehensive supportive services.

Objective 7.1:

Increase culturally specific support services and resources available through the Fond du Lac Human Services Division for Fond du Lac community members who are cancer caregivers.

Strategies:

1. Partner with Fond du Lac Human Services Division Community Health Services Caregivers Program to address cancer caregiver needs.
2. Form a Task Force including Fond du Lac community members who are or have been cancer caregivers and staff from the Fond du Lac Human Services Division to develop services and programs for cancer caregiving.
3. Provide web links to appropriate cancer information resources through the FDL Reservation website.
4. Develop and facilitate support group for caregivers and families of persons with cancer.
5. Link Fond du Lac community members who are cancer caregivers to support services through FDL HSD Behavioral Health, Medical, Social Services and Home Health Services Departments.
6. Provide education for the FDL HSD Departments about issues impacting and resources available to support cancer caregivers.
7. Provide education for the Fond du Lac community about issues and resources available for Fond du Lac community cancer caregivers.

A Caregiver's Story

My younger sister Nada K. Joseph was diagnosed with Stage IV breast cancer in 1997—she fought the demon until she no longer could and walked on in 1999. I made a promise to her that I would continue her fight until my last breath.

We have a large family (nine children) and I was closest to her. Not only was she a member of the Fond du Lac Band of Lake Superior Chippewa but she was also a member of the Lesbian/Gay community. She was an athlete, a nonsmoker who took care of herself, and I believe an experience of this magnitude is even more difficult knowing you've always been "healthy."

She asked me to help—to become her caregiver and I was, and am honored. First of all most of us really know so little about this "demon" except we immediately think of death. I jumped in and began to do my own research. The medical jargon alone is overwhelming and because there is no "cure" for cancer, I observed many of her healthcare providers debate over which treatment plan would be the best and then leave it up to her. While we were actively involved in her healthcare decisions, this aspect of her journey was probably the most frustrating. All treatments and protocols were gut wrenching decisions.

This experience is almost indescribable but think of every verb that describes sadness, helplessness and any other emotionally crippling pain—that is how a caregiver feels. To navigate through the "unknown" is scary enough but to know deep in your heart and soul that Stage IV patients rarely survive never leaves your thoughts.

There is no magic answer as to what is right or wrong in caring for a cancer patient. Most of the time I felt paralyzed but somehow I had to step up to the plate and offer her what help I could. One really has to keep an open mind and heart throughout the journey for there will actually be good days as well as those bad days that rear their ugly heads. The hardest for me was to not take things personally. My sister, like so many who are fighting this disease, would have days of anger and rage, days of total silence, days of great hope and days of little hope, days of joy and far too many days and nights of unpredictability.

Most everyone had incredibly high expectations of her—I suppose because she was such a gregarious and healthy person. It was difficult for them to see her in a weakened state but these daily expectations took their toll on her very quickly as she felt it was her duty to "counsel" everyone who was feeling bad. That exhausted her and one day she said to me, "Don't they realize I'm fighting for my life?" It was then that I had to change her daily schedule and "thin the herd" as we called it. I put a voice mail message

on the telephone offering a daily update and that most often she was resting and unable to come to the phone. I screened all visitors, including family members, which was perceived as “being shut out.” All of her energy had to focus on the battle.

Even though she had a bone marrow (stem cell) transplant she was never totally cancer free and had three recurrences. When she first called to tell me I was packed and in the car in fifteen minutes. Five hours later I walked into her kitchen and she was wearing this sleeveless white tee shirt. That “lump” drew me directly to it but I refused to allow it to disrupt our usual greeting of hugs and kisses. My sister then took my hand and placed it on the evil spot and I was shocked and felt sick to my stomach as I tried to maneuver it around, but it wouldn’t budge! Huge as a grapefruit and hard as a rock. Because I had lost eight close friends and colleagues to breast cancer in the past three years, I had some familiarity with the “stages” but this scared the daylights out of me. When the biopsy was done and the syringe produced no liquid from the area my heart sank. I knew then that she was terminal. I never spoke those words out loud to anyone and this is the first time I’ve publicly stated this.

Early detection is KEY! Mammograms and breast self-examinations can save your life. My sister knew she waited too long to go in . . . she only told me that once during her two year struggle. At that time we couldn’t find any American Indian support group much less any resources in the Lesbian community. There is a huge need for support in all forms that is culturally appropriate for our people including two spirited people.

When she had her stem cell transplant at Karmonos Hospital on the Wayne State University Campus in Detroit, she was the first American Indian person to ever participate in that program. The head of the program was so intrigued he came to visit Nada often, which we were told was rare. He eventually asked me to ask Nada if she would be interested in being interviewed by all three local television stations (NBC, CBS and ABC). The interviews not only focused on her cancer but on the importance and impact her cultural beliefs and traditions had on her as she prepared for battle each day, and then finally as she prepared for her spiritual journey.

