South Dakota Comprehensive Cancer Control Plan

2005 - 2010

Comprehensive CANCER CONTROL SOUTH DAKOTA

South Dakota Comprehensive Cancer Control Plan

Published June 2005

M. Michael Rounds, Governor

Doneen Hollingsworth,
South Dakota Secretary of Health

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June 2005

Dear South Dakotans:

I am pleased to share with you South Dakota's first ever Comprehensive Cancer Control Plan. It was developed by the South Dakota Comprehensive Cancer Coalition, a diverse, dedicated and compassionate group of people who share a vision of working together to reduce the burden of cancer for the residents of our state.

The Comprehensive Cancer Control Plan is the beginning point on our map toward that goal. It will help all of us involved in cancer prevention and control focus our resources on our common goals. As we progress in our efforts to reduce cancer rates and improve the lives of those touched by cancer, this plan will also change. Cancer is a formidable disease – no one agency, no one organization, no one system can reduce the burden of cancer alone. It will take the concerted efforts of us all and will require new ways of thinking as we collaborate in sharing resources.

There is a place for all of us – communities, public agencies, private organizations, businesses, and individuals – in the fight against cancer. I urge you to find the strategic area where you can become involved and work with us to make a difference in the lives of South Dakotans affected by cancer.

Thank you to the stakeholders that have been involved in developing this plan. Thank you especially to all of the South Dakotans who have shared their stories and have made suggestions throughout the planning process. Now, the work of implementation lies ahead of us. We invite you to join in this effort to lift the burden of cancer from South Dakota.

Sincerely,

Doneen Hollingsworth
Secretary of Health

Dear People of South Dakota:

The South Dakota Comprehensive Cancer Consortium is pleased to present you with the first ever comprehensive plan to increase the number of South Dakotans leading cancer free lives. This plan contains strategies and actions to guide the efforts of partners collaborating to fight cancer for the next five years.

The plan is only the beginning of the long road leading to the eventual eradication of cancer. As scientific breakthroughs occur and as people understand the importance that their health decisions make on preventing cancer, more effective tools and strategies will be developed. New challenges and practical experiences will give us new insights on innovative ways to prevent cancer, to control cancer, and increase the quality of life for cancer survivors. The plan can only be considered finished when cancer is no longer a burden for any South Dakotan.

Finally, the plan is an invitation for you to be involved in implementing the strategies for comprehensive cancer control. Volunteer to assist in an activity sponsored by a local organization, volunteer to serve on a committee working directly to achieve a priority, support community activities focused on cancer control. Cancer affects individuals, friends, families, and loved ones and it will take all of us working together to remove it as a threat.

Sincerely,

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SD Comprehensive Cancer Control Chair

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Executive Summary

Comprehensive cancer control is an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation and palliation.

-Centers for Disease Control and Prevention

The South Dakota Cancer Control Consortium is dedicated to bringing together individuals, organizations, health care providers, and agencies in order to reduce the burden that cancer places on the people of our state. The South Dakota Comprehensive Cancer Control Plan is focused on prevention, early detection, treatment, data and research, survivor issues, and end of life/palliation. The plan includes the top priorities that cancer control professionals believe should be the focal point for immediate action in order to reduce the burden of cancer.

A draft of the plan was presented to over 500 adults aged 20-85 in 22 South Dakota communities in order to assure that it reflects the concerns of the people of the state. Their views are expressed throughout the plan.

The plan has the following components:

- A look at how cancer affects South Dakota
- Mission and goals of the project
- Objectives and Strategies covering the following areas:
  - Prevention
  - Early Detection
  - Treatment
  - Survivor Issues
  - End of Life/Palliation
  - Data and Research

Finally, the plan offers an opportunity for all South Dakotans to become involved in the work of controlling cancer. Please complete and send in the reply form at the end of the plan. Take the opportunity to get involved and make a difference!

How CancerAffects South Dakotans

Cancer is the second leading cause of death in South Dakota. About 1,600 people each year die from cancer. Based on estimates for 2004 (ACS 2004), 5 in 10,000 South Dakotans were diagnosed with cancer and one in four of all deaths were due to cancer. If present trends continue cancer could become the leading cause of death. These trends include an aging population and a decrease in deaths from heart disease and stroke. Everyone in South Dakota is affected by cancer either by living with the disease themselves or by having family and friends with a malignancy.

Incidence:

- South Dakota registered approximately 3,864 new cases of invasive cancers (cancers that have spread) and in situ (contained) bladder cancers in 2002.
- The age-adjusted incidence rate was 484.8 compared to the national rate of 458.2 per 100,000 in 2002.
- Prostate cancer was the most common cancer reported with breast, colorectal and lung following in that order.
- The top four cancers accounted for approximately 57 percent of all cases reported.
- Of all cancers reported in South Dakota in 2002, 87 percent were among persons age 50 or older with half of these cases diagnosed between ages 65-79.

Mortality:

- In 2002 the state's age-adjusted death rate with 1,561 deaths was 187.4 per 100,000 compared to the national rate of 193.3 per 100,000.
- The top four causes of cancer deaths were lung and bronchus, colorectal, prostate and pancreatic cancers, accounting for approximately 50 percent of all cancer deaths.
- The age-adjusted death rate for the five year period 1998-2002 was 189.2 compared to the U.S. rate of 197.8 per 100,000 persons.
- Trends in all sites of cancer death in South Dakota have decreased slightly from 1993-2002 with an annual percent change (APC) of -0.4 percent compared to -1.1 percent for the U.S.
- American Indians in South Dakota had the largest decrease with a statistically significant APC of -3.7 percent.

-Cancer Burden in South Dakota, 2004

South Dakota Cancer Health Disparities

As a society, we work to improve thelives of every individual, regardless of age, race, ethnicity, or economic status. Despite the best of intentions, disparities in health status continue to increase. Our rural, poor, and minority populations continue to be the groups associated with high levels of cancer causing risk factors, the last to receive the newest forms of medical treatment, and the most likely to die from cancer.

The National Cancer Institute states that

> *cancer health disparities occur when members of certain population groups do not enjoy the same health status as other groups. Disparities are most often identified along racial and ethnic lines – showing that African Americans, Hispanics, Native Americans, Asian Americans, Alaska Natives and whites have different disease rates and survival rates. But disparities also extend beyond race and ethnicity. For example, cancer health disparities can involve biological, environmental, and behavioral factors, as well as differences noted on the basis of income and education.*

The National Cancer Institute also states that

> *disparities are determined and measured by three health statistics – incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another.*

What does all of this mean for South Dakota? It means that our American Indian, our geographically isolated, and our poor populations are carrying a greater portion of the cancer burden than they should be. To eliminate this problem, the SD Cancer Consortium used input from three sources to ensure that this comprehensive cancer control plan indeed addresses cancer health disparities:

1) The consortium used results from the "American Indian Cancer Summit" held in Rapid City, SD in October, 2004.

2) The consortium used a series of community listening sessions called the "Voices of the Community: Perceptions of the South Dakota Cancer Control Plan."

3) The consortium used the valuable input from planning members who represent the different disparate populations.

Photo by South Dakota Tourism

From this input, the following cancer disparity issues are addressed in this comprehensive cancer control plan:

Prevention

- Commercial tobacco use is high among our American Indian communities. Culturally sensitive action is encouraged to address this, especially among American Indian youth.
- Education regarding healthy lifestyles is encouraged utilizing cultural role models.

Early Detection

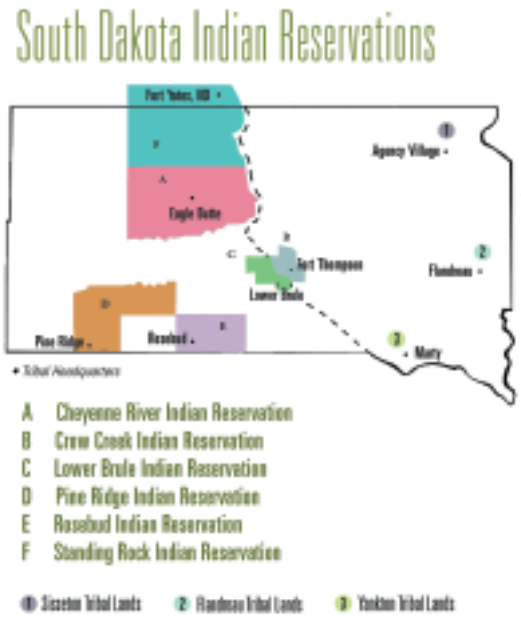
- There is need for basic and easy-to-understand education concerning the multiple recommended cancer screenings.
- There is a high level of fear among our disparate populations concerning cancer screening (i.e. What if the doctor finds something?).

Treatment

- There is a strong geographic barrier that prohibits many rural, poor, and Native individuals from accessing the most effective cancer treatment options.
- There is a low participation of rural, poor, and Native individuals in cancer clinical trials.
- Increasing participation in clinical trials results in access to the latest methods of cancer prevention, detection and treatment.
- There is strong interest in strengthening culturally competent healthcare in SD.

Survivorship

- There is strong reliance on informal social networks to provide support for cancer patients.
- There is an identified need to increase the role of cancer survivors in providing support to cancer patients.



End of Life

- There is an identified need to educate patients, families, and health professionals about end of life care, especially within disparate populations.

Research / Data

- It is known that the number of American Indian cancer cases is under-reported. Action is encouraged to increase the accuracy of our racial and ethnic data.
- Clear and simple communication of cancer data is needed.
- There is a need for participatory research.

Background: Comprehensive Cancer Planning

Comprehensive Cancer Control, a Coalition of Partners Fighting Cancer

> *"During the last decade there has been tremendous growth in the scope and number of programs designed to reduce the burden of cancer; these programs generally address a particular cancer site (breast, prostate, etc.) or reducing specific risk factors (e.g. tobacco use).*
>
> *The experience and knowledge gained from these categorical programs provides a solid basis for a more comprehensive approach to cancer prevention and control. The significant growth of cancer prevention and control programs within health agencies has resulted in recognizing that improved coordination of cancer control activities is essential to maximize resources and achieve desired cancer control outcomes. Comprehensive cancer control (CCC) results in many benefits including increased efficiency for delivering public health messages and services to the public. Individual leaders are willing to join together to focus time, resources, and staff on a comprehensive cancer control approach. They can make decisions and take actions that affect cancer control across the whole community."*
>
> The Centers for Disease Control and Prevention

In 2002 a group of representatives from agencies focused on cancer control began to make this vision a reality in South Dakota. A team of 14 people attended a Cancer Leadership Training Institute sponsored by the American Cancer Society, the American College of Surgeons, the Association of State and Territorial Health Officers, C-Change, the Centers for Disease Control and Prevention, the Chronic Disease Directors, the Intercultural Cancer Council, the National Cancer Institute, and the North American Association of Central Cancer Registries. The purpose of the institute was to provide a strategic opportunity for a group of highly skilled, influential individuals to engage in collective action to support implementation efforts for a comprehensive cancer control approach within the state.

During the last three years the group has grown. In October 2004 over 75 partners convened to begin the process of planning a comprehensive cancer control initiative in which all have a part. Smaller planning groups were formed around the issues concerning data and research, prevention, early detection, treatment, survivorship, and end of life. Meeting by phone and in person, each group developed priorities for action in the next five years to reduce the burden of cancer in South Dakota.

The Vision of Comprehensive Cancer Control

The vision of the South Dakota Comprehensive Cancer Control Consortium (SDCCCC) is to reduce the human and economic impact of cancer on South Dakotans through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control.

The Goal of Comprehensive Cancer Control

The goal of the SDCCCC is to ensure that all South Dakotans have access to quality cancer prevention and control information and services in order to reduce the number of new cancer cases as well as the illness, disability, and death caused by cancer and for survivors to live the best quality of life possible.

- All South Dakotans should receive culturally appropriate information about cancer risks and prompt access to high quality cancer prevention, screening, diagnosis, treatment, and rehabilitation information and services;
- Strong, collaborative partnerships at the state and local levels will help reduce the human and financial impact of cancer on the people of South Dakota;
- A collaborative and unified effort by public, private, and volunteer agencies and individuals increases the effective use of limited resources and minimizes duplication of efforts.

Creating the Plan

The group of 14 that attended the Leadership Institute became the first members of the Comprehensive Cancer Control Steering Committee. Its purpose was to provide leadership for the fledgling project by establishing protocols for making decisions and moving ahead with funding. During this year long period the American Cancer Society (ACS) provided funding for consultation, logistics support and technical assistance. A funding proposal was submitted to the Centers for Disease Control and Prevention (CDC) with the Department of Health serving as the funding recipient and the ACS continuing its support for consultation. Under the leadership of the Steering Committee the plan for infrastructure was put into place awaiting funding. In 2004, with financial support in place, a facilitator was employed and the first of several meetings was held with additional cancer stakeholders.

Over 75 individuals committed to serving a four month term on a planning committee to develop a draft of the plan. The planning framework followed the disease continuum in six sections: Prevention, Early Detection, Data and Research, Treatment, Survivor Issues, and End of life issues. Sub-committees lead by co-chairs met by phone and in person to develop a draft document. All committees had technical assistance available

from the project consultant, the project facilitator, CDC, and the collective expertise of their members. An additional Leadership Institute, to which all of the committee co-chairs were invited, was held in Chicago in the fall.

From the beginning, the planning committee recognized that the plan for Comprehensive Cancer Control belonged to all of the people in South Dakota. So, they sought the opinions of a varied group of South Dakota residents to understand what was important to them about cancer and whether it was included in the plan. South Dakota State University nursing students, American Cancer Society staff, and trained individuals facilitated 32 meetings in 22 communities. The communities and attendees reflected the diversity of South Dakota. Meetings were held across the state in large and small communities, including the reservations. The voices of the more than 500 individuals who participated are reflected throughout the plan. It is truly a plan for the people.

Photo by South Dakota Tourism

Prevention

"There is no greater imperative in American health care than switching from a treatment-oriented society, to a prevention-oriented society."

-Vice Admiral Richard Carmona, M.D., M.P.H, FACS - US Surgeon General

The goal of the SDCCC prevention component is to lower the population's risk of cancer by limiting the number of modifiable risk factors. These risk factors are in three major areas of cancer prevention: tobacco use, nutrition, and physical activity. These three areas contribute to approximately 60 percent of cancer cases. By working to decrease risk factors such as smoking and obesity, the occurrence of cancer will be greatly reduced.

The American Cancer Society estimates that half of the expected 570,280 cancer deaths that will occur in the U.S. in 2005 could have been prevented.

The 1996 Harvard Report on Cancer Prevention researched the risk factors for cancer. The estimated percent of total cancer deaths attributed to established causes of cancer were:

Risk Factor	Percentage
Tobacco	30%
Adult diet/obesity	30%
Sedentary lifestyle	5%
Occupational factors	5%
Family history of cancer	5%
Viruses/biological agents	5%
Perinatal factors/growth	5%
Reproductive factors	5%
Alcohol	3%
Socioeconomic status	3%
Environmental pollution	2%
Ionizing /UV radiation	2%
Prescription drugs/medical procedures	1%
Salt/food additives/contaminants	1%

Tobacco

Tobacco use is the most significant preventable cause of cancer. The use of tobacco has been shown to increase the risk of cancer of the lung, liver, pancreas, kidney, bladder, uterine cervix, oral cavity, larynx, stomach and esophagus. The American Cancer Society estimated that in 2004 more than 180,000 cancer deaths were caused by tobacco

use in the U.S. Tobacco use is responsible for over $1,600 per smoker in excess medical expenditures each year (Centers for Disease Control and Prevention).

South Dakota has made strides in recent years to reduce tobacco use. The tax on cigarettes has been raised and the South Dakota QuitLine is available to all South Dakotans. However, much remains to be done. Approximately 23 percent of South Dakotans are still smoking. Over 30 percent of 18-24 year olds recently surveyed in the 2003 Behavior Risk Factor Surveillance Survey (BRFSS) reported they were currently smokers. This alarmingly high number shows a great need for tobacco prevention education in our schools.

Voices of the Community
"Our elected officials need to get the word that 74 percent of the people in South Dakota do not smoke. We do not want smoking in any public places. Why can't we breathe clean air?"

Nutrition / Physical Activity

Other than not using tobacco, nutrition and physical activity are the next most important approaches to reducing cancer risk.

Studies in the last several years have shown a link between vegetable and fruit consumption and the decreased risk of developing certain types of cancer. Eating a diet rich in fruits and vegetables reduces the chance of developing colorectal, stomach, lung, and esophageal cancer.

Approximately 81 percent of South Dakotans consume less than five servings of fruit and vegetables per day. The recent Dietary Guidelines for Americans 2005 recommends four to five servings of fruit and four to five servings of vegetables for the average 2000 calorie a day diet. There are several factors that have been identified that relate to low fruit and vegetable consumption. Availability, cost and lack of convenience are all felt to play a part. However, these barriers must be overcome if South Dakotans are to achieve their optimal health status.

Obesity is defined as a body mass index (BMI) of 30 or more and overweight is defined as a body mass index of 25-30. In South Dakota 21.2 percent of our residents are obese and 39.4 percent are overweight. Physical activity decreases the risk of colon, breast and prostate cancer. Including physical activity in a daily routine will help to lower body mass index. Almost 23.8 percent of South Dakotans report having no physical activity in the past month.

Skin Cancer

The vast majority of skin cancers are due to unprotected and excessive ultraviolet (UV) radiation exposure. The American Cancer Society estimates that UV exposure is associated with more then 1 million cases of basal and squamous cell cancers and 59,580 cases of malignant melanoma annually. Artificial sources, such as tanning booths, add to UV exposure. Regular practice of sun protection behaviors can lead to significant reductions in sun exposure and risk of skin cancer. Because sunburn during childhood can increase risk of melanoma and other skin cancers, and because much of an individual's lifetime sun exposure occurs during childhood, it is extremely important that sun protection behaviors begin early in life.

Voices of the Community
"What about tanning beds? This whole fake and bake mentality among youth and young adults has got to change. Skin cancer rates are going to continue to climb."

Photos by South Dakota Tourism

Prevention

Goal: To lower the population's risk of cancer by limiting the number of modifiable risk factors.

Strategy:
Eliminate commercial tobacco use.

Outcomes:

- Reduce the number of youth using commercial tobacco products.
  Baseline- 30 percent of students smoked cigarettes on one or more of the past 30 days (South Dakota 2003 Youth Risk Behavior Survey)
  Target- 27 percent (South Dakota Tobacco Plan)
- Increase the number of people that quit using commercial tobacco products.
  Baseline- 22.6 percent of adults in South Dakota smoke (South Dakota 2002 Behavioral Risk Factor Surveillance Survey Data)
  Target- 18 percent (South Dakota Department of Health Healthy People 2010 Initiative)
- Reduce the number of people exposed to environmental tobacco smoke (second hand smoke).