Bonnie Wallace, Giidaagahbinesikwe (Spotted Eagle Woman)

SECTION VIII: EVALUATION

Program evaluation is “the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development” (Patton 2008). Evaluation is essential to providing programmatic direction, demonstrating the use of resources, and indicating the need for program revisions and improvements. Additionally, regular, systematic, and accurate assessment and timely reporting of evaluation findings is important to program sustainability. Key stakeholders will be engaged throughout the evaluation planning process to ensure a clear understanding of the program’s activities and desired outcomes, evaluation questions, and insight into the feasibility and program capacity for data collection.

The Fond du Lac Wiidookaage Cancer Program has been providing culturally specific cancer interventions in the FDL community for over thirteen years. The program is in constant implementation and maintenance phases, so information needs for evaluation will include measures to assess program outputs, short, intermediate, and long term outcomes. Process and outcome documentation will include continuous collection of data on outcome indicators and key performance measures to monitor progress toward the stated program objectives and goals. The results from evaluation findings will be used to make recommendations for improving and advancing the Fond du Lac Wiidookaage Cancer Plan.

The FDL NCCCP evaluation findings will be disseminated to all program stakeholders in the form best suited for the particular audience. Documents summarizing the evaluation plan implementation, results, and recommendations for program improvement will be developed

and presented for the FDL HSD, the FDL Wiidookaage Cancer Team, and the FDL RBC (if requested). Informative findings will be available and presented to FDL community members and participants in program activities through newsletters and flyers. The Evaluation Team recognizes the grant requirement to create at least four unique dissemination documents and one peer reviewed manuscript over the five-year period based on performance monitoring data, health assessment data, and other program related information. Evaluation results are imperative for the FDL Wiidookaage Cancer Team and grant staff to make informed decisions, improve program activities, focus efforts, and continue to build the FDL NCCCP to reach its intended outcomes and goals.

Throughout the planning process, FDL's evaluation plan includes evaluation activities identified in the Building Blocks for Comprehensive Cancer Control Planning. The FDL evaluation activities utilize CDC's Comprehensive Cancer Control Branch Program Evaluation Toolkit (June 2010), which is aligned with the six steps of the CDC Framework for Program Evaluation in Public Health: 1) Engage Stakeholders, 2) Describe the program, 3) Focus the evaluation design, 4) Gather evidence, 5) Justify conclusions, and 6) Ensure use and share lessons learned. Application of this framework assists in answering questions such as:

- » *What will we evaluate?*
- » *What criteria will we use to critique program performance?*
- » *Who are our primary intended users and stakeholders?*
- » *How will we use our evaluation findings?*
- » *To what extent are our goals and objectives being met?*
- » *How well is our program functioning?*
- » *What resources do we need to assist us with our evaluation efforts?*

Knowing that this framework is non-prescriptive and participatory in nature, we believe that the implementation of this framework will provide the starting points around which FDL can tailor an evaluation to best meet our needs. While we recognize that each step supports the others and prior steps provide the foundation for future progress, it is also a model that allows for sensitivity to our programs' unique aspects and context. We are confident that this model will allow us to focus our efforts to promote capacity building, mobilize the community, develop and maintain partnerships, instill program integration and coordination and the sharing and monitoring of resources for planning, implementation and evaluation.

Goal 8: Establish a systematic evaluation plan to monitor the progress of Fond du Lac's Comprehensive Cancer Plan activities.

Objective 8.1:

Maintain an evaluation structure that follows the components of the CDC Framework for Public Health Evaluation and the Building Blocks for Comprehensive Cancer Control Planning.



Strategies:

1. Engage stakeholders: Identify an evaluation team that includes internal and external resources and staff to include a contracted Evaluation Consultant to support the evaluation of the FDL Cancer Program and other individuals invested in the program.
2. Describe the program: Work with stakeholders to clarify program activities and expected outcomes, and to describe the context of the evaluation program and how it fits into the FDL HSD and FDL community.
3. Focus the evaluation design: Design the evaluation, the users, the uses for the evaluation, stakeholder interests, evaluation questions, methods, timeline, systems for monitoring, tracking, and documenting implementation activities and sharing results.
4. Gather evidence: Develop indicators and methods to collect, analyze, and interpret data.
5. Justify conclusions: Justify conclusions in conjunction with stakeholders and evaluation team.
6. Ensure use and share lessons learned: Report to stakeholders and the community on recommendations and conclusions.

Objective 8.2:

Integrate the evaluation of Fond du Lac's Comprehensive Cancer Plan into the Fond du Lac Human Services Division's Continuous Quality Improvement (CQI) Program.

Strategies:

1. FDL Wiidookaage Cancer Team prioritizes and selects strategies from FDL Wiidookaage Cancer Plan for implementation.
2. Develop measurable CQI indicators and objectives for selected strategies from the Cancer Plan.
3. Monitor achievement of action plan indicators and objectives through the FDL HSD CQI process.