Action Steps:

- Support programs of the Department of Health Tobacco Control Program.
- Encourage schools to decline contributions offered to school-related organizations and activities that come from organizations that promote the use of tobacco.
- Encourage and assist communities and schools to use effective tobacco-prevention curricula, along with other effective prevention strategies.
- Share effective prevention strategies for post-secondary campuses with staff and student leadership at post-secondary campuses.
- Promote the statewide QuitLine by providing referral materials to local coalitions, local public health offices, private health care providers, hospitals, health plans and others.
- Provide information about the Public Health Service Guidelines for Treating Tobacco Use and Dependence, along with support material to health care providers and organizations.
- Collaborate with other state agencies, such as Medicaid to promote cost-saving measures such as using the South Dakota QuitLine and promoting providers' cessation advice to clients.
- Provide communities and businesses with information about the economic benefits of smoke-free policies and employee cessation opportunities.
- Provide public education messages about the link between commercial tobacco use and cancer.
- Support tobacco prevention and control advocacy through policy and legislation.

Ex-smoker says quitting not as hard as he thought it would be

Bob Leonard and his friend, Merry Steensland. Jim Holland, Journal staff

After 45 years, Bob Leonard stubbed out his last cigarette on Dec. 9, 2002. Almost a year later, he's still cigarette free and darn happy about it. "I feel so much better," he said.

The Rapid City Realtor/broker joined the smoking culture as a teenager, along with many of his peers. Over the years, his peers eventually dropped the addiction. He didn't. By the time he finally quit last year, he was sporting a habit of two packs a day. At today's costs, that's about $1,460 a year spent on cigarettes. Leonard said he awoke every morning with a fierce, hacking cough that "even scared the cat a couple of times." His children and grandchildren all encouraged him to give it up, and his girlfriend had difficulty dealing with the secondhand smoke.

It was time to quit," he said. Leonard, who gives his age as 60-plus, had tried and failed to quit before. What finally changed his luck? Good advice, ample help and the wonders of medication. The first push came from his physician, Dr. Allen Nord of Rapid City. After a visit, Nord told Leonard that except for the smoking, he was a fairly healthy man. I thought, "Why wait until they tell me I'm in bad shape," Leonard said.

Next, he called the South Dakota Quit Line, which provides smokers who strive to quit with everything from nicotine patches to medication to counseling. Leonard was given free medications, patches, telephone counseling and a plethora of written information and tips about ridding oneself of cigarettes. He used a photo of his girlfriend, his "high school sweetheart," as a reminder of why he is doing it. "The key is, you've got to want to quit," Leonard said. "But you've got to have some help."

Leonard said he never had any intense physical withdrawal symptoms because of the medication. The counseling and information helped with the emotional element of smoking. In the end, it wasn't such an ordeal after all. "If I would have known that it was as easy as it was, I would have quit years ago," he said. The only down side from quitting smoking turned into a positive. He gained 10 pounds after he dropped the cigarettes, which got him started on a workout program. He has lost 7 pounds of that weight and developed a taste for exercise. "I can ride my bike to the fairgrounds and back now. I couldn't do that before," he said. At a recent doctor's appointment, Leonard reminded Dr. Nord that he was nearing his one-year anniversary of quitting smoking. The doctor reminded him to stay vigilant, but Leonard said he is not worried about a relapse. His hack-free days are enough to convince him he's made the right step. "I'm done with it," he said.

Excerpt from an article by Lynn Taylor Rick, Rapid City Journal staff writer, published on Dec. 3, 2003

Strategy:
Increase healthy dietary behaviors.

Outcomes:

- Increase fruit and vegetable consumption.
  Baseline- 19 percent of adults consume five servings of fruits and vegetables per day (South Dakota 2003 Behavior Risk Factor Surveillance Survey)
  Target- 55 percent of adults consuming five servings of fruit and vegetables daily (South Dakota Department of Health Healthy People 2010 Initiative)
- Increase knowledge of portion size and quality of diet.

Action Steps:

- Provide a public awareness media campaign focusing on:
  - Increasing fruit and vegetable consumption
  - Educating on portion sizes
  - Identifying foods that decrease cancer risk
  - Identifying health risks of sweetened beverages

- Provide education:
  - Distribute nutrition materials to healthcare providers
  - Support Department of Education school nutrition curriculums
  - Support quality foods through food stamp program
  - Increase knowledge about the benefits of fruits and vegetables
  - Increase skill in food preparation
  - Develop website resource for healthy eating
  - Support and encourage use of gardening programs
  - Provide education programs to all food stamp recipients
  - Provide information on most recent dietary guidelines

- Increase access to healthy foods:
  - Advocate for healthy choices in restaurants
  - Advocate for healthy vending choices
  - Facilitate grocery store access
  - Increase the number of vans/buses that provide transportation for shopping
  - Encourage healthy choices in convenience stores
  - Encourage 5 A Day grocers
  - Encourage community gardens

- Promote policy and legislation for:
  - Increased tax on low quality foods
  - Policy in school/public buildings related to vending
  - Policy regarding school meal programs
  - Policy related to food stamps and quality foods allowed

Strategy:
Increase physical activity to at least 30 minutes every day.

Baseline- 46.5 percent of adults did meet recommended guidelines for moderate physical activity (South Dakota 2003 Behavior Risk Factor Surveillance Survey (BRFSS))
Target- 50 percent of adults meeting physical activity guidelines (South Dakota Department of Health Healthy People 2010 Initiative)

Outcomes
- A reduction in TV viewing.
  - Reduction in TV viewing is an assumed outcome of increased physical activity.
- Creation of environments that promote physical activity

Action Steps
- Create point of decision prompts to encourage physical activity for schools and worksites.
- Support and promote worksite health promotion programs. Provide incentives to employers/employees that provide worksite health programs.
- Assess community needs and develop individualized physical activity plans for them.
- Monitor collaborations of other organizations and utilize resources available.
- Secure funding for statewide physical activity programs.
- Provide information on economic benefits of physical activity.
- Support a policy for daily physical education in schools.

Strategy:
Increase number of South Dakotan's who practice sun protection behaviors.

Outcomes
- Increased number of youth and adults who are aware of the potential harm in unprotected UV exposure.
- Increased number of youth and adults who use sun protective measures.

Community Themes
- Limit smoking in public places
- Enforce youth tobacco policies
- Require physical activity and healthy eating in child care and school settings
- Use culturally relevant methods for health behavior change
- Address sun exposure

Action Steps
- Collaborate with existing entities to provide information on the dangers of sun-exposure and sun-protective measures.
- Advocate for a policy for sun safety programs in schools.

Strategy:
Increase the participation of consumers in their health care.

Outcome

- Increase patient participation in routine health care provider appointments.
  - No data is currently available to measure patient participation in routine health care provider appointments.

Action Steps

- Provide information on recommended screenings; for example the American Cancer Society or the American College of Obstetrics and Gynecology recommended screening guidelines.
- Develop a guideline for routine health care provider appointments.
- Provide information on suggested questions to ask your health care provider.
- Make prevention information available through health care providers.

Photo by South Dakota Tourism

Early Detection

Effective screening for cancer will provide detection at earlier stages when treatment is more likely to be successful. Screening has been shown to reduce mortality from cancers of the breast, uterine cervix, and colon and rectum. There are other cancers for which screening may be associated with lower mortality, but evidence of these is less certain.

Evidence supports the effectiveness of routine screening. To encourage routine screening guidelines, such as those published by the American Cancer Society, have been established. If a person is not screened regularly, but rather waits until symptoms appear it is much more likely that the cancer will be discovered at a later stage. Additionally, studies show that people who receive a clinician's recommendation for cancer screening are more likely to be screened compared to those who do not receive a recommendation. Studies document that people who lack health care insurance have reduced access to preventative care and are less likely to get timely cancer screening examinations. Multiple interventions directed at patients, physicians, and health care systems may provide the best approach to improving rates of cancer screenings.

Photo by South Dakota Tourism

Early Detection

Goal: To increase appropriate screening and early detection for cancer

Colorectal Cancer

Colon and rectal cancers are the third leading reported cancer and the second leading cause of cancer death in South Dakota. Colorectal cancer screening reduces death from colorectal cancer. It can also prevent the development of colon cancer by identifying and removing benign polyps, from which colon cancer often develops. Early diagnosis and treatment of colorectal cancer results in a survival rate of greater than 90 percent (American Cancer Society- Cancer Prevention & Early Detection Facts & Figures 2005).

Colorectal cancer deaths are decreasing in South Dakota with the 1993-2002 10 year trend in death rates of –1.2 annual percent change (APC). However, males had an increase in deaths with an APC of 2.6 while females had a decrease in deaths at a –3.3 APC.

As a result of collaboration among partners working toward colorectal cancer control we will increase the number of persons receiving recommended colorectal cancer screenings.

Baseline- (South Dakota 2002 Behavioral Risk Factor Surveillance System)

- 29 percent of adults age 50 years and older reported having had a fecal occult blood test (FOBT) within the preceding two years
- 41.8 percent of adults age 50 and older reported having ever had a sigmoidoscopy / colonoscopy.

Target- 50 percent of adults age 50 and older receiving colorectal cancer screening (Healthy People 2010)

Increase the number of those diagnosed with colorectal cancer at in situ or localized stages.

Baseline- 35 percent (Cancer in South Dakota 2001)

Target- 50 percent (CCC Workgroup)

Strategy:

Promote the importance and benefits of colorectal cancer screening with personal empowerment messages.

Outcomes

- South Dakotans will have increased exposure to colorectal cancer screening facts and information.
- There will be an increased number of patients speaking to healthcare providers about colorectal cancer screening.
  - No data currently available to measure these outcomes.
  - Measurements to be established.

Action Steps

- Review educational materials, awareness materials and media campaigns available for the public and medical providers.
- Select and implement campaigns to increase public and medical provider awareness of colorectal cancer risk factors, screening tests, and individual roles/responsibilities.
- Utilize Behavioral Risk Factor Surveillance System to monitor progress.

Strategy:

Ensure healthcare providers provide or refer patients to appropriate screening and follow-up services for colorectal cancer.

Outcomes

- Enhanced technology to simplify a screening reminder system.
- Increased number of patients receiving colorectal cancer screening.

  Baseline- (South Dakota 2002 Behavioral Risk Factor Surveillance System Data)
  - 29 percent of adults age 50 years and older reported having had a fecal occult blood test (FOBT) within the preceding 2 years
  - 41.8 percent of adults aged 50 and older reported having ever had a sigmoidoscopy

  Target- 50 percent of adults age 50 and older receiving colorectal cancer screening (Healthy People 2010)

Action Steps

- Provide accurate information on colorectal cancer screening to healthcare providers through continuing medical education opportunities.
- Support efforts to implement systems to assist clinicians in counseling at-risk patients about screening and to manage referrals and follow-up.
- Support efforts to implement reminder systems for screenings.

Strategy:
Eliminate disparities and barriers to colorectal cancer screening and diagnostic services.

Outcome

- Decrease the number of barriers to colorectal cancer screenings for underserved populations.
  - No data presently available.

Action Steps

- Identify and address gaps in access and capacity for colorectal cancer screening services using the Centers for Disease Control and Prevention's state Survey of Endoscpoic Capacity Report (CDC SECAP).
- Analyze legislative mandates and insurance coverage for cancer screening to determine gaps and advocate for reducing the gaps.

Photo by South Dakota Tourism

January 29, 1999, was the day that forever changed my life. It was the day my Dad was diagnosed with end stage colon cancer. I remember thinking as I made the drive that day to see him in the hospital, "this has to be bad. In my 29 plus years, Dad has never been in a hospital." After a two plus year fight, many rounds of chemotherapy, two surgeries and many tears, my Dad died in November 2001 at the young age of 59, leaving my family and I wondering had his doctor ordered a colonoscopy 10, five or even three years sooner, would he be here today?

Tyann Gildemaster

Breast Cancer

Breast cancer is the most common cancer among women in South Dakota (Cancer Burden in South Dakota). Breast cancer screening has been shown to reduce breast cancer mortality (American Cancer Society- Cancer Prevention & Early Detection Facts & Figures 2005). The five-year relative survival rate for localized breast cancer is 97 percent -i.e. if the cancer has not spread to other locations and/or into the lymph nodes (Cancer Burden in South Dakota).

White women had an incidence rate three times that of American Indian women, however, age-adjusted mortality rate is higher among American Indian women than for white women. (Cancer Burden in South Dakota)

An increase in the number of American Indian women receiving recommended screenings will translate into a lower mortality rate.

Baseline- 86.9 percent of women over the age of 40 have received a mammogram with the preceding two years (South Dakota 2002 Behavioral Risk Factor Surveillance System)

Target- 90 percent of all women age 40 and older receiving a mammogram with in the preceding 2 years (CCC Workgroup)

Strategy:

Eliminate disparities and barriers to breast cancer screening and diagnostic services.

Outcomes

- A decreased number of advanced stage breast cancer diagnoses.
  - Late-stage diagnosis of breast cancer:
    4 percent of breast cancers in SD were diagnosed at the distant stage. Nationally it has been 7 percent from 1992-1999. (SD Cancer Registry Data, 2002)

- Eliminate barriers that prevent women from seeking and receiving screening services.
  Baseline- 39.4 percent of American Indian women ages 50 and older reported having had a clinical breast exam and mammogram within the preceding two years (South Dakota 2002 Behavioral Risk Factor Surveillance System)
  Target- 90 percent of American Indian women ages 50 and over receiving a mammogram within the preceding two years (CCC Workgroup)

Action Steps

- Identify and address gaps in access and capacity for breast cancer screening services.
- Develop resources and access for women in South Dakota to address disparities of minority/ethnic/rural/underinsured or uninsured and others who have not been screened for breast cancer.
- Support and increase utilization of the "All Women Count!" (AWC!) program in South Dakota.
  - Seek additional funding to expand diagnostic services.
  - Seek additional funding to expand ability to pay for screenings of those outside current AWC! Guidelines (lower age from 50 years to 40).

Strategy:

Promote the importance and benefits of breast cancer screening with personal empowerment messages.

Outcome

- Increased awareness of breast cancer screening importance.

The following question was included in the 2001 South Dakota BRFSS:

Asked of women who had not had a mammogram:

What was the most important reason for not having a mammogram:

-Not recommended by doctor/doctor never said it was needed 26.4 percent

-Not needed/not necessary 23.1 percent

Respondents who have heard of the "All Women Count!" Program:

Yes- 30.5 percent No- 69.5 percent

Action Steps

- Disseminate culturally appropriate materials for informed decision making on breast cancer screening.
- Target women in underserved counties.

Strategy:

Assure healthcare providers provide or refer patients to appropriate screening and follow-up for breast cancer.

Outcome

- Expansion of "All Women Count!" services.
  Women enrolled in "All Women Count!"("AWC!") (May 2005)
  Total enrollment from 3-18-1997 to 5-11-05 = 8,492 women

  Present "All Women Count!" enrollment criteria:
  - 30-64 years of age for cervical screening
  - 50-64 years of age for non-symptomatic breast screening
  - Income <200% of the federal poverty income guideline

Action Step

- Update primary care providers to changes to established guidelines through "All Women Count!" program, continuing medical education opportunities, and the South Dakota Foundation for Medical Care.

Community Themes

- Promote colonoscopy
- Clarify prostate cancer screening objectives
- Consistent information on age appropriate screenings, cost and insurance coverage
- Promote "All Women Count!"
- Better screening access for uninsured and underinsured

Photo by South Dakota Toursim

Cervical Cancer

Cervical cancer is one of the most successfully treatable cancers (American Cancer Society- Cancer Prevention & Early Detection Facts & Figures 2005). The Pap test examines cervical cells that are removed during examination and can detect cancer and pre-invasive conditions or lesions. Pre-invasive lesions are 100 percent curable. At early stages, women with localized lesions have a five-year survival rate of 92 percent (Cancer Burden in South Dakota).

The age-adjusted incidence rate for American Indian women is twice that of the rate for white women in South Dakota. The mortality data showed American Indians with a six-fold rate of death when compared to whites and to the South Dakota totals for 2001 and for the five-year period 1997-2001 (Cancer Burden in South Dakota).

Through collaborative efforts the number of women receiving Pap tests will increase.

Baseline- 88.4 percent of adults age 18 years and older who reported having had a pap test within the preceding three years (South Dakota 2002 Behavioral Risk Factor Surveillance System)

Target- 90 percent of women age 18 years and older who receive a Pap test within the preceding three years (Healthy People 2010)

Increase the number of those diagnosed at the localized stage.

Baseline- 53 percent (Cancer in South Dakota 2001)

Target- 75 percent (CCC Workgroup)

Strategy:

Promote the importance/benefits of cervical cancer screening with personal empowerment messages.

Outcomes

- Increased knowledge of cervical cancer screening importance.
- Increased knowledge of the connection between sexually transmitted diseases and cervical cancer.

-Currently there is no data to measure these outcomes.

Action Steps

- Disseminate culturally appropriate materials for informed decision-making on cervical cancer.
- Support educational efforts for men and women on the connection between Human Papilloma Virus (HPV) and cervical cancer.

Strategy:
Engage physicians in screening or referring patients to appropriate screening for cervical cancer.

Outcome

- Enhanced communication system to inform health care providers of changes in guidelines.
  - Currently there is no data to measure these outcomes.

Action Step

- Update primary care providers of changes to established guidelines through "All Women Count!" program, continuing medical education opportunities, and the South Dakota Foundation for Medical Care.

Strategy:
Eliminate disparities and barriers to cervical cancer screening and diagnostic services. (High priority population - American Indian women)

Outcome

- Reduce barriers that prevent women from seeking and receiving screening services.
  Of women enrolled in the "All Women Count!" Program (May 2005)
  - American Indian: 1,399 women or 16 percent
  - Other: 216 women or 3 percent
  - Unknown/no response: 108 women or 1 percent

  - Explore more population based data sources.

Action Steps

- Identify and address gaps in access and capacity for cervical cancer screening services.
- Develop resources and access for women at risk (age 18 and older) in South Dakota to address disparities of minority/ethnic/rural/underinsured or uninsured and others who have not been screened for cervical cancer.
- Support and increase utilization of the "All Women Count!" program in South Dakota (currently serving ages 30-64 for cervical cancer screening).
  - Seek additional funding to expand diagnostic services.
  - Seek additional funding to expand ability to pay for screenings of those outside current guidelines.

Prostate Cancer

Prostate cancer is the most common cancer in males. However, the five-year survival rate for cases diagnosed in the localized and regional stage is 100 percent (Cancer Burden in South Dakota). The American Cancer Society and other medical organizations are in agreement that shared decision making about testing for early prostate cancer should occur between men and their doctors.

Strategy:

Promote informed decision-making related to prostate cancer screening for all men.

Outcome

- A decreased mortality from prostate cancer

  Baseline- 33.6 deaths per 100,000 people (Cancer in South Dakota 2001)
  Target- 28.8 deaths per 100,000 people (Healthy People 2010)

Action Steps

- Review educational materials, awareness materials and media campaigns available for the public and medical providers.
- Select and implement campaigns to increase public and medical provider awareness of prostate cancer risk factors, screening tests, and individual roles and responsibilities.

Skin Cancer

Skin cancers are the most common cancers. Most skin cancers are basal cell and squamous cell carcinomas that are highly curable. Melanoma is more dangerous because it can quickly spread but it is also highly curable if detected early. For localized melanoma, the five-year survival rate is 97 percent (Cancer Burden in South Dakota).