Objective 8.3:

Monitor cancer screening data and report to stakeholders on an annual basis.

Strategies:

1. Utilize the Meaningful Use Indicators selected by FDL HSD Medical Clinic for developing evaluation indicators for cancer screening.
2. NextGen Electronic Medical Record System is enhanced to be able to generate reports for selected cancer screening data.
3. FDL HSD CQI committee reviews reports on an annual basis and makes recommendations for program improvement.

Objective 8.4:

Activities focused on reduction of non-ceremonial tobacco use are routinely monitored.

Strategies:

1. Monitor tobacco use through the Biennial Community Needs Assessment.
2. Partner with other programs within the FDL HSD that are addressing tobacco issues.



Acknowledgements

Fond du Lac Wiidookaage Cancer Team and other Contributors to the development of the Fond du Lac Band of Lake Superior Chippewa Wiidookaage Cancer Plan 2025:

Contributors:

Amber Cardinal;
Bonnie Wallace;
Brandie Buckless;
Bunny Jaakola;
Caroline Woods;
Carolyn Olson;
Catherine Marshall;
Charissa Blue-Downs;
Charles Kendall;
Chris Davis;
Chuck Walt;
Cody Bassett;
Colleen Baggs;
Colleen Carlson;
Craig Wethington;
Crystal Greensky;
Daanis Chosa;
David Perdue;
DeAnna Finifrock;
Dara Topping;
Deb Rissanen;
Debra Johnson-Fuller;
Donna McDuffie;
Emily Smith;
Gay Lynn Richards;
Heather Hirsch;
Jared Dunlap;
Jeanne Rice;
Jim McLean;
Joyce La Porte;
Kara Stoneburner;
Karen DuFault;
Katie Gokee;
Kelly Emmons;
Kevin Walsh;
Kim Largo;
Kristine Rhodes;
Laura Keyes;
Margarita Omeonu;
Marilyn Grover;
Marjorie Johnson;
Mary Durfee;
Mary Jo Koszarek;
Melanie Plucinski;

Melissa Lewis;
Michele Flatau;
Michelle Johnson-Jennings;
Miigis Gonzalez;
Nada Joseph;
Nathan Sandman;
Nathan Tesch;
Patrick Tschida;
Peggy Anderson;
Peggy O'Halloran;
Phil Norrgard;
Roberta Marie;
Robin Johnson;
Rosemary Thomas;
Rozanne Hink;
Sharon R. Johnson;
Shirley Soukkala;
Tina Roberts;
Valerie La Fave

Review Team:

Gay Lynn Richards;
Marjorie Johnson;
Catherine Marshall;
Miigis Gonzales;
Melissa Lewis

Writing Team:

Brandie Buckless;
DeAnna Finifrock;
Margarita Omeonu;
Marjorie Johnson;
Bonnie Wallace;
Roberta Marie;
Dara Topping;
Melanie Plucinski;
Peggy O'Hallaron;
Charissa Blue-Downs;
Amber Cardinal;
Jessica Harjo

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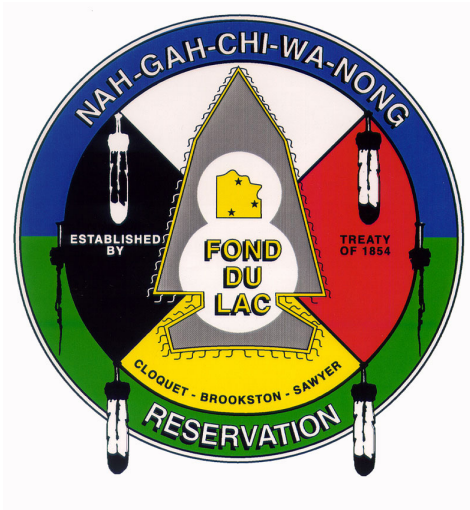
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We gratefully acknowledge and thank the American Indian Cancer Foundation for their support in making the publication of this document possible.



For more information contact:

Fond du Lac Human Services Division
Community Health Services Department
Fond du Lac Wiidookaage Cancer Program
927 Trettel Lane
Cloquet, MN 55720
Tel: 218-879-1227



Fond du Lac Band of Lake Superior Chippewa
1720 Big Lake Road
Cloquet, MN 55720



Fond du Lac Human Services Division
927 Trettel Lane
Cloquet, MN 55720

This publication was made possible through a grant from the Centers for Disease Control and Prevention: Fond Du Lac Reservation Cooperative Agreement Number: 5 U58DP003873-04-00: Cancer Prevention and Control Programs for State, Territorial and Tribal Organizations FOA number: DP12-1205; Component 2: Policy and Environmental Approaches and Community-Clinical Linkages in the National Comprehensive Cancer Control Program (NCCCCP).