Strategy:

Encourage people to speak to a medical provider immediately regarding skin changes.

Outcome

- Decreased mortality from skin cancer

  Baseline- 2.6 deaths per 100,000 people (Cancer in South Dakota 2001)
  Target- 2 deaths per 100,000 people (CCC Workgroup)

Action Steps

- Review educational/awareness materials and media campaigns available for the public and medical providers.
- Select and implement campaigns to increase public and medical provider awareness of skin cancer risk factors, skin examinations/ABCDE rule, and individual roles/personal empowerment.

Treatment

After cancer is diagnosed there are decisions to be made, information to be considered and much to learn. Easily accessible information on treatment options and access to quality care are factors that increase survival rates.

Successful treatment is a partnership that involves health care providers, patients and their families and supporters. While family members and supporters are sometimes reluctant to become involved, having the option is essential. When patients understand their treatment and feel a part of the treatment decisions they are more likely to complete their treatment despite expected side effects.

Typically, treatment options include surgery, chemotherapy, and radiation therapy, and immunotherapy alone or in combination, depending on the site, the type, and the stage of the cancer diagnosis. Palliative treatment is aimed at relieving symptoms.

Access to quality cancer treatment is limited in South Dakota by lack of health insurance, cost of care, geographic location, travel time, transportation, education, cultural and language barriers. These barriers can influence treatment decisions and completion of the treatment plan.

South Dakota was one of the first four states to implement the Federal Breast and Cervical Treatment Act of 2000 (BCCPTA). This allows states to provide full Medicaid benefits for income and age eligible women who have a breast or cervical cancer diagnosis for the duration of their treatment. The women must be without insurance coverage and enrolled in the All Women Count! Program. This federal legislation has helped to address the ethical issue of offering free screening without viable treatment options.

Community Themes

- Address indirect and direct cancer costs
- Improve local access to care
- Improve culturally competent care of American Indian people
- Reduce delays in cancer care

Geographic Distance From the Cancer Center May be a Treatment Barrier for American Indians Undergoing Radiotherapy – a retrospective study done by Rapid City Regional Hospital in western South Dakota.

- Median distance from cancer center to home was 109 miles
- 37 percent of patients traveled at least 150 miles each way

Voice of the Community

"It just costs too much to have cancer. Time off work, yet no sick leave. Travel to Rapid City , but nowhere to stay at a low cost. Insurance co-payments, medications and supply costs, these all add up."

Treatment

Goal: To assure that all persons diagnosed with cancer receive the best possible care.

Strategy:
Improve access to and utilization of cancer treatment facilities in order to encourage patients to complete their course of treatment.

Outcome

- An increased number of patients completing their course of treatment without interruptions due to travel, lodging or social issues.
  - No data is presently available

Action Steps

- Assess affordable housing options for patients receiving cancer treatment in seven regional cities in South Dakota.
- Develop a survey for cancer treatment facilities to establish baseline data on patients involved in treatment, the barriers encountered, and the supports enabling treatment completion.
- Assess barriers to a radiation treatment facility to serve people in central South Dakota.

Strategy:
Increase the number of South Dakotans with cancer who receive the most up to date treatment and follow-up, based on current standards of care.

Outcomes

- Increased number of persons with cancer who have information to make decisions about their cancer treatment.
- Increased number of health care providers following current standards of care.
  - Baseline to be established.

Action Steps

- Promote among health care providers the awareness of current clinical care guidelines regarding breast cancer, colorectal cancer, prostate cancer, cervical cancer, and other sites.
- Promote the awareness of existing resources, including the internet, providing balanced and accurate information about cancer treatment options, outcomes, and quality of life.
- Increase patient and family awareness of symptom management for cancer treatment to promote completion of the treatment plan.
- Provide information to cancer patients about facilities in South Dakota where cancer treatment is available.

Strategy:
Increase the number of physician specialists who serve cancer patients in communities where health disparities exist.

Outcomes

- An increased number of cancer specialists providing services through the Indian Health Service.
- An increased number of cancer specialists in more rural locations.
- Decrease in the time from initial presentation to diagnosis and treatment for American Indians in South Dakota.
  - No data is presently available

Action Steps

- Explore with Indian Health Service (IHS) the advantages and issues of centralized credentialing of specialists in IHS facilities.
- Educate tribal administrative boards on the benefits of centralized credentialing.
- Assist in the process of re-drafting policies and protocols for credentials when that becomes appropriate.

Photo by South Dakota Tourism

Pat Urdahl
Breast Cancer Survivor and Administrative Assistant,
Indian Health Service, Aberdeen Area Office

At age 56, I had never had a mammogram. Why would I? No one in my family had ever had cancer, so certainly I was not at risk. On September 12, 1999, I noticed a lump on the upper portion of my breast but told myself that the dog must have scratched me hopping out of her bath. It couldn't be anything else. After all, no one in my family had ever had cancer. On October 15, 1999, I was in for a yearly check-up, and Theresa Cameron, PA, convinced me to have a mammogram. She scheduled it for that week. I never told her about the lump, and I did not know if she suspected it, which would account for her insistence on the test. After the sonogram, the radiologist said she would schedule me for surgery immediately. What I had not told even my husband was that deep down I knew it was the big "C."

I decided to undergo care in Fargo, ND, where my daughter lives. I knew I would need her support. I felt sort of out of control, not sure of my decisions and very scared. My daughter, Anita, set up everything for me and kept track of my venture into "Cancerland." My husband, Tom, continued in his role as my prayer warrior, only it became full-time. My daughter Carmen came from Colorado for support, calling up several prayers chains to sustain us. While waiting to go into surgery, Tom read me verses from the Bible. Before I was taken off to the surgical area, my daughters, a pastor, my husband, and members of the hospital staff surrounded me and prayed for God's will. I was extremely nervous. After I was alone in the surgery holding area, the Lord sent a Christian nurse to be with me. She prayed for me, and I was totally at peace with whatever happened. The surgery went well. Dr. Lindquist performed a lumpectomy with sentinel lymph node dissection to see which, if any lymph nodes were affected. By doing this, the procedure was less invasive. She only had to go into two lymph nodes. After the results of the pathology report were in, the surgeon and oncologist were sure they had gotten it all, much to our relief. They scheduled me for one month of radiotherapy treatments. My follow-up has been Tamoxifen therapy for five years; I still follow-up with my oncologist every six months, and I have a mammogram and a sonogram once a year.

It has been a life changing experience for my family. Anyone can get cancer, and I feel my having it has done some good things. My daughters are now aware that they are at risk, and have had baseline mammograms in their thirties. Many of my friends and extended family went for mammograms for the first time. One friend was found to have a malignant tumor stage two. I think my method of holding myself together through all this was having the support of my family, always with a sense of humor, all the prayer support, knowing and trusting in the Lord as my personal Savior, and the wonderful surgeon and her staff. I also think growing up on the Ft. Berthold Indian reservation in North Dakota has given me a real sense of who I am.

Survivor Issues

Everyone is potentially at risk for cancer. If current trends continue, one-third of Americans will be diagnosed with cancer in their lifetime (NCI, 203a).

The diagnosis of cancer is not the same as it once was. With the improvements in early detection, research and treatments more and more people are becoming cancer survivors.

> *"When cancer was considered incurable, the term 'survivor' was used to describe family members who survived the loss of a loved one to cancer. As knowledge and success in understanding cancer increased, physicians began to use a 5-year time frame to define survivorship. If cancer did not recur in the five years following either diagnosis or treatment, patients were considered to have become 'survivors.'"*
>
> Lance Armstrong Foundation

Currently, the definition of survivor has expanded to include a wider circle of those affected by the disease. The Lance Armstrong Foundation and the Centers for Disease Control and Prevention now define a survivor as those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers. A person becomes a cancer survivor at the moment of diagnosis and continues to be a survivor throughout the remainder of his or her life.

With over 4,000 new cancer cases expected in South Dakota in 2005, the number of cancer survivors continues to grow. The diagnosis of cancer affects every part of a person's life. Cancer takes a toll physically, financially, and spiritually. It is with this in mind that we set out to address some of the obstacles that cancer survivors face on a daily basis.

Voices of the Community
"People out here (rural SD) look out for one another. Food appears on your doorstep. The men in the church congregation meet to plan for your travel to radiation treatment. People come and clean the house. It just happens."

Survivor Issues

Goal: To advocate for the needs of the increasing number of persons who have ever had a cancer diagnosis.

Strategy:
Increase access to, and utilization of a comprehensive, statewide information resource directory to include comprehensive cancer information, resources, services and cancer survivor activities.

Outcomes

- An increased awareness of community resources for survivors.
- An improvement in the quality of life through usage of local, regional and national resources and through participation in cancer survivor activities.
- A decrease in gaps in services and information regarding those services throughout the state.
- An improvement in the quality and effectiveness of survivor cancer care for all populations including the underserved and minority populations.

Action Steps

- Identify collaborative programs to populate the directory.
- Use the current Community Resource Database as the framework.
- Develop media plans to promote the directory.
- Locate existing agendas and programs through which the directory can be promoted.
- Utilize a personal faces, personal stories approach for promotion of the project.
- Establish data gathering systems to monitor progress toward accomplishing strategies.

Strategy:
Promote the development and use of culturally and linguistically appropriate materials and methods for cancer care and education.

Outcomes

- Increased awareness of cultural, linguistic, gender, literacy and age unique survivorship needs.
- Increased availability and use of culturally, linguistically, gender, literacy and age appropriate materials for cancer care and education.
- An improvement in the quality and effectiveness of survivor cancer care for all populations including the underserved and minority populations.
- A decrease in gaps in services and information throughout the state.

Action Steps

- Identify issues specific to patients, providers, and family/community.
- Develop a provider education plan.
- Assist with capacity building of state wide medical providers.
- Identify collaboration resources for providers in rural and reservation areas to work with providers from urban areas.
- Develop a long-term mechanism to keep providers informed of events, opportunities, current research studies and programs available for use in their practices and for educating and updating patients regarding treatment options.
- Develop a list of orientation resources for cross cultural training.
- Ensure the availability and use of culturally, linguistically, gender, literacy and age appropriate materials for cancer care and education.
- Identify process measures to monitor progress toward strategies.

Strategy:

Improve access to quality care in South Dakota through reducing financial and geographic barriers and by increasing the proportion of residents who have a source of primary care.

Outcomes

- Reduced disparities in cost and outcomes for cancer care.
- Improved quality of life for survivors and families.
- Reduced cancer burden for the state of South Dakota.
  - See "Cancer in South Dakota" annual cancer registry report for site specific and aggregate data.
- Improved availability and quality of providers for all areas of South Dakota.

Action Steps

- Reduce financial barriers to cancer care, for example:
  - Explore employment and insurance issues related to cancer survivorship.
  - Identify successful approaches used in other states.
  - Increase affordable health insurance coverage for all South Dakota residents, especially to those already diagnosed with cancer.
  - Provide immediate medical coverage for the uninsured and supplemental coverage for the underinsured upon a diagnosis of cancer.
  - Examine the cost of cancer services and develop a statewide financial aid system to help offset the expense of a cancer diagnosis, treatment, and ongoing monitoring and services.
  - Support/promote legislation to expand financial resources available to provide cancer treatment, by expanding Medicaid and subsidizing health insurance premiums for low-income cancer patients.

- Expand retrospective study of Rapid City Regional hospital to establish statewide baseline and progress on disparities.
- Develop a method to measure the cost of cancer in South Dakota.

- Reduce geographic barriers to cancer care
  - Assess access to transportation, housing, home health/hospice, respite care and psychosocial services in rural and reservation communities.
  - Extend state of the art cancer care to rural and other underserved areas by expanding the use of telemedicine.
  - Explore incentives to practice in medically underserved areas.
  - Promote development of patient navigator programs that help people obtain cancer information, screening, treatment, and supportive services.

- Increase the proportion of South Dakota residents who report having a usual source of primary care.
  - Promote programs that provide incentives for medical professionals to work in primary care.
  - Promote programs that increase availability of primary care medical professionals in rural and underserved communities.
  - Educate the public on the importance of establishing a usual source of primary care.

Strategy:
Establish effective Comprehensive Cancer Control (CCC) and member organization advocacy groups for cancer related public policy and legislative priorities.

Outcomes
- CCC and member organizations are engaged in effective advocacy for CCC priorities.
- Public policy and legislative leadership will support CCC priorities.
- Public policy and legislative actions that positively impact CCC priorities and the South Dakota cancer burden will be implemented.
  - Anecdotal data will be used to measure progress.

Community Themes
- Better communication about cancer
- More support groups
- A better system of support for family members

Action Steps

- Develop overall CCC public policy objectives and priorities and communicate those to stakeholders and policymakers:
  - Establish cross workgroup public policy priorities
  - Establish workgroup public policy responsibilities
  - Develop process and guidelines for working with policy makers and legislators.
  - Provide policy makers with information about CCC and its priorities.
  - Provide member organizations with appropriate information for key legislation related to CCC priorities.
  - Provide information and training to CCC members.

- Develop plan to support CCC public policy priorities:
  - Protect and enhance existing laws assuring health insurance coverage of cancer screenings.
  - Support legislation to expand financial resources available to provide cancer treatment.
  - Ensure that health insurance and managed care plans facilitate prompt access to appropriate cancer screening, treatment and supportive services including clinical trials.
  - Develop transportation and housing assistance programs with tax credits for those donating services for cancer patients.
  - Eliminate public exposure to secondhand smoke.
  - Establish policies that prevent employers and insurance companies from discriminatory actions as a result of genetic information including disclosure, denial or limitation of coverage for individuals or relatives, differential rates, or employment issues.

Photo by South Dakota Toursim

End of Life / Palliative Care

The purpose of palliative care is to relieve symptoms and side effects of cancer and cancer treatment in order to improve quality of life. The World Health Organization defines palliative care as "the active total care of patients whose diseases are not responsive to curative treatment. Symptom control is paramount and includes the alleviation of symptoms whether they are physical, psychological, social, or spiritual. The goal of palliative care is the achievement of the best possible quality of life for patients and their families." Most often palliation is referred to as pain control, but it also includes symptoms such as nausea, vomiting, loss of appetite and fatigue. Some people think of palliative care as end of life care but it can be part of a patient's care at any time during their cancer treatment.

Hospice provides physical, social, emotional and spiritual care to terminally ill patients and their families when the life expectancy is around six months and they are no longer seeking cure-oriented treatments. The goal of hospice care is to improve the quality of a patient's last days by offering comfort and dignity. It addresses all symptoms of a disease, with a special emphasis on controlling a patient's pain and discomfort. Hospice care neither hastens nor postpones death. Palliative care, ideally, will segue into hospice care as the illness advances.

To achieve the type of comprehensive care needed an interdisciplinary team of physicians, nurses, social workers, chaplains, pharmacists, volunteers, and dieticians must work together.

In November of 2002 a report was released by the *Last Acts* coalition that rated several areas of South Dakota's end of life care.
Findings:

- Only 13 percent of South Dakota residents used hospice.
- Only 27 percent of South Dakota hospitals offered a pain management program.
- Only 39 percent of South Dakota hospitals offered hospice programs.
  South Dakota is doing a very poor job of training nurses and a mediocre job of training physicians in palliative care. Only 0.12 percent of nurses and 0.27 percent of physicians are certified in palliative care.
- South Dakota received a grade of 2.5 out of a possible 5 on advance planning care.

Dying to Know – A study was done in Sioux Falls, South Dakota to create a profile of knowledge and attitudes about dying and end of life care.
Findings:

- 50 percent have never heard of hospice or have heard 'a little' about hospice.
- 65 percent would want hospice support if they were dying.
- 67 percent would prefer hospice at home.
- 43 percent said their doctor should initiate end of life conversation.
- 30 percent had a living will, durable power of attorney or advance directives.

End of Life / Palliative Care

Goal: To maintain an optimum quality of life until death.

Strategy:
Determine where the gaps in access to end of life care exist in South Dakota. Address gaps found.

Outcome

- Gaps in access will be identified, prioritized, and action plans developed to address gaps.

Community Themes

- Improve access to hospice training for rural communities
- Assure local hospice care providers
- Educate tribal leaders on cancer an end of life care

Action Steps

- Assess the attitudes of South Dakotans about dying and end of life care by replicating the *Dying to Know* study in additional South Dakota communities.
- Gather information on end of life programs available in South Dakota to include location and service area, model types, and providers through surveys, South Dakota vital statistics and networking with other related departments/programs that provide any type of end of life care.
- Assess the availability and consistency of quality of life care for the pediatric cancer patient.
- Explore other models of end of life care for feasibility and practicality such as additional elder housing, telehospice, and residential hospice in hospitals.
- Determine gaps in access and utilization of hospice services by the American Indian population.
- Research and apply for grant funding to increase access to hospice and palliative care services.

Strategy:
Education of general public and healthcare providers to increase awareness/knowledge of hospice and palliative care in order to increase utilization of programs focused on end of life care.

Outcome

- Increased access, referral and length of stay for hospice and palliative care patients in South Dakota.
  - Average length of stay in hospice is 27 days (Last Acts)
  - Use of hospice in South Dakota is 13 percent (Last Acts)
  - Target to be established.

Action Steps

- Expand on existing end of life curriculum and in-service opportunities for health care workers, social workers, clergy, volunteers, etc..
- Include end of life education for schools preparing nurses, social workers, pharmacy workers, and clergy.
- Develop education for physicians on how to transition from a curative to a palliative care plan.
- Develop education for physicians on pediatric palliative care.
- Develop education for public and health care providers on advance care planning and on the benefits of palliative care and hospice.
- Educate/update local health care providers on hospice and palliative care services in their region.
- Educate the public and health care providers on the services provided by hospice and palliative care units.
- Reach patients earlier and increase length of stay in end of life programs.
- Expand data sources to establish targets.

Voice of the Community
"We need (hospice) nurses and volunteers who know us here in this community. We need training. Why don't we get training out here in the rural areas?"

Strategy:
Education of health care providers on pain management issues.

Outcome

- Increased knowledge of pain management for health care providers.
  - 45 percent of non-hospice residents report persistent pain (Last Acts)

Action Steps

- Seek out an existing group for collaboration.
- Develop and disseminate information on pain management to health care providers.

Strategy:
Develop strategic partnerships with primary care, clergy, legal services and others.

Outcome

- A comprehensive delivery of hospice and palliative care services.
  - No data is presently available.

Action Steps

- Identify possible partners.
- Establish open communication with partners.
- Explore and develop collaborative relationships with partners.

Research / Data

Cancer surveillance is the systematic collection of specific information about cancer cases. It includes demographic information as well as details about the cancer itself. By South Dakota law a list of data elements about each cancer case is required to be reported by healthcare providers to the South Dakota Department of Health within six months of most cancer diagnoses. This information is kept confidential.

This cancer reporting is important because it allows health professionals to identify risk factors causing cancer, to calculate morbidity, mortality, and survival rates to determine cancer burden at the state and local level and to make comparisons with national data. It is also important to epidemiologists as they analyze trends to discover patterns in the cancer burden and to provide advice on control and prevention measures. Researchers can identify risk factors, develop new ways to detect cancer at its earliest stages and look at patterns in cancer development. Environmental risk factors are also be studied to determine their association with cancer diagnosis. The South Dakota Cancer Registry in the Department of Health is the entity responsible for collecting, analyzing, reporting, and maintaining the cancer data for the state of South Dakota.

Clinical trials are research studies that involve people. Clinical trials must take place in order to take new treatments out of a scientist's laboratory and into the oncology centers. Clinical trials try to answer specific questions about new and better ways to screen, detect, prevent and treat various types of cancer. Most of the advances in cancer care that are common now, were once in clinical trials. While there are many benefits from trials, the number of cancer patients who enroll remains low. There are many causes of low enrollment such as lack of awareness, knowledge and access to trials. It is the purpose of this part of the plan to increase cancer surveillance, encourage use of data for research and assist cancer patients' awareness of clinical trials and encourage those who meet research criteria to enroll in cancer clinical trials.

Other forms of non-clinical research will also be needed to overcome health disparities in South Dakota. Research that is respectful of American Indian values and beliefs as well as responsive to their needs is an important component. Community-based participatory research (CBPR) has been identified as the preferred form of research within American Indian communities in South Dakota. CBPR is a process by which the community works directly with the researcher to identify the problem, develop the research protocol that will address the problem, and release the results of the research back to the community. This plan will encourage community-based participatory research in South Dakota in hope that the needs of our American Indian population can be met through partnership with researchers and research institutions.

Research / Data

Data Goal: Increase the scope of the statewide cancer surveillance system.

Strategy:
Improve cancer reporting to a statewide population based surveillance system

Outcomes

- Increased number of facilities, health care providers, health care facilities, pathology laboratories and free standing radiology centers that report each cancer case detected to the state surveillance system.
  - Baseline- Currently all American College of Surgeons (ACoS) facilities, pathology laboratories, three small hospitals and a number of clinics report cancer cases.
  - Target- All healthcare facilities, clinics, free standing radiology centers and health care providers will be reporting cancer cases to the central registry.
- The South Dakota Cancer Registry (SDCR) will meet all North American Association of Central Cancer Registries (NAACCR) and National Program of Cancer Registries (NPCR) requirements for the gold standard accreditation and publication.
- All facilities will meet North American Central Cancer Registries and National Program of Cancer Registries mandate requirements for completeness, timeliness, and data quality.

Action Steps

- Educate legislators and the public about the importance of the cancer surveillance system.
- Work with associations such as the South Dakota Medical Association, radiologists, dermatologists, and hospitals who do not currently report to inform them of new reporting laws and rules.
- Train current and new facilities on new mandate requirements.
- Assess and develop leading cancer indicators in addition to those listed by the Council on State and Territorial Epidemiologists. These should include incidence and mortality information and 2010 Healthy People goals as well as stage and behavioral risk factors.
- Establish feedback mechanisms for users of cancer surveillance information.
- Facilitate training opportunities for cancer registrars in South Dakota.
- Increase the number of Certified Tumor Registrars in South Dakota.
- Explore ways to reduce barriers in how data is reported to communities and tribal health leaders.

Strategy:
Ensure infrastructure and staffing are available to effectively implement all functions of the statewide surveillance system.

Outcomes

- The South Dakota Cancer Registry will obtain 98 percent completeness of all cancer cases detected to meet the North American Association of Central Cancer Registries Gold Standard and publication criteria for national data.
- Increased cancer surveillance staff from two to three people.

Action Steps

- Hire consultant (s) equal to one FTE (full time equivalent) position.
- Provide a mechanism for systems to provide feedback on what is currently working and what needs to be enhanced.
- Train current and new facilities about case ascertainment and reporting new cases.
- Increase the number of Certified Tumor Registrars in South Dakota.
- Communicate reporting changes to hospital registrars through virtual town hall meetings.
- Facilitate training opportunities for cancer registrars in South Dakota.

Strategy:
Disseminate cancer surveillance data to increase cancer awareness, provide cancer disparities information, and promote the implementation of cancer control programs and policy.

Outcomes

- A link on the South Dakota Department of Health website will be created for people to generate user-defined reports of cancer data from the cancer surveillance system.
- The South Dakota Cancer Registry Annual Report will be disseminated within six months of the end of the reporting year (e.g. 2002 report will be disseminated by July 2005)
- Data will be disseminated in press releases to increase media coverage for cancer-related findings.

Community Themes

- Clear, simple communication of comparative cancer rates
- Share cancer research findings with the public

Action Steps

- Prepare press releases for American Indian news sources to report findings.
- Establish feedback mechanisms for users of cancer surveillance information.
- Explore ways to reduce barriers in how data is reported to communities and tribal health leaders.
- Continue to report the relationship between behavioral risk factors, incidence and mortality cancer data.
- Explore the feasibility of creating a link between the South Dakota Department of Health website and the cancer registry system.

Strategy:

Support efforts to increase melanoma cancer reporting to the South Dakota Cancer Registry.

Outcomes

- Increase the number of expected cases reported to the South Dakota Cancer Registry.

  Baseline- <50 percent of expected cases of melanoma reported in 2001 (Cancer Burden in South Dakota)

  Target- 95 percent (accreditation standard, North American Association of Central Cancer Registries)

Action Steps

- Review current reporting structure and requirements.
- Advocate for reporting.

Photo by South Dakota Tourism

Research Goal: Increase awareness of cancer research projects in the state and support the translation of research into practice.

Strategy:
Provide mechanisms to communicate and increase awareness of published research projects, data, and results in a timely and efficient manner.

Outcome

- A master research list of South Dakota research projects posted on SD CCC website linked to PLANET, CDC Wonder, South Dakota Department of Health, and other organizations' websites
  - South Dakota specific data is not currently available on the PLANET website.

Action Steps

- Disseminate research list to cancer professionals
- Establish SD CCC website as a central communication method
- Obtain reports from the various internal review boards (IRBs) on ongoing cancer related projects.
- Develop and maintain an annual master list of cancer research projects in SD.

Strategy:
Promote and encourage research projects in South Dakota, particularly those that are responsive to the needs of American Indian communities.

Outcomes

- Increased number of research projects in South Dakota.
- South Dakota universities/colleges and private hospitals will build partnerships with and reach out to American Indian communities/organizations for research.
- Increased number of participatory research projects approved in South Dakota.
  - No data is presently available.

Action Steps

- Train tribes in identifying effective health communication methods that empower utilization of resources.
- Educate tribes and tribal institutional review boards on participatory research models.
- Establish baseline of research projects in South Dakota.
- Train educational and medical school institutional review boards on participatory research models.
- Train communities in identifying effective health communication methods that improve utilization of resources.
- Define standards for participatory research.

Strategy:
Establish a mechanism for releasing South Dakota Department of Health data following human subject's protection guidelines.

Outcome
- Policies and procedures developed for release of cancer data

Action Steps
- Explore the creation of a South Dakota Department of Health Institutional Review Board (IRB) or partnering with an institution that has an existing IRB.
- Establish a log of requests for sensitive data requested by researchers.

Strategy:
Ensure access to clinical trials for all eligible South Dakotans.

Outcomes
- An increased level of insurance coverage available for cancer clinical trials.
- An increased participation of minority and medically underserved in clinical trials.
- An increase of sites that offer clinical trials.
- A publicly accessible list of cancer clinical trials available in South Dakota.

Action Steps
- Post a directory of clinical trials on SD CCC website.
- Define the Medicare standard for clinical trials.
- Develop a list of which insurance companies currently cover clinical trials.
- Negotiate a voluntary agreement with insurance plans for coverage of clinical trials.
- Advocate legislation for clinical trial insurance coverage for all eligible South Dakotans at Medicare standards.
- Educate South Dakotans on clinical trials.
- Encourage behavioral research to determine healthcare professionals' knowledge, attitudes, beliefs, and practices regarding clinical trials and perceived barriers regarding patient participation in clinical trials.
- Provide professional education opportunities for health care professionals that could offer clinical trials to patients at their practices.
- Educate tribal leaders on clinical trials.
- Give tribal leaders the list of what insurance plans currently cover.
- Advocate for researchers to cover costs of transportation, hotel, childcare, etc. for participants in clinical trials.

Next Steps

This presentation of the first South Dakota Comprehensive Cancer Control Plan marks the beginning of a new way of working together rather than the end of a planning project. Now the work of implementing the priority cancer control strategies becomes the focus of our joint agenda. Because cancer is a chronic disease, a diagnosis brings the psychological, physical, economic, and spiritual concerns to individuals and their loved ones that last a lifetime. A comprehensive statewide cancer prevention and control system must exist to meet all of these needs, in addition to reducing cancer incidence and eliminating disparities within our state.

Cancer does not discriminate on the basis of age, ethnic group, socio-economic status, or gender. It affects everyone. However, cancer data does indicate that the burden of cancer is not equally shared among all of our residents. Those who live far from diagnosis and treatment facilities are less likely to follow early detection guidelines and to complete treatment after diagnosis. In addition, while the cancer incidence rate of whites and American Indians is similar, cancer is generally diagnosed at a later stage in American Indians. And, the cancer death rate for South Dakota's American Indians is higher.

Throughout the discussions and deliberations of the more than 75 partners who developed the plan and in conversations with community members, several themes became evident:

- Eliminating disparities
- Public and professional education
- Patient support
- Communication and data

In the coming months individuals who are committed to comprehensive cancer control will meet to create new ways of working together to integrate these themes and priority strategies. Progress toward completing priorities will be monitored and reports will be made available to the public.

This cancer plan is written for all of South Dakota's people. You can become a part of it and we invite you to join this important work.

Join Us

The undertaking of creating a truly comprehensive cancer control program lies in the hands of the citizens of South Dakota. If you are interested in becoming a member of this coalition please complete this form and return it to the address below.

Name: _____

Organization: _____

Address: _____

City/State/Zip: _____

Phone: _____

Fax: _____

Email: _____

Please indicate which area is of most interest to you.

_____Education: Public & Professional

_____Disparities

_____Patient Support

_____Evaluation / Communication / Data

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Glossary

Baseline
An initial or known value to which later measurements can be compared.

Benign
In this document a growth that contains no cancerous cells.

Body Mass Index
A way to state the relationship between height and weight. (weight in kilograms divided by height in meters squared (kg/m^2).

Cancer
The umbrella term to describe many different diseases in which cells grow and reproduce out of control.

Cancer Burden
Overall impact of cancer in a community.

Clinical Trials
Research studies of new methods or agents to prevent, detect, or treat a disease, or to study quality of life issues. Treatment trials with cancer patients usually involve three phases to compare the current best treatment to a promising new treatment.

Endoscopy
For this plan refers to examination of the lining of the gastrointestinal tract using a thin, flexible, lighted tube. Flexible sigmoidoscoy allows examination of the rectum and lower part of the colon. Colonoscopy allows examination of the rectum and entire colon; polyps can be removed during this procedure.

Incidence
The number of new cases of a condition within a specific population in a given time interval, usually one year.

Informed Decision-Making
Happens when a person understands the nature and risks of their cancer diagnosis and treatment options. Informed decisions are reflected by the person's preferences and values.

Mammogram
An X-ray of the breast used for the early detection of breast cancer.

Melanoma
The least common but most life-threatening form of skin cancer.

Metastasis
The spread of cancer cells from the original site to other parts of the body.

Morbidity
Presence of disease.

Mortality Rate (Death rate)
The rate of deaths in a given population, for a given time.

Pap (Papanicolaou) Test
A test for cervical cancer that examines cells that are scraped from the cervix; can detect cancer and pre-cancerous conditions.

Prevalence Rate
Proportion of people with a certain disease at a given time**.**

Prostate Specific Antigen Test (PSA)
A test to detect levels of a blood protein. Elevated PSA levels may indicate prostate cancer, prostate inflammation, or benign prostate conditions.

Risk Factor
An element that may increase the chance of developing a disease. Some examples include using tobacco, obesity, age, a family history for some cancers.

Staging

In situ Cancer: Early neoplasm which has not penetrated the membrane surrounding the tissue of origin.
Localized Cancer: Invasive malignant cancer confined entirely to the organ where the cancer began.
Regional Cancer: Cancer that has extended beyond the original (primary) organ to nearby organs or tissues, or has spread via the lymphatic system to regional lymph nodes or both.
Distant Cancer: Cancer that has spread from the original (primary) organ to distant organs or distant lymph nodes.

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South Dakota Tobacco Control Program Strategic Plan. 2004

Fast Facts

- 30 percent of students smoked cigarettes on one or more of the past 30 days.
- 22.6 percent of adults in South Dakota smoke 19 percent of adults consume five servings of fruits and vegetables per day.
- 46.5 percent of adults did meet recommended guidelines for moderate physical activity.
- 41.8 percent of adults age 50 and older reported having ever had a sigmoidoscopy / colonoscopy.
- Asked of women who had not had a mammogram:
  What was the most important reason for not having a mammogram:
  -Not recommended by doctor/doctor never said it was needed 26.4 percent
  -Not needed/not necessary 23.1 percent

Incidence:

- South Dakota registered approximately 3,900 new cases of invasive cancers (cancers that have spread) and in situ (contained) bladder cancers in 2002.
- Prostate cancer was the most common cancer reported with breast, colorectal and lung following in that order.
- The top four cancers accounted for approximately 60 percent of all cases reported.
- Approximately 40 percent of cancers were diagnosed at more advanced stages with 20 percent at regional stage and 19.5 percent at distant stage.
- Of all cancers reported in South Dakota in 2001, 89 percent were among persons age 50 or older with half of these cases diagnosed between ages 65-79.

Mortality:

- In 2002 the state's age-adjusted death rate with 1,561 deaths was 187.4 per 100,000 compared to the national rate of 193.3 per 100,000.
- The top four causes of cancer deaths were lung and bronchus, colorectal, prostate and pancreatic cancers, accounting for approximately 50 percent of all cancer deaths.
- The age-adjusted death rate for the five year period 1998-2002 was 189.2 compared to the U.S. rate of 197.8 per 100,000 persons.

"We all know family members or friends who have battled cancer. Cancer is a huge burden in our state and this plan gives us an opportunity to reduce that burden. The plan is a blueprint for working together on cancer issues ranging from prevention and detection to treatment and survivorship that can make a real difference in our lives."

~ Governor M. Michael Rounds

High Priority Strategies

Prevention

Strategy:
Eliminate commercial tobacco use.

Strategy:
Increase healthy dietary behaviors.

Strategy:
Increase physical activity to at least 30 minutes every day.

Early Detection

Strategy:
Promote the importance and benefits of colorectal cancer screening with personal empowerment messages.

Strategy:
Promote the importance and benefits of breast cancer screening with personal empowerment messages.

Treatment

Strategy:
Improve access to and utilization of cancer treatment facilities in order to encourage patients to complete their course of treatment.

Survivor Issues

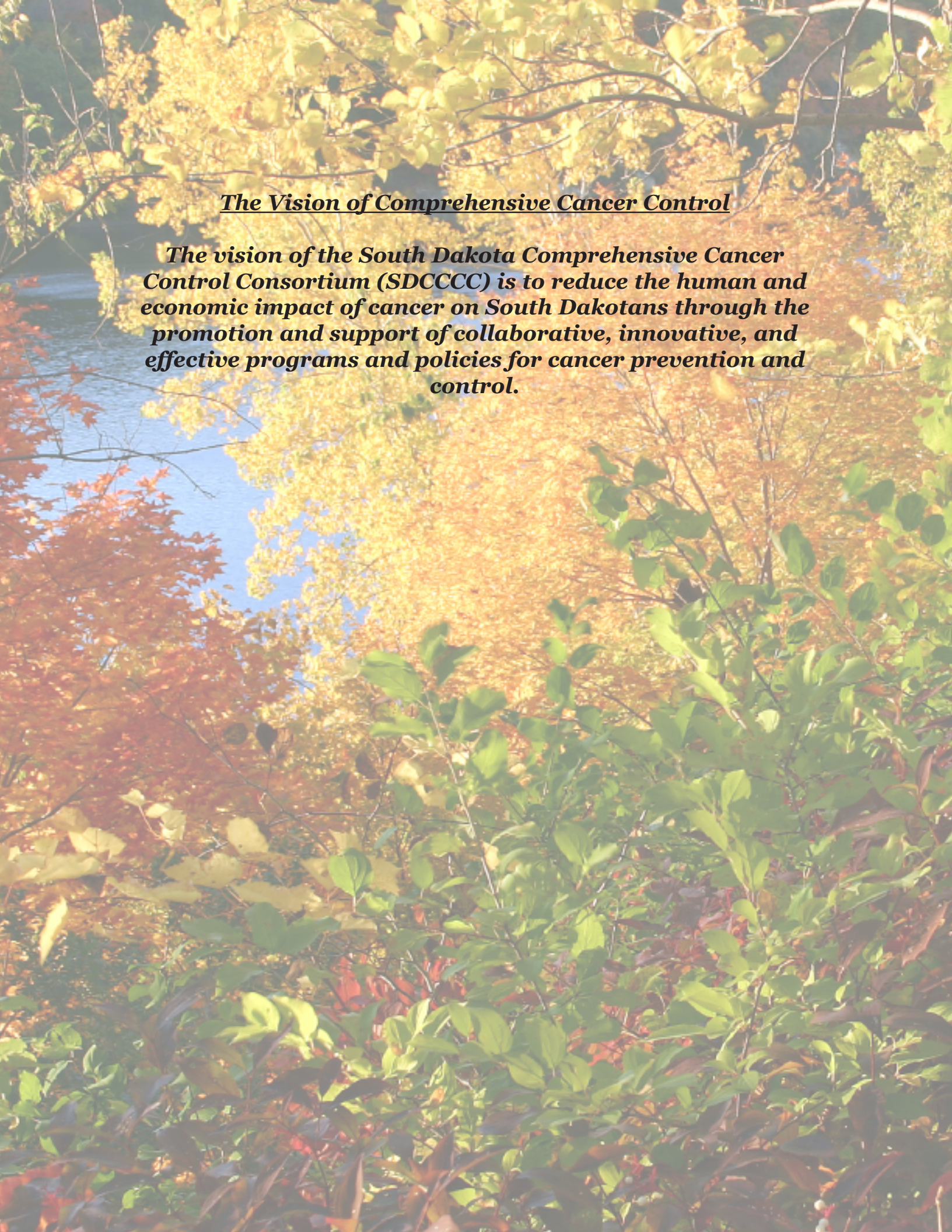
Strategy:
Improve access to quality care in South Dakota through reducing financial and geographic barriers and by increasing the proportion of residents who have a source of primary care.

End of Life / Palliative Care

Strategy:
Education of general public and healthcare providers to increase awareness/knowledge of hospice and palliative care in order to increase utilization of programs focused on end of life care.

Research / Data

Strategy:
Improve cancer reporting to a statewide population based surveillance system.



The Vision of Comprehensive Cancer Control

The vision of the South Dakota Comprehensive Cancer Control Consortium (SDCCCC) is to reduce the human and economic impact of cancer on South Dakotans through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control